

The needs of older people with acquired hearing and sight loss: findings from 20 case studies

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“Experiences of people with both hearing and sight loss”

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Contents

Acknowledgements	4
Executive summary	5
Introduction	15
Context, purpose and overview	15
Background to the project	16
Phase 1 – secondary data analysis	18
Methods	22
Rationale	22
Personal stories of people with hearing and sight loss	22
Diaries	24
Follow-up interviews	25
Discussion with others involved with the individual	25
Analysis	26
Sampling strategy	27
The recruitment process	29
Description of the final sample of 20 participants	33
Findings from the 20 case studies	34
Detailed descriptions of the 20 participants	34
Participant 1 – Delia	35
Participant 2 - Belinda	36
Participant 3 – Mary	37
Participant 4 – Julie	39
Participant 5 – Jackie	41
Participant 6 – Eva	42
Participant 7 – Keith	43
Participant 8 – Molly	45
Participant 9 – Fiona	47
Participant 10 – Pamela	48
Participant 11 – Colin	50
Participant 12 – Rajat	52
Participant 13 – Kulvir	53
Participant 14 – Lionel	55
Participant 15 – Jeremy	56
Participant 16 – Emily	57
Participant 17 – Jack	59
Participant 18 – Lawrence	61
Participant 19 – Norris	62
Participant 20 – Betty	63
Findings by Theme	66
Vision and hearing	66
Other health problems or disabilities	73
Communication and social interaction	82
Accessing information	90
Leaving the home and getting out and about	97
Activities within and beyond the home	103
Daily living and sources of support	118
Access to and participation in medical services	135
Social and emotional issues	147

Residential accommodation	156
Views of the participants' families.....	163
Professional views of services	169
Eligibility criteria for receiving the services	169
Registers of people with sight and hearing loss	170
Description of caseload and referral routes to services.....	170
Description of services offered	171
Description of services that are not currently offered	173
Discussion	174
References	186

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Executive summary

Aim and overview

This report presents results from part of a project entitled 'Experiences of People with both Hearing and Sight Loss'. The project was funded by the Thomas Pocklington Trust. The aim of the research was to increase the knowledge base concerning the experiences, needs and goals of older people with both sight and hearing loss, and raise awareness of these needs and those of people living and working with them.

The project had two distinct phases. The first phase analysed two already existing datasets relating to 609 older people with hearing and sight loss. This analysis has been previously presented in a report by Pavey, Bodsworth, Douglas, Clare and Hodges (2007). The second phase focused on case studies of 20 older people with hearing and sight loss. The findings from this research are presented in this report.

The report presents summaries of the background and methods adopted in the study. However, the bulk of the report is given to presenting the views expressed during a series of in-depth interviews in which the 20 participants told the researcher their personal stories. We try to capture these personal stories by first presenting short summaries of each participant case-by-case. We then present the results of analysis in which data from all the participants is gathered into themes. These themes are summarised in the executive summary, but readers are encouraged to immerse themselves in the voices of the participants and their powerful stories presented in the main section of the report. This will give a better sense of the experiences of the participants and evidence they gave the research team which has enabled us to draw out the themes.

Participants and recruitment

This study focused on case studies of 20 older people with sight and hearing loss. In summary, the participants had the following characteristics:

- Age ranged from 58 to 92 years (14 participants were in their 80s);
- 11 women and 9 men;
- 18 described themselves as being of white British origin, while two described themselves as Indian;
- 7 lived alone, 12 with family (spouse or children) and one lived in a residential home;
- All but one had health problems or disabilities in addition to their hearing and sight loss;
- The participants lived in a range of locations, both urban and rural, from around the UK.

The details of participants' households, homes, neighbourhoods, visual and hearing impairments, and other health problems are summarised in the main report.

The research team recruited participants through a range of statutory and voluntary sectors in the hope of recruiting people who had experienced a range of services. The recruitment process was extremely time consuming. This was partly due to the complexities of working through a number of gate keepers (including ethical approval, ADASS approval, Research Governance Framework Committee approval, and professional contacts). In addition the recruitment process demonstrated the challenges faced by older people with hearing and sight loss: some organisations found it difficult to identify individuals with hearing and sight loss, it was difficult communicating information effectively to potential participants, and a number of potential participants had poor and deteriorating health.

Methods of data collection and analysis

Life story interviews were chosen to allow participants to speak of their past, present, and hopes or fears for the future. Interview schedules were designed which enabled the research to gather some key demographic data, but most importantly to enable participants to talk openly and freely about their lives. The purpose of this was to increase the opportunities for participants to take control of the direction and focus of the interview so that the research had a better chance of gaining information which was of importance to the participant. These interviews involved visiting the participants' homes and took between one and four hours. In addition to these extensive interviews, further information was gathered from some participants in a second interview, in collecting 'diaries', and from other people linked with the participants (either family or professionals).

This data collection generated large volumes of researcher notes and audio recordings. These were transcribed and exported into the qualitative data analysis software programme NVivo (version 8) for further analysis. The data was then analysed following a grounded, generative approach in which the data was coded to draw out themes.

Initial results were presented to over 30 professionals at a 'round table discussion' (RTD) meeting held at Birmingham in July 2008. The discussion and feedback from this meeting helped further shape the analysis.

Key themes

1. Vision, hearing and other disabilities and health problems

The participants had a variety of levels of hearing and sight, though, partly because of how the sample was constructed, no participants were profoundly

deaf. With some exceptions, it was common for participants to have limited knowledge of the medical conditions which caused their sensory loss (e.g. they rarely knew the medical name of their condition). This seemed to particularly be the case in relation to their hearing loss.

The vast majority of participants reported additional health problems or other disabilities (e.g. arthritis, heart problems, mobility problems, problems linked to bowels and stomach), some of which were clearly very debilitating.

In most cases the participant's hearing and sight had deteriorated over the previous year (indeed often their general health was deteriorating also). This change in circumstances would mean that many would likely have benefited from assessments in relation to low vision aids, lighting and hearing aids, but attendance at appropriate clinics may have been problematic given common mobility and travel difficulties.

Generally there were positive views of both hearing aids and low vision aids which enabled the participants to do things which were otherwise impossible, like reading their own mail or participating in conversations. Nevertheless, there was some discussion about some of the inadequacies of the technology, and clearly some of the participants did not know how to correctly operate the aids that they had been given or required further hearing or low vision assessments to ensure they had the appropriate aid for their current level of sight or hearing (which was reported as changing by most).

The data revealed a variety of different interpretations of the participants' disabilities when asked. Often the participants described their disability in medical terms (e.g. associated with an illness), while others reflected upon a loss of part of themselves and the skills they once had. Many also linked their disabilities with old age. Nevertheless, many participants appeared to rationalise their disabilities with pragmatism ('nothing can be done', 'you've got to get on with it'), reference to their faith, and that they were in a relatively fortunate situation compared with others who were worse off. Exceptions to this may be those participants who had a hearing or sight loss from a younger age.

Linked with general health were that many participants were very vulnerable to suffering falls within their homes; only a few had a safety system in place (e.g. personal alarm services) or modifications to the home (e.g. handrails). In fact, in some cases the presence of a personal alarm service caused participants anxiety as they did not know how it worked and they sometimes did not want to disturb their family, who would be called should an emergency arise.

2. Identification

In terms of identification as sight and hearing impaired, it is interesting to note participants' relatively low awareness of their registration status as deafblind (in contrast to a clearer understanding of their registration as blind or partially

sighted). This may be partly explained by the fact that the statutory requirement for deafblind registers is relatively recent, and also the process of registration may feel less formal or important (and therefore less memorable) to people because it does not involve medical staff.

Reasons for low registration as a deaf or hard of hearing person (or certainly lower awareness of it) are even more speculative. We are confident that many of the sample were *not* registered perhaps reflecting that our sample contained people with relatively less impaired hearing (compared with sight) – for example there were no people with profound hearing loss in the sample. Also fewer people in the population as a whole are registered as deaf or hard of hearing compared with blind or partially sighted.

In terms of being identified by services as having hearing and sight loss, most participants had been identified by a voluntary organisation at the very least, though in some cases this was through an informal referral by a friend or family member. Professionals at the RTD talked at length about the best ways of ensuring that people who are assessed by non-deafblind specialists in generic services are identified as having hearing and sight loss and referred on to appropriate services where necessary, but also to ensure that the professionals can then seek advice on how best to communicate with them.

3. Communication and social interaction

An extremely strong theme to emerge from the research was the communication challenges faced by many. Communication in groups was very difficult, but also difficulties with mobility and travel beyond the home for those who lived alone meant that opportunities for communication were also limited. The telephone was problematic for some but these problems of access were overcome for many (e.g. by adding amplifiers).

This difficulty with communication meant that some felt very isolated, e.g. *“I go for days and days and days [without company].” (Pamela, 86); “After you’ve gone it will be just like a morgue again” (Colin, 92).*

4. Leaving the home and getting out and about

In terms of leaving the home, participants often described difficulties they face. Often they talked about personal / health barriers (e.g. energy, difficulty walking, and fear of falling). Nevertheless, many described strategies that they have when travelling (ringing ahead, asking people, using public transport, taxis). It was common for people to go out with others, in particular partners they were living with. Some described a fear of crime which prevented them from going outside.

5. Activities within and beyond the home

Many participants described leisure activities relating to the spoken word (e.g. talking books, radio, and television). People often talked about the importance of people (friends, family) visiting their homes. Contact with religious groups was highlighted by many as very important and in particular its role in connecting them with a community of people. Many re-iterated difficulties they had leaving their home and how that reduced opportunities to do things outside. Some, not surprisingly given the lack of variety in their life and reduced opportunities to go out, talked positively and at length about holidays and breaks that they had experienced. Others did not see the need or thought it too difficult / too much trouble.

Day centres were discussed in a largely negative way by participants. Participants were negative about the inability of staff to cater for a range of people and their different needs. They felt that many had an institutionalised feeling. Data from the RTD suggested that this is a common problem.

6. Daily living and sources of support

While people had or required different levels of support, a key source of support for many participants was family (whether family who lived with participants or family who lived locally). Discussions about support revealed many different views about independence and dependence. Certainly for some participants avoiding 'feeling a burden' to family or friends was a great concern.

Having support to carry out shopping was highlighted by many. The RTD professionals talked about the importance of offering support to enable participants to go shopping with a helper, rather than having someone doing the shopping for them as this can lead to a reduction in the food choices the participant's can make, thereby increasing their feelings of dependence and lack of power/choice further.

Nevertheless, there may have been some evidence that while participants were keen to maintain their independence (including financial independence), this can lead to unusual decisions (and potential vulnerability to people who might exploit them) – for example two participants who did not want to rely on others described spending a lot of money on technical equipment which they could have had on free loan.

Whilst many participants were in contact with a support service for people with sight loss and/or sensory loss, the referral routes were not always clear, and in some cases participants still required support for particular needs that were not being met. This demonstrates that participants who have difficulty with communication and accessing information often need support in accessing support services.

It is clear that there was very little awareness of rights or involvement in processes with which the participants could influence services. Those who did discuss their 'rights' in this manner (e.g. awareness of DDA, participation in access forums/groups) were younger participants (with only one exception).

The importance of including people with acquired hearing and sight loss in service decision making was highlighted by many professionals who attended the RTD as being of key importance. This may be difficult for many of the older people who participated in the research who appear to align themselves with a culture which emphasises personal responsibility and a reluctance to ask others for help. Nevertheless, professionals who attended the RTD described many examples of where this had successfully worked.

7. Daily living and independent living skills

It was clear that the participants faced many challenges, both large and small, on a daily basis; being able to complete what might seem to outsiders as small, simple tasks, can mean a lot to older people who have lived their lives independently. Clearly, the participants' sight and hearing loss (but particularly the sight loss) made many of the tasks difficult, though this was often exacerbated by additional health problems and disabilities affecting the participant's strength, dexterity and mobility.

Of central importance to the participants was the need to retain independence, therefore solutions aimed at overcoming any difficulties should attempt to enable the participant to carry out the task independently where possible, taking additional disabilities and health problems into account (e.g. provide ILS training and specialist equipment like a liquid level indicator to enable them to make themselves a cup of tea, or suggest other strategies where the hearing loss prevents audible specialist equipment being used).

Some of the participants were concerned that they were a burden upon their family, therefore input from services, in particular communicator-guides and volunteers to help around the home, are of key importance for enabling participants to live independently without them having to rely solely upon the support of family members who often live far away. Professionals may also have to play a role in ensuring the participants understand that using services does not constitute failure in terms of living independently.

8. Accessing information

The participants who had attended courses for those who were newly registered or diagnosed appeared to have obtained a lot of value from them. Whilst some participants could not recall details of the support or information they had received at the time of diagnosis, the participants who attended courses running over a number of weeks appeared to have much better recall about the information they received. This suggests that attendance on courses, rather than just giving out leaflets and verbal advice, could be a

better source of information for participants. Additionally, the courses enable socialising and communication with other people with hearing and sight loss which many participants viewed as important.

The support provided to partners and carers on such courses was also appreciated by both the person with hearing and sight loss and the carer. A greater understanding of how the sight and hearing loss affects their relative (both practically and emotionally) may improve communication between them, and reduce the participant's feeling of being a burden upon their family, since the carer will have a better understanding of how they can facilitate their independence, rather than dependence.

Some of the participants in this study appeared to have attended courses that focused upon sight loss. In light of the little knowledge the participants appeared to have about their hearing loss and available services, it would seem prudent to offer courses that covered hearing loss also.

Whilst only four participants were using computers, it was clear that it offered them many opportunities, and that they were using them very effectively. The participants who were using them had received support from family members on how to use and set up the computer, or had experienced using them in their previous occupation pre-retirement. There is a need for provision of one-to-one support for older people with sight and hearing loss to enable them to be included in the opportunities that technology affords.

9. Access to and participation in medical services

In terms of medical services and their sight loss, many participants reflected upon their medical experiences. Inevitably these were often told as harrowing and emotionally painful personal journeys. In some cases the stories perhaps reflected the participant's own confusion about the treatment they were receiving (it has already been highlighted that participants had relatively limited knowledge of their medical conditions). There were also both negative (e.g. insensitive staff, lack of continuity, poor communication) and positive (e.g. "wonderful" staff) recollections of the services received. It may be that some dissatisfaction and confusion experienced by participants was linked to poor communication and hearing loss, i.e. this may reflect that patients in eye clinics with hearing loss may be finding it more difficult to understand the information being given to them by staff.

In terms of medical services and their hearing loss, for some participants it was clear that visits to hearing specialists were difficult due to their sight loss. Maintenance of hearing aids can also be difficult. There was a general feeling amongst some of the participants that prioritising those with sight loss for hearing aids is important. However, many seemed vague about the services on offer relating to hearing loss. In the case of hearing aids in particular, there was a lot of confusion in terms of referral routes, the boundaries between NHS and private services, and cost.

In terms of receiving general medical services, many of the participants were unclear (and passive) regarding referral routes and there were a number of examples where they had encountered difficulty in getting these services (e.g. Colin who finally received a flu jab at home after his communicator-guide intervened). The experiences were mixed however, since other participants appeared to receive regular visits to ensure they were up to date with required vaccinations and general health check-ups.

There were also mixed experiences regarding hospital admissions; most were negative and often linked to staff not identifying the communication needs of patients. In addition, the difficulties some of the participants faced were not related to staff failing to identify that they had hearing and sight loss, but rather a lack of understanding about the implications of their sensory loss, and additional support they would need in terms of communication and information whilst they were in the hospital.

10. Social and emotional needs

Many of the participants felt somewhat negative about their current life and prospects for the future. This seemed to be particularly true (though not exclusively) for those who lived alone.

Unsurprisingly given the age of this group, bereavement was also common. Key coping strategies appeared to be drawing upon positive memories and their religion (the latter played a strong role in many of the participants' lives).

In terms of the future, many felt they lived day to day, and coped with their anxieties about the future by refusing to let themselves think about it. However, many expressed anxiety about their health and sight (in case either deteriorated further); about becoming a burden upon their families (particularly their children); and being able to stay in their own homes rather than having to go into residential care. Interestingly, the latter two anxieties are somewhat incompatible, in that for many, the only way they could remain living in their own homes is with the support of their families. It is likely that such tensions play on participant's minds causing further anxiety. Even participants with a high level of care put in place by social services required a lot of daily support from their family in order to stay in their own homes (e.g. Colin, who had daily support from his daughters in terms of cleaning the house and preparing his daily meals).

11. Residential care homes

The participants seemed overwhelmingly negative about the thought of moving into a residential home. This seems to be linked to feelings of losing independence, and was seen as the ultimate price when participants lost 'the fight' to remain living independently in their own homes. It is difficult to clearly decipher why the participants felt this way, but it is likely that negative

experiences of visiting homes coupled with negative portrayals of such care in the media have heightened their anxiety regarding such a fate.

One participant (Pamela) lived in a residential home. Her experiences of living in a residential home for over 15 years suggest dissatisfaction with the care she receives, though interestingly she would still not want to move elsewhere if such an option was possible. This suggests the importance of the 'familiar' and 'routine' for older people who have lost their hearing and sight. However, it was clear that she was frustrated by her lack of power and 'voice' within the home compared to how she perceived things to have been when she first came. It is difficult to speculate about problems in the home and why they have emerged in recent years. However, Pamela's hearing and sight have deteriorated over that time and it might be that staff have failed to recognise or respond to her changing needs, and this has resulted in her increasing isolation and loneliness. Certainly, professionals at the RTD felt that training issues for staff in residential homes was a problem for many.

12. Views of the participants' families

Though it was a small dataset, the data from interviews with the families gave an indication of how much support they give to the participants on a daily basis. There were various issues that would relate to carers generally, e.g. the need for respite care, and advice and support about the caring role, but an issue particularly relevant with this older group is that the spouses were themselves vulnerable to aging and complications of deteriorating health and disabilities. It was clear that the participants in the study who had spouses had more comprehensive care and companionship, and appeared happier than those who lived alone. However, there was a feeling that this support was delicately balanced because at any point it could be reduced or taken away. This anxiety was expressed by a number of participants but most clearly realised by participants who had recently suffered bereavement of loved ones.

13. Professionals' views of services

Although the sample of only nine professionals is small, the responses illustrated that they had a range of ways of managing caseloads and making use of registers of deafblind people.

The professional respondents provided the research team with a list of the different services they aim to provide. Positively, these services mirror many of the issues and needs raised in the interviews with the participants with hearing and sight loss. The difficulty may therefore be that time and resources are not sufficient for the professional to adequately assess the needs of, or provide the resources for, each person in the depth that is required. Some of the professionals felt frustrated because this was all they could manage.

Awareness training of staff in allied sectors was also seen as an important role (e.g. for generic staff in day centres, residential homes, and hospitals). However, scarce resources and clients who need potentially high levels of support meant that professionals felt unable to carry out this work very often.

Introduction

Context, purpose and overview

This project is the result of 15 months study into the lives of older people with both sight and hearing loss. It was commissioned by the Thomas Pocklington Trust following a previous project which carried out a literature review in this area (see Hodges and Douglas, 2005)

The present study was commissioned to increase the knowledge base concerning the experiences, needs and goals of older people with both sight and hearing loss, and raise awareness of these needs and those of people living and working with them. The results and conclusions give some indications of how services could be improved and what kind of intervention may be effective.

The group on which this study was focused are those who have a combined sensory loss and who are older than fifty, with a particular interest in those who are older. One or both of the sensory losses (sight or hearing) will have been acquired in later life. There has been until now little empirical study of this group, and material available has been largely anecdotal or part of policy documents. This project was designed to be a systematic investigation of older people's lives in relation to their sensory losses. The major part of the study was detailed discussion with twenty older people about their own lives, supported by additional information from diaries, further interviews, and discussion with professionals. Individuals from relevant professional backgrounds, in sensory loss or generic services, were included in data collection and validation through two round table discussions, which supported the data collection and validated and contributed to the eventual findings.

This study is based on rich source material and has been analysed both 'participant-by-participant' and by 'theme'. The themes are then embellished by comments from other parties, such as professionals, family members and literature. The qualitative nature of this investigation allowed a deep insight into the lives of older people with both sight and hearing loss in their own words. The report identifies key areas of concern and discusses these in their context.

In addition, the research project also carried out a further analysis of data which already exists from two investigations into older people with sensory loss. This allowed access to information about 609 people over the age of 50 who have combined hearing and sight loss. This investigation has been previously been published in a report by Pavey, Bodsworth, Douglas, Clare and Hodges (2007) and is summarised below.

Background to the project

The current research project draws on work from Hodges and Douglas (2005) which reviewed published literature and other accounts about the needs of and provision for older people with combined sight and hearing loss. In the review, the key issues examined were:

- Definitions and prevalence;
- The needs of older people with combined sight and hearing loss;
- Policy and services for older people.

A short summary of the review is below.

Definitions and prevalence

Defining the population which is encompassed by the study was difficult. The definitions presented by organisations which work with this population are usually functional, based on the effect of combined sensory impairment on communication, orientation and mobility and access to information. The terminology used by both government and voluntary organisations usually refers to this group as 'deafblind' (sometimes as 'dual sensory impaired'). However older people who have difficulty with sight and hearing are more likely to see themselves as having difficulty with sight/hearing as a natural consequence of getting older, and not as related to 'visual impairment' or 'deafness'. This may result in them not seeking help, not being willing to use help offered, or their needs being overlooked by others, including services.

Partly because of this, it is difficult to ascertain how many older people have both sight and hearing loss, and it is likely that this population is underestimated and under-identified. Some previous estimates have included as many as 2.1 million people (DoH 2001).

Needs of older people with sight and hearing loss

The review noted that literature discussed a range of issues as key to the needs of older people with sight and hearing loss:

Access to information was difficult for this group, from difficulty in reading food labels to difficulty in knowing about services for people with sight or hearing loss. Where adaptations were available, they did not always avail themselves of them. Key individuals (such as family members) might be the gatekeepers for information, which may mean it is restricted because of time or interpretation.

Communication is one of the defining issues of deafblindness, and it is a key difficulty. Difficulty in communication is often related to hearing

(or seeing) what is said, as many older people maintain good speech (expressive communication) despite hearing loss. Communication affects interpersonal relationships, with family, friends and community groups, as well as making sense of what service providers, in particular health and social service workers are saying. Older people may use alternative means of communication but they are not usually assertive in asking others to use them.

Mobility and transport related to communication and information difficulties (not being able to read bus timetables or numbers) as well as to physical difficulties in travel. Specialist services for disabled people did not always understand the needs of people with sensory impairments.

There were many examples of people who had difficulty in finding activities they could continue with despite sensory loss, in particular, in meeting other people. Daily living tasks may have been taken out of their hands.

Isolation was related to difficulty in communication; grieving (for friends and family members who had passed on); and adjustment to changes in life, partly at least related to sensory loss, were also frequently mentioned.

Specialist equipment and facilities were often mentioned in professionals' writing; including the provision of some specialist housing for people with combined sight and hearing loss. Simple solutions were also available, but staff in residential care homes, for example, did not always know about them, or how to use equipment such as induction loops.

While there is no reason to believe that there are fewer older people with combined sight and hearing loss who are from minority communities, this group was very underrepresented by the literature. There may be particular issues experienced by this group in relation to communication or to expectations of family care.

Service provision and policy

A number of policy documents, including some from central government, have influenced thinking in this field. *Think dual sensory* (DoH 1997) and *Social care for deafblind children and adults* (DoH 2001) are perhaps the most influential, recognising the particular needs of this group and describing appropriate services for them. These services included specialist help, such as communicator-guide (guide-help) services which can assist individuals to carry out daily tasks themselves, rather than taking them out of their hands – allowing them to go shopping, pay bills, or visit hospitals with more confidence. Little evaluation of these services has been carried out. In more generic

services, a need for staff training and understanding was reported. Assessment for identification and for service provision was also discussed as an important part of developing services.

The final review report (Hodges and Douglas, 2005) suggested a number of further investigations which could be carried out, including for example: operationalising the definitions of dual sensory impairment in this group; evaluation of service provision, including that of communicator-guides; investigation of staff training in relation to dual sensory impairment in generic direct care staff; and further work relating to the needs, circumstances and quality of life of older people with hearing and sight loss. It was argued that the use of already existing data sources would support this, in addition to case studies on older individuals with sight and hearing loss.

In part, this review led to the current project which had two main phases. In the first phase, there was a detailed examination of two archives of research material which had already been collected in relation to other projects, one by the University of Birmingham (Network 1000 study) and one by Deafblind UK and the University of Cambridge (Cambridge study). During this phase, key themes in relation to older people with sight and hearing loss were identified, particularly in relation to what they considered to be important for themselves. This analysis helped with the framework for the second phase of the investigation, which was a series of twenty case studies of older individuals with both sight and hearing loss. The rich and deep data generated is the foundation of this report.

Phase 1 – secondary data analysis

Phase 1 of the project (presented in a previous 62 page report) was based upon a secondary 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 Network 1000 dataset 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 involves 404 participants who were members of Deafblind UK and took part in a postal questionnaire in 2005.

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

- 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;
- to generate ideas regarding possible areas for investigation with participants during the case study phase of the project (which is presented in this report).

Some key findings from Phase 1

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 (35%, n=205) is interesting in itself. It is also interesting that few identified it as a disability until they were prompted (this was particularly true of older people).
- In spite of there being few obvious other 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 clear difference observed was that those with reported difficulties with their hearing had greater difficulty communicating by telephone;
 - A third lived alone, others with a spouse or their (adult) children;
 - The majority had additional health problems or disabilities;
 - Over half wore a hearing aid;
 - Difficulties with travel, transport and mobility were common amongst the group;
 - Difficulties with independent living skills and communication and reading were also prevalent.

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 is an established self-report test encompassing 12 questions used to screen for mental distress and psychological ill-health; the measure is a clinically validated and internationally recognised self-report measure that has been shortened from the GHQ-60 (Goldberg and Williams, 1991).

This was accompanied by demographic data about the participants, and more qualitative data that described the thoughts and feelings participants had 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 old, with a mean age of 80;
- 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.

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, provided likely explanations for their high levels of psychological distress (which were much higher levels than found within general or older populations). Although the Network 1000 study did not include a measure of mental health, the qualitative data presented from that study also provided many examples of difficulties that participants face on a daily basis.

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 the use of the valuable DoH 1997 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 these groups. Of additional relevance to both groups were 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.

Some key implications for Phase 2

The findings from the secondary data analyses had two broad implications for the case study phase of the project – firstly, the content of the case studies and secondly, methods of communication used with participants in the case studies.

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 (described in following sections) aimed to encourage each 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 as general feelings of mental distress (a clear finding from the Cambridge study).

In terms of the implications for methods of communication, phase 1 gave us additional insight into the challenges of communicating *to* participants. Particular things which were highlighted were considerations such as care with the environment (lighting, background noise), the speed and approach to communication, and, most obviously, the inappropriateness of the telephone.

There were also other more profound implications, for example that it would be likely that (at least some) case study participants would be feeling and experiencing loneliness and isolation, and depression. Of particular importance would 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'.

Methods

Rationale

The main focus of this study was the design, collection and analysis of detailed case studies. A key characteristic of case study research is the use of multiple sources of evidence (Gillham 2000). Our approach involved the use of various methods to enable 20 people with acquired hearing and sight loss to tell us about their lives. Where possible, we also aimed to speak to people involved with them, for example family members and professionals who may be the main source of formal or informal support to the participant.

A variety of methods were proposed, including face to face interviews with participants, diaries recording their daily life, follow-up interviews after a six month period, and interviews with members of the family and others close to the participant. Additionally, a telephone interview and online survey was carried out with professionals involved in service delivery to older people with hearing and sight loss. These methods will now be described in turn.

Personal stories of people with hearing and sight loss

The life story/history method was proposed in order to gather deep and rich information without being shaped too much by the point of view of the research team. Participants were given the opportunity to talk about their past, present and future lives through the use of techniques that gather the participants' life-stories. The format of the interview varied from one participant to another, but the conversations about their life were embellished by any items participants chose to share in the interview that especially related to their lives, for example, photographs of activities and objects connected with events.

The life story interview has a wide range of applications (Atkinson 1998); the aim of a life story interview is to allow the participant to take control of the direction and focus of the interview, so that the participant becomes the storyteller whilst the researcher acts as a guide or director in the process. The life story interview can help to unpick "how people see themselves and how they want others to see them" (p20).

There are broadly two types of approaches to the life story interview; a 'life history' interview might focus upon a specific aspect of a person's life, whereas a 'life story' interview may look at a person's entire life, and the final presentation of the 'story' can vary from being a first-person narrative to the researcher's account of what was said. In this study, the main focus of the interview was upon the participants' experiences of living with hearing and sight loss, though at times this might touch upon their life before the onset of the hearing and sight loss where relevant, and the presentation of the 'story' is

more akin to a summarised account of the participants' lives by the researcher.

Encouraging participants to construct timelines of key events in their life, with an emphasis on experiences which relate to the focus of the research, provided a useful structure for the interviews (Goodson and Sikes 2001). To this end, the life-story section of the interviews carried out with the 20 participants involved an exploration of four particular phases of their lives plus an 'interview closure' section, including:

- *Phase 1 – onset of sight and hearing loss* (i.e. describing the time they started to lose their sight/hearing). Potential prompts were used where necessary relating to: medical details / history; speed and order of onset; social circumstances, context; feelings and emotions; family; and experience of services (social and medical).
- *Phase 2 – the past* (i.e. describing their life before they had difficulty hearing and seeing). Potential prompts were used as necessary relating to: their professional life; family life; key events (accomplishments, challenges, etc); education; leisure; happy times and sad times.
- *Phase 3 – the present* (i.e. description of their life at the present time). Potential prompts (as necessary) included: family and friends; worries; how would you describe yourself at this point in your life? (is it different to the past?); most important thing(s) in your life; leisure; and daily life.
- *Phase 4 – the future* (i.e. their personal view of their life in the future). Potential prompts (as necessary) included: hopes; fears; upcoming events in their life.
- *Phase 5 – interview closure* (i.e. an opportunity to provide any additional information they would like to share with the researcher, and their feelings about the interview and all that it covered).

In order to collect more factual / standardised information about the circumstances of their lives, participants were also asked a series of questions similar to those posed in the Network 1000 survey (Pavey, Douglas, Corcoran, 2005); these were designed to capture the detail of their lives, and related to the nature of their impairments, their household and family circumstances, the level and nature of any support they receive now or in the past, and other relevant 'demographic' data.

The length of a life story interview can vary considerably (Atkinson 1998); the interviews in this research took anything from 1 hour to 4 hours, but were typically about 1.5 hours in length. Due to the nature of the participants' circumstances (in terms of difficulties in receptive communication and in some cases their ability to take part in long sessions), the participants were reminded throughout that they could stop at anytime should they feel the need to. In some cases, interviews were broken in to more than one session to allow for toilet or refreshment breaks, but all of the interviews were carried out in one visit rather than requiring repeat visits (not including the follow-up interviews discussed below. It is worth noting that when asked for feedback about the interview, many of the participants remarked that it hadn't felt like a formal interview at all; rather, it had felt like a conversation with a friend, which

they had very much enjoyed. Often they were surprised at how long the interview had taken.

Whilst support for communication was available and offered where required, all of the participants used speech as their primary communication method in the interviews. In addition to speech, one participant who spoke using a voice synthesiser wrote notes on a writing pad when the researcher had difficulty understanding what he was trying to say. The use of finger spelling, enlarged print or text as a main means of communication, or the use of devices (other than participants wearing their usual hearing aids) to enhance hearing were not needed in the interviews. As anticipated at the outset, consideration of the environment in which the interview was carried out (e.g. minimising background noise), the use of touch and of clear and steady speech by the researcher, and careful observation of the participant's body language proved to be more important than the use of technical or interpreting aids. In addition, we invited the participants to suggest the best time to visit them (in the location of their choice) so that they were able to participate to the best of their ability.

Diaries

A number of the participants who were interviewed before Christmas 2007 were invited to keep a diary recording their daily activities over a 7 day period. In particular, we wanted the participants to describe what happened to them each day and how they felt about the day (recording this at the end of each of the 7 days). It was felt that this data could provide a further, more detailed insight into the daily activities of older people with hearing and sight loss, including how everyday tasks were achieved and difficulties overcome.

The researcher invited those who she felt would be physically able to record a diary using a tape recorder provided by the research team, following a brief demonstration of how to use the equipment. The tape recorders which had an inbuilt loudspeaker were chosen for their ease of use by people with visual impairment, and were sold and recommended by a national voluntary organisation for people with visual impairment. In order to provide clear instructions on how to use the equipment and the sort of information that we required, the research team recorded a brief message on a 'talking label' (e.g. see www.TalkingProducts.com) that could be replayed by simply pushing a button. Where participants felt unable to use a tape recorder, alternative methods were suggested including: recording their activities on a computer and emailing the finished diary to the research team (where participants were already using this method of communication), the researcher telephoning the participant for a description of each day, and in one case, the professional contact offered to visit the participant and record the participant describing their day using a video camera.

Of the six participants who were invited to take part in keeping a diary, 5 originally agreed; however, in the end 2 of these participants did not keep a diary as their eyesight had deteriorated and they felt unable to carry out the

task. Of the 3 who did keep a diary, one used the tape recorder but only managed to do so for 4 days; one recorded a diary for a 7 day period with the support of the professional contact who visited them regularly to record a description of the participant's activities using a video camera; and another participant struggled to use the tape recorder and decided instead to dictate her diary to her husband who typed the notes for her.

The reluctance to use the equipment by some of the participants, as well as the difficulties encountered by those who attempted to keep a diary was an interesting finding in itself.

Follow-up interviews

The participants who took part in interviews before the Christmas period were asked at the end of the main interview whether they would be happy to meet the researcher again and take part in a follow-up interview in the spring of 2008. All of the 11 participants agreed. The aim of the follow-up interviews was to provide an overview of the winter period that occurred between the two visits by the researcher, as well as following up on any key events that had happened in the lives of the participants from the time when they had first met with the researcher. In addition to this, it also involved a diary element whereby the participants were asked to describe the previous day in detail from getting up in the morning to going to bed at night (which made up for the reduced amount of data that was collected using the self-completion diary method described above).

Unfortunately, two of the participants were unable to take part in the follow up interviews due to deterioration in their health, which once again demonstrates the potential for rapid and unexpected decline in the health of this particular population (see the sampling section also, for a description of other participants who were unable to take part in the project due to sudden ill health).

Discussion with others involved with the individual

In order to provide a context and more specific information about the individual, it was intended that open discussions would be carried out with participants' immediate family and any professionals with whom they have direct contact. These would offer different perspectives about the participants' needs and circumstances, and in cases where the 'other' person was a family member, they would also provide an insight into the impact that caring for or living with a person with combined hearing and sight loss makes upon their life.

The research team decided that other people could only be approached and interviewed if the main participant gave their consent, since they would be the main focus of the interview. Therefore, all of the participants were asked at the end of the main (life story) interview if there was anybody that they felt it

would be useful for the research team to interview with regard to their hearing and sight loss, whether they be family members or professionals that work with them. If the participant suggested someone, the research team approached that person (either in person or by letter) about participating in an interview. However, the majority of participants did not suggest anyone, and in some cases stated that they would not like to suggest particular family members as they wouldn't want to bother or 'burden' them. Of those who did suggest someone, two suggested their spouse, another suggested one of his daughters, and a further two participants suggested professionals who worked with them (one was a volunteer from a voluntary organisation for the elderly; the other was a communicator-guide working for a local branch of a national voluntary organisation for deafblind people). Of these, only one of the spouses agreed to take part, and was subsequently interviewed over the telephone at a later date using a semi-structured interview schedule to gather information. The others were either unwilling to take part, unavailable, or did not respond to messages.

Whilst the original intention was to interview them separately once both parties had given consent, in practice seven more relatives (including five spouses and a son and daughter-in-law) of six of the main participants took part in the project by participating simultaneously in the interview with the main participant. This enabled a more limited amount of data capture of their views and experiences of living with and supporting a person with hearing and sight loss. All of those who participated in this way were asked for their consent to use any information that they had shared.

Originally, it was hoped that interviews about each of the participants and their circumstances would be carried out with professionals working with the participants, but the research team decided that there were a number of ethical issues relating to this that were of concern. Also, only two of the participants suggested that we talk to the professional or volunteer that they were in contact with. Therefore, the professionals who were contacted in order to help with the sampling at the outset of the project (see 'The recruitment process' section) were invited to complete an online survey that sought their views on the services available to older people with hearing and sight loss in their area (including those provided by the service they worked for and other services in the area), as well as their views on the needs of older people with hearing and sight loss generally. This enabled the collection of relevant and important information about services for people with hearing and sight loss generally, without reference to the particular needs and circumstances of the 20 individuals taking part in the project. This data is in addition to the views and opinions collected from the 26 professionals who attended the Round Table Discussion that took place near the end of the project.

Analysis

The information gathered comprises highly individual stories with much detail and background. The analysis of this information provides a rich overview of

the lives and views of older people with both hearing and sight loss, illustrated with their own personal stories as well as the opinions of those around them.

Following transcription of the interviews and diaries, the large amount of data generated was then exported into the qualitative data analysis software programme NVivo (version 8) for further analysis. The data was then analysed following a grounded, generative approach in which the data was coded to draw out themes. This involved a process of scrolling through the documents and highlighting text that related to themes including those previously identified in the secondary data analyses of the Network 1000 and Cambridge studies (phase one of the project – see Pavey et al, 2007) as well as new themes.

Sampling strategy

In order to gain meaningful data in sufficient detail to allow the individual voices of the participants to be recorded, a purposive sample of 20 individuals with both hearing and sight loss was selected. Whilst a sample of this size could not claim to be representative of the wider population, the aim was to include those from ethnic minorities, to balance men and women (among older groups, there are more women in the population), and to include participants of varying ages over 50, including people aged between 50-64, 65-74, and 75+ from around the UK.

Early in the project, a variety of health and social professionals who were specialists in the areas of vision, hearing, deafblindness and gerontology were invited to an initial round table discussion. The rationale for the discussion was to engage professionals and raise awareness of the relevant issues, and to seek advice and support for the design of the case study phase of the project, particularly with regard to sampling and the identification of routes to recruit participants for the case studies. With regard to the latter, a number of professional contacts were identified, including:

- A home support services officer in a regional-based voluntary organisation that provides services to elderly people;
- An information officer working for a local branch of a voluntary organisation that provides services to elderly people nationally;
- The manager of a sheltered housing service for people with sight loss over the age of 55, which forms part of a national voluntary organisation providing services to people with visual impairment;
- The deafblind worker from a regional voluntary organisation providing services to people with visual impairment;
- A regional outreach services manager and two community and family services workers based in local branches of a national voluntary organisation that supports and campaigns for deafblind people;
- Specialists in deafblindness working in four social services departments around the UK (including a dual sensory worker, deafblind specialist worker, deafblind services coordinator, and a regional development officer

employed by a national UK voluntary organisation contracted in to provide services to people with dual sensory loss).

Following the acquisition of research governance approval where appropriate (see later section on 'research governance framework approval') the contacts were asked to help identify potential participants, and following consultation with the research team, approach them in the first instance to minimise stress or pressure on the individuals. To help them identify suitable participants, the research team provided the following criteria of the sort of people we were hoping to recruit:

- People falling into three age groups, including 50-64, 65-74 and 75+; this was to ensure that we recruited people across the age range;
- They would have one of the following combinations of hearing and sight loss:
 - a person who was identified as having sight loss in the past but has more recently acquired hearing loss;
 - a person who was identified as having hearing loss in the past but has more recently acquired visual loss (but not a person who uses BSL);
 - a person who has been identified earlier as dual sensory impaired and is now getting older;
 - a person who has not previously been recognised as having a dual sensory impairment.
- Both men and women;
- People living in a variety of different circumstances, e.g. residential care (both specialist sensory provision and mainstream), in their own homes, in supported accommodation, living with extended family, etc;
- Both people who are receiving services (deafblind related or otherwise) and those who are not;
- People who are able to *personally* give informed consent to taking part in the project, and fully understand what their involvement would be (an assurance was given that we would provide as much information as necessary to ensure that they were able to make a fully-informed decision). The research team recognised that some older people with both sight and hearing loss may have dementia, or be diagnosed with dementia; whilst the needs and circumstances of this group are important, the approach and research method used here would not have been appropriate.

Once potential participants were identified by the professional contacts, the first step was to send the research team a brief (anonymous) description of them to ensure that a range of people were being recruited to the project. Once the participants that met the research team's criteria were confirmed, the professional contacts gave each potential participant a 'participant pack' that described the project and what their role as a participant would entail, which also enabled them to give us their consent (which could be either in writing, by completing and returning the consent form, or verbal, at the time of the interview, as appropriate). The format of these packs was tailored to the individual communication needs of each participant (e.g. in large print, on audio tape or CD, via email).

The recruitment process

The recruitment process took longer than anticipated due to a number of unforeseen challenges that were encountered, including delays in acquiring research governance approval from social services departments, difficulties in communicating with and gaining informed consent from potential participants, potential participants being unable to take part due to the onset of illness or passing away, and leads that had to eventually be abandoned. These are described in turn.

Research Governance Framework (RGF) approval

Social services departments within the UK are now required to ensure that any research carried out with their staff or service users meets the guidelines of the Research Governance Framework for Health and Social Care (RGF), which was first launched in May 2004 (see Department of Health (DoH) 2005); the framework sets out principles of good practice and summarises the responsibilities of partners involved in research across health and social care. In particular, social services departments are expected to obtain evidence from any organisation intending to conduct research that it will be conducted to high scientific and ethical standards. Whilst it was intended that a national system for social care ethics review would be established by June 2006, a survey published that year found that under half of all councils with social services responsibilities had systems for reviewing potential research in place; similarly, few were able to offer independent expert review of the ethics and research methods of external research. Furthermore, only half of all councils had a system to ensure that all staff were aware of the RGF. Since the RGF is relatively new and evolving, the report spends some time reflecting upon our experiences which may be helpful in the planning of other similar projects.

This mixed level of implementation of the RGF was certainly reflected in the research team's experience when applying for RGF approval for the project with the four social services departments who had agreed in principle to support the project. The first difficulty encountered was establishing who the key person was that dealt with RGF applications within each department, as it was clear that the majority of front-line staff we spoke to were not familiar with the RGF. Once contact was made with the appropriate person, the process that the research team was required to follow varied between departments and took between 5 and 11 weeks; three departments had their own application form (one of which was borrowed from another department as they had not yet developed their own) which was then submitted to the relevant committee; one such committee met every 3 months whilst the other two were formed as and when applications were received; the fourth simply required a brief outline of the research with a statement that we (the research team) believed that it fulfilled the criteria of the RGF. Only two of the departments were interested in the outcome of the team's successful application made to the ADASS (Association of Directors of Adult Social Services) for multi-site research approval, since they felt it bears little in relation to the RGF.

Whilst applications for RGF approval were being processed, sampling continued with the other professional contacts who worked in non-statutory organisations where RGF approval was not required.

Recruiting participants from a day centre for visually impaired people

Here we provide a detailed account of an ultimately unsuccessful attempt to recruit participants to the project. We feel the detailed account is useful because in many regards the challenges encountered by the research team at this stage of the recruitment reflect some of the barriers to communication and access to information encountered by people with hearing and sight loss.

One of the contacts working in a local-area branch of a voluntary organisation that provides services to elderly people nationally invited a member of the research team to attend their weekly day centre which caters for elderly people with sight loss, in order to talk to the members about the project and their possible involvement. There were only 5 members left in the group as many had passed away, and all apparently had difficulty with their hearing in addition to sight loss. When visited, only 3 of the group were present, two of whom (referred to here as 'Eleanor' and 'Ivy', both pseudonyms) had significant hearing loss as well as a visual impairment. Of the others, one lady who had both hearing and sight loss had recently suffered a fall and was in hospital, and another was on holiday, but it was subsequently established that she did not, in any case, have a significant hearing loss.

There was no opportunity to talk individually to either Eleanor or Ivy in detail about the project and to find out whether they would like to take part; rather, the researcher attempted to describe the project to all 3 members of the group (plus the volunteer and day centre worker that were also present). This proved very difficult, since one member in particular dominated the conversation and would answer for Eleanor whenever she was personally addressed. At one point, one of the members thought that the researcher's visit was the data collection. Due to the circumstances at the time of the visit (i.e. the group setting with the constant banter of the rest of the group and the background noise of sequence dancing taking place down the hall), it is likely that Eleanor understood even less about the project. For this reason there was concern that she would not be able to give informed consent even though she had apparently expressed an interest when the project had been introduced the previous week. When this was discussed later with the professional contact, it was agreed that both Eleanor and Ivy would be given the large print information sheets when they next attended to help them decide whether they would like to take part and that Eleanor's daughter would be contacted in order to see whether she would read the information about the project to her in a more appropriate setting. Some time later the professional contact confirmed that both Eleanor and Ivy were willing to take part in the project. Therefore the researcher visited a second time in order to confirm their participation, and to arrange interviews in a place of their choosing at a later date. However, whilst both Eleanor and Ivy seemed

pleased to see the researcher again, in the end, neither agreed to take part, for reasons that were never fully established or communicated to the research team. Eleanor in particular was quite confused about the project and what it involved.

Although the visit to the group did not help recruit participants to take part in the project, it was still informative as it enabled a first hand observation of the difficulties older people with both hearing and sight loss can experience when in a group situation, which is, in itself, data. Whilst the volunteer and day centre worker were both caring, well-intentioned individuals, the needs of the members with additional hearing loss simply were not catered for. Ivy at first seemed to have good hearing since she was joining in with the banter; however, it slowly became clear that she struggled to hear some things in detail and on several occasions had to ask people to repeat themselves. She was obviously very good friends with the more dominant lady in the group, and enjoyed joining in with the general banter and joke-telling within the group. Eleanor was sat a seat apart from the rest of the group, and on first impressions seemed a very frail, quiet lady who didn't speak much unless directly spoken to. Like Ivy, she was 87. She did not join in with the general banter, and it was explained that this was because her hearing (and sight, presumably) was quite poor. After some time, it was apparent that despite sitting in close proximity to the group, she was actually quite isolated from them. Eleanor could not follow what the researcher was saying, despite numerous attempts to engage her in the conversation. The researcher sensed that the other members were actually quite dismissive of her, and answered questions for her. It was discovered later, by asking Eleanor directly, that she could hear better on her left side – and yet she had been seated in the room in a position where everyone was on her right-hand side, hence the difficulty in hearing what people were saying. A further example of how isolated Eleanor was due to her dual sensory loss occurred following lunch, when the volunteer announced it was time to play Bingo. When asked why Eleanor was not playing, it was explained that she couldn't see the numbers on the board nor hear them being called out. So once again she was isolated from the group activities, and sat in silence whilst the others participated. In the end the researcher offered to play with Eleanor, and sat beside her on her left (which led to the discovery that her left-hand side was her good side for hearing) and repeated the numbers as they were called out, and told her the numbers that they needed to win. The Bingo boards did not appear to be very user friendly for people with visual impairment as the shiny laminated cover made the numbers difficult to see when the light shone on them, and the round pieces of plastic used to cover the numbers simply slid off if the card was tipped.

In conclusion then, whilst the exercise was not particularly successful in recruiting participants, it demonstrated some of the difficulties that older people with both hearing and sight loss can face in receptive communication and social interaction with others. It became apparent that it really is not suitable or appropriate to communicate with people whilst in a group setting, due to the many interruptions and background noise. This reconfirmed that we needed to interview people in a quiet, private setting, ideally in their own

homes. It was also useful in developing the skills of the researcher to provide good information in appropriate settings, and on the pitfalls to communication and access to information for this group.

Drop-out due to illness, death and misunderstandings

Once initial contact had been made with the potential participants by the professional contact, permission was sought for the research team to contact them directly to confirm they would like to take part and arrange an interview date. On most occasions, this was straightforward, and interviews were either arranged with the participant directly or via a family member or friend if they had difficulty communicating over the telephone (the research team also offered to arrange interview dates by letter or email, if preferred). On one occasion however, a friend who relayed messages to the potential participant did not describe the project very well and despite trying to reiterate what the project was about and why we wanted her to participate, the participant said she had accepted her sight and hearing loss and didn't want to talk about it, despite initially agreeing to take part when the professional contact first approached her.

The grandson of one potential participant was approached by the professional contact to see whether he thought his granddad would be interested in taking part; he felt that he would be interested, but before he was able to approach his granddad and talk to him about the project, his granddad fell and fractured his hip, and was hospitalised. It was later discovered that he had died in hospital shortly before Christmas.

Similarly, two other participants who initially confirmed to the professional contacts that they would like to take part were taken ill before contact was made by the research team, and therefore had to withdraw from the project.

Lack of participants fitting the criteria of dual sensory loss

Despite initial communication with the research team that suggested that there were two potential participants, one of the voluntary organisations that provided support to older people couldn't identify any service users who met the criteria of having difficulty with both their sight and hearing, following a look through their records of over 100 service users.

Other potential leads

Although contact was initially made with the manager of a sheltered housing service for older people with sight loss in which one resident was identified as having both sight and hearing loss, the lead was abandoned due to repeated lack of contact.

Another potential contact was identified informally when a member of the research team discovered that the parent of a colleague had sight and hearing loss, and later confirmed that she would like to take part in the project.

Description of the final sample of 20 participants

Following an intensive period of recruitment, 20 participants were recruited to the project and interviewed in their own homes. The following is a brief description of the final sample (detailed accounts are presented in the findings section):

- They were aged between 58 and 92 years old (most were in their 80's);
- 11 females, 9 males;
- Eighteen participants described their ethnicity as "White British/English", the remaining 2 were Indian;
- In terms of their home circumstances:
 - 7 lived alone
 - 11 lived with their spouse
 - 5 lived with child(ren) (2 in child's home, 3 in their own home)
 - 1 lived in a residential home for the elderly
- In terms of tenure:
 - 13 participants owned their home outright
 - 1 was buying it with a mortgage
 - 3 rented from the council or a housing association
 - Others were in residential home (1) or living in child's home (2)
- They had a variety of visual impairments and hearing impairments, and times of onset;
- All but one had other health problems and/or disabilities;
- In terms of registration:
 - As visually impaired: 10 registered blind, 7 partially sighted, 1 was registered but didn't know the category, and 2 said they were not registered;
 - As hearing impaired: only 2 said they were, 11 said they were not registered, 7 didn't know;
 - As deafblind: 4 said yes (but 2 were prompted by the deafblind specialist worker who was present at the time of the interview), 10 said they weren't registered, and 6 didn't know;
 - As disabled: 5 said they were, 4 said they were not, 11 didn't know or weren't sure.
- The participants lived in a range of locations, both urban and rural, from around the UK.

Findings from the 20 case studies

Detailed descriptions of the 20 participants

The following section provides an overview of the lives and circumstances of each of the 20 participants who took part in the project. Each description includes the following information: personal data relating to their age and date of birth, marital status, place of birth, ethnic group, and religion; the participant's household composition and support network (i.e. their main sources of daily or regular support); a description of their home and home area, including the proximity of local mainstream services (e.g. shops, GP, etc); the participant's visual and hearing impairments; other health problems/disabilities; and the extent of their participation in the project. All names used are pseudonyms.

The description of each participant's home area utilises the ACORN ("A Classification of Residential Neighbourhoods") classification system (developed by CACI Ltd; see <http://www.datadepot.co.uk> for further details). It is based upon Census and lifestyle data and is used to describe the populations' consumer lifestyle and purchasing characteristics, and classifies the people and households within each postcode in the whole of the UK. The classification scheme is used in this report to give an indication of the demographic, employment and housing characteristics of the surrounding neighbourhood in which each participant lives, as measured by the 2001 Census. It does not classify the participant's own characteristics or that of their family.

The case studies also describe the level of functional vision each participant had, at the time of the first interview; participants were asked six questions regarding how much they could see, as used in a number of surveys including the 1991 RNIB Adults Needs Survey (Bruce, McKennell and Walker 1991) and the Network 1000 study (Douglas, Corcoran and Pavey, 2006). The six questions enabled the 'scoring' of participants' maximum or 'best' level of functional vision on a seven point scale (0-6), which is reported for each of the participants; a score of level 0 indicates no light perception at all; level 1 indicates light perception only; level 2 – can see the shapes of furniture in a room; level 3 – can recognise a friend if close to his or her face; level 4 – can recognise a friend at arm's length away; level 5 – can recognise a friend across a room; and level 6 – can recognise a friend across a road.

An overview of the sample is given in the section entitled 'Description of the final sample of 20 participants' at the end of the 'Methods' section (on the previous page).

Participant 1 – Delia

Sex	Female
Date of birth / Age at time of 1st interview	01-11-1920 / 86
Place of birth	UK
Ethnic Group (self-described)	White British
Religion	Baptist

Marital status

- At the time of the first interview, D was married to Reginald, and had been for 56 years. He passed away suddenly just after Christmas, a few months before the follow-up interview.

Household composition/Support network

- At the time of the first interview, D lived with her husband and her son who was 53 years old and also partially sighted (from birth), though his sight is better than D's.
- Following her husband's death, D still lives with her son. She has no other children.
- Her son is her main source of daily support though she also has occasional support from a local voluntary organisation for people with sight loss, and friends from church who take her shopping every week.

Description of home

- D lives in a small two bedroom bungalow in a quiet cul-de-sac in an area described as type 9 in the ACORN classification scheme, which describes this postcode area as being characterised by older families living in prosperous suburbs.
- She and her husband owned the property outright, and have lived there for the past 26 years.
- In terms of special adaptations, social services recently fitted a handle and seat in her bath so that D can continue to shower independently; she was having trouble getting in and out of the bath.

Proximity of local mainstream services (e.g. shops, GP, etc)

- D does not go out alone. Her son does not drive due to his visual impairment, so they rely on public transport and taxis, or lifts from friends.

Visual Impairment

- D has age related macular degeneration, and first noticed it affecting everyday things when she was 84. She is registered as partially sighted.
- At the time of the first interview she had level 2 functional vision (could see the shapes of furniture in a room). She cannot read print at all. When visited for a follow-up interview, D felt her sight had deteriorated further.
- D described herself as sometimes feeling “depressed” about her sight loss and how it makes certain everyday tasks like shopping and cooking difficult; these feelings have worsened since losing her husband who was her main source of daily support and companionship.

Hearing Impairment

- D wears two hearing aids and has had difficulty with her hearing for many years, since her early 30's. She does not know the cause of her hearing loss.
- D has difficulty hearing someone talk in a quiet room. She has had a loop system fitted so that she can hear the television, but she cannot see the screen so does not watch it very often. She can hear the doorbell and telephone ring if she is wearing her hearing aids.
- At the time of the follow-up interview, D felt her level of hearing was about the same as when we first met her.

Other health problems/disabilities

- D has bowel problems, which affects her on a daily basis and was described as a “nuisance” making travel away from the home difficult due to its unpredictable nature.
- She also has arthritis in her fingers which makes any independent living skills requiring dexterity difficult.
- D is registered as a disabled person.

Participation in the project

- D took part in both an initial interview and a follow-up interview.
- She at first agreed to keep a diary, but found it too difficult to operate the tape recorder due to deterioration in her vision.

Participant 2 - Belinda

<u>Sex</u>	Female
<u>Date of birth / Age at time of 1st interview</u>	17-02-1925 / 82
<u>Place of birth</u>	UK
<u>Ethnic Group (self-described)</u>	White English
<u>Religion</u>	Church of England

Marital status

- Belinda was widowed 14 years ago

Household composition/Support network

- B lives alone since being widowed. She does not have any children of her own, though she has step children who she is in contact with and sees occasionally.
- Her main source of support and companionship is her two nieces who both live nearby (one on the same housing estate).

Description of home

- B lives in a mid-terrace 2 bedroom ex-local authority house that she owns outright. She has lived in the property since she was 11 years old as it was previously her parents' home. The area is described as type 47 in the ACORN classification system, which describes this postcode area as being characterised by low income families living in terraced estates.
- B said her neighbours aren't particularly friendly, and can be noisy but ignore you if you ask them to be quiet.
- The house does not have any special adaptations fitted.

Proximity of local mainstream services (e.g. shops, GP, etc)

- At the end of B's street is an assortment of small retail shops, and buses into local suburbs with more substantial shopping centres stop outside of B's home.
- She uses the buses, unaccompanied, several times per week. Although she finds mobility difficult due to the combination of her visual impairment and leg problems, she manages to get around on foot and by bus.

Visual Impairment

- B has always had some difficulty with the sight in her right eye ("only 9%"), but a stroke in 1999 then affected her left eye which she described as "devastating".
- At the time of the first interview she had, at best, level 5 functional vision (could recognise a friend across a room) though she said she could do this only sometimes.
- She could see well enough to read a newspaper headline, but not ordinary newspaper print or a large print book.
- When visited for a follow-up interview, B felt her sight had deteriorated further.
- B has to administer eye drops several times a day as she suffers from dry eyes; she described her consultant as being unsympathetic when she told him that she had trouble doing this each day due to her visual impairment.

Hearing Impairment

- B was in her 50's when she first noticed having difficulty with her hearing. She does not know the cause of her hearing impairment.
- She wears two digital hearing aids, one which she bought privately at "great expense" and one from the NHS; she described the NHS hearing aid as being much better out of the two.
- B says she has difficulty hearing someone talk in a quiet room if they "mutter" and don't talk clearly. She can follow a TV programme with the sound up, and hear the doorbell or a telephone ring. She uses a big button telephone and uses the hands-free facility.

Other health problems/disabilities

- B has diabetes which she manages using medication and a carefully controlled diet.
- The stroke also affected her mobility and coordination, making walking difficult and slow. At the time of the follow-up interview, B said she found walking more difficult than when we first met her.
- B had also struggled to recover from a flu and diarrhoea bug just after Christmas and had to attend hospital as a day patient. It was aggravated by her diverticulitis (a chronic inflammation of the gut which typically presents itself as periodic fever and abdominal pain).

Participation in the project

- B took part in both an initial interview and a follow-up interview.

Participant 3 – Mary

Sex	Female
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<u>Date of birth / Age at time of 1st interview</u>	12-08-1923 / 84
<u>Place of birth</u>	UK (City currently resides in)
<u>Ethnic Group (self-described)</u>	White English
<u>Religion</u>	Church of England, but not a regular church goer

Marital Status

- Widowed and has been for some years; they had been married for 50 years.

Household composition/Support network

- M lives alone.
- She has a daughter who lives approx. 25 miles away, who visits once a week. M had another daughter who passed away a few years ago. She is still in touch with her grandchildren but none of them live in close proximity.
- M's main source of support is a volunteer from Age Concern who visits once a week to take M shopping and help with chores around the home, particularly preparing meals for the forthcoming week. She is also an important companion and friend to M, who describes her as "absolutely wonderful".
- Recently, another lady has started visiting for two hours per week from another local charity as M's daughter apparently felt she needed additional support; she also carries out odd chores and provides companionship.

Description of home

- M lives in an area described as type 33 in the ACORN classification scheme, which describes this postcode area as being characterised by middle income, older couples. M's home is a post-war semi-detached house on a main road, with front and back gardens. There is a separate lounge and dining room, a small kitchen and an upstairs bathroom. She employs a gardener to help with the garden as she can no longer manage due to her sight loss.
- At the time of the first interview she did not have any special adaptations in her home, but she recently fell in her bathroom when trying to get into the shower; she described this as very frightening, as she was alone and couldn't call anyone for help. She has since had the bath removed and a walk-in shower fitted by a relative.
- M owns the house outright and has lived there for 54 years.

Proximity of local mainstream services (e.g. shops, GP, etc)

- There is a large supermarket at the end of her street, but M does not go out unaccompanied as she is not confident walking due to her sight loss.

Visual Impairment

- M could not remember the name of her eye condition, but after prompting, said she had macular degeneration. She described it as being in a "grey fog", and said the weather makes a difference, so she dreads the darker days of winter.
- She first noticed difficulty with her sight about 5 years ago. She believes she is registered as blind.

- At the time of the first interview she had level 4 functional vision (could recognise a friend at arm's length away). She cannot read print and misses doing crosswords and reading 'Take a Break' magazine. When visited for a follow-up interview, M felt her sight had deteriorated further.

Hearing Impairment

- M wears one hearing aid. She does not know the cause of her hearing loss but suspects it may be due to loud music played in local hotels and pubs where she used to entertain as a member of a band, and the noise in the factory where she used to work. She has had difficulty with her hearing for the past 25 years or so.
- M can hear someone talk in a quiet room ok when she is wearing her hearing aid. She cannot hear the doorbell, telephone ring or alarm clock if she is asleep and not wearing her hearing aid.
- At the time of the follow-up interview, M felt her level of hearing was about the same as when we first met her.

Other health problems/disabilities

- She has bronchiactisis but it is not as bad as it used to be, and no longer keeps her up at night coughing.
- She often feels tired and lacks energy in the daytime and has to have frequent periods of rest.
- She fell about a year ago in her garden as she could not see a box that had been placed by a well-meaning neighbour as a step, and bent her thumb; she did not go to the doctor or hospital at the time (she didn't want to bother anyone), and now it is permanently bent making some household tasks difficult.
- As far as she is aware she is not registered as a disabled person, or as deaf or deafblind.

Participation in the project

- M took part in both an initial interview and a follow-up interview.

Participant 4 – Julie

<u>Sex</u>	Female
<u>Date of birth / Age at time of 1st interview</u>	12-02-1938 / 70
<u>Place of birth</u>	UK (City she currently resides in)
<u>Ethnic Group (self-described)</u>	White English
<u>Religion</u>	Church of England

Marital Status

- J has been married for 50 years.

Household composition/Support network

- J lives with her husband who is still working and one of her grown up sons who has a disability and does not currently work.
- She also has another son who lives in a nearby suburb with his family; he often provides transport for J and her husband if they cannot travel to a destination using public transport.

- J has retained a high level of independence, and travels unaccompanied on buses for social activities and carrying out voluntary work for two local charities.
- Her son built her a computer and adapted it to her visual impairment, and gave instruction on how to use it.

Description of home

- J lives in a 3 bedroom Victorian terrace, with a large garden in an area described as type 13 in the ACORN classification scheme, which describes this postcode area as being populated by well-off professionals living in larger houses and converted flats.
- J and her husband have lived in the property for 21 years, and they own it outright.
- The only special adaptation to the home is a handrail up the stairs installed by one of her sons to aid her mobility.

Proximity of local mainstream services (e.g. shops, GP, etc)

- At the end of the street is a variety of small and medium size stores, plus a bank and a post office. Neither her husband nor son drives, so they use public transport for trips farther afield, or rely on J's other son who lives nearby and has his own car.

Visual Impairment

- J does not know what has caused her sight loss, but she has had problems for the past 20 years, and her sight has gradually deteriorated over that period. She has Sjogren's syndrome, and has to put drops/artificial tears in regularly to avoid having dry eyes.
- She describes her vision as blurred, with quite a lot of 'floaters'. Her optician recently told her that her retina was stretched, but not detached.
- J has level 5 functional vision (can see well enough to recognise a friend across a room). As far as she is aware she is not registered as visually impaired, hearing impaired, or as deafblind, although she receives Attendance Allowance.

Hearing Impairment

- J has a digital hearing aid that she bought privately, but she doesn't always wear it as it is uncomfortable. She is hoping to get referred by her doctor to see a specialist soon and see whether she can get a better aid.
- She can hear someone talking in a quiet room, but struggles if there is background noise.
- She does not know the cause of her hearing loss which began 7 years ago, and assumes it is just down to old age.

Other health problems/disabilities

- J has both rheumatoid and osteo-arthritis (latter only recently diagnosed), and also experiences stiffness in her hands and joints from the Sjogren's syndrome (often associated with rheumatoid arthritis). The pain tends to be more intense in the afternoon, though she has pain in her hands and hips all of the time. She doesn't like taking pain killers too often as they upset her stomach as she also has diverticulitis.

Participation in the project

- J took part in one interview for the project.

Participant 5 – Jackie

<u>Sex</u>	Female
<u>Date of birth / Age at time of 1st interview</u>	06-02-1919 / 88
<u>Place of birth</u>	UK
<u>Ethnic Group (self-described)</u>	White British
<u>Religion</u>	Church of England

Marital Status

- J is single, and has never been married.

Household composition/Support network

- J lives alone, and has never been married or had any children. She was an only child.
- J's only living relatives are a cousin who has two children, but she lives and works in another city and does not visit J as often as J would like.
- J finds shopping difficult due to the large numbers of people around, and aisles that "appear to stretch to infinity". J is aware that she could ask a shop assistant for help, but does not feel confident doing so and thus prefers someone doing it for her. Following a nurse's suggestion she asked friends at the Church to help, one of whom has fetched her shopping every week; but this informal arrangement is not sustainable in the long term. It later emerged that a local voluntary organisation were planning to visit J to discuss her requirements for help with shopping.
- J has a friend who does the garden, and another who does the housework (services for which J pays). She described her friends as "very good", since she doesn't have any family to provide support.

Description of home

- J lives in a large detached 4 bedroom house with a large rear garden, in an area described as type 31 in the ACORN classification scheme, which describes this postcode area as being typically populated by home owning Asian families, with high levels of family income, high levels of interest in current affairs, and a high number of degree level qualifications.
- The property used to belong to J's parents; J now owns the property outright and has lived there for 50 years.
- She doesn't have any special adaptations to the home, and finds getting about quite easy. She wishes she had installed a downstairs' bathroom years ago, but feels it is too late in life to do so now, due to all the upheaval.

Proximity of local mainstream services (e.g. shops, GP, etc)

- J's church, which she attends regularly, is directly opposite her house.
- There is also a bus stop nearby that J uses to travel to the local shops, social gatherings related to the church and visual impairment support group meetings. However, as her sight and hearing deteriorate, she is finding this increasingly difficult to do.

Visual Impairment

- J said she has macular degeneration in both eyes, and has recently been registered as partially sighted. It was diagnosed recently in the past year.

- J has been paying for private treatment but it is expensive so she will probably ask for NHS treatment in the near future.
- J has level 4 functional vision (can see well enough to recognise a friend at arm's length).

Hearing Impairment

- She does not know the cause of her hearing loss, explaining “it’s just that it’s failing”.
- She wears two hearing aids that need cleaning and do not work very well; she is hoping to make a case for digital hearing aids supplied by the NHS as she has both the sight and hearing loss to cope with and crossing roads is becoming difficult and dangerous.

Other health problems/disabilities

- J feels grateful that other than her hearing and sight loss, she is quite well, and does not suffer from arthritis or other debilitating ailments. She hopes to be able to remain independent and living in her home for as long as possible.
- She suffers from problems with her “water works”, for which she feels she receives adequate support from a visiting nurse; she uses pads and is careful about when she has a drink if she is planning to go out.

Participation in the project

- J took part in one interview for the project.
- Following a second visit, J seemed a little confused about the project and who the researcher was; her memory seemed to have deteriorated, and therefore a second interview was considered inappropriate and was not carried out in the spring.
- She did, however, agree to keep a diary before the Christmas period; in practice she found this difficult and recorded a diary for 4 days out of the 7 we initially asked for, using the tape recorder we supplied.

Participant 6 – Eva

<u>Sex</u>	Female
<u>Date of birth / Age at time of 1st interview</u>	10-03-1920 / 88
<u>Place of birth</u>	UK (City where residing)
<u>Ethnic Group (self-described)</u>	White British
<u>Religion</u>	Church of England

Marital Status

- E was widowed 24 years ago.

Household composition/Support network

- Since being widowed, E has lived alone.
- She has one daughter who lives over 200 miles away; however, her daughter visits every month to help E deal with her post and other matters, and at least once per year E goes to stay with her daughter, normally at Christmas time, though she is concerned that she is a burden so may not go again.

- E’s main support network is her daughter, and the deafblind worker contracted in to social services who has helped with special equipment (e.g. liquid level indicators, bump-ons) and takes her to hospital appointments.

Description of home

- E lives in a 2 bedroom end of terrace house which she rents from the council. She has lived in the house since it was built, approximately 32 years ago.
- The property is in an area described as type 45 in the ACORN classification scheme, which is commonly populated by low income, older people living in smaller semi-detached houses few of whom will have mortgages or be educated to degree level.
- There are no special adaptations in the house.

Proximity of local mainstream services (e.g. shops, GP, etc)

- E still manages to use the buses to get to the local shopping centres, although she has had some problems with unhelpful bus drivers. She has to stop every bus to ask if it’s the right one, or relies on other people at the bus stop to help her and, most of the time, they do.

Visual Impairment

- E has level 3 functional vision (can recognise a friend if close to her face). She struggles to read any print without a magnifying aid.
- She first noticed difficulty with her sight 7/8 years ago, and was diagnosed with macular degeneration. She described the medical staff who dealt with her as “wonderful”, for explaining the prognosis carefully to her. She is registered partially sighted and recorded as deafblind by social services.

Hearing Impairment

- E’s difficulty with her hearing started when she was a small child and she had measles. She now wears two digital hearing aids.
- When wearing her aids, she has no trouble hearing people talking in a quiet room or her doorbell/telephone ring, though she does struggle if there is background noise. She uses a big button telephone with an amplifier.

Other health problems/disabilities

- E has thyroid trouble, arthritis, angina and asthma, and takes medication for these conditions every day. She is very organised, so is able to administer her own medication.

Participation in the project

- E took part in one interview for the project.
- The professional contact was present during the interview as E did not want to be interviewed alone.

Participant 7 – Keith

Sex	Male
<u>Date of birth / Age at time of 1st interview</u>	21-07-1920 / 87
<u>Place of birth</u>	UK

Ethnic Group (self-described)	White British
Religion	Christian

Marital Status

- K is divorced.

Household composition/Support network

- K lives alone. He has 7 children although one died at birth. The others are all grown up. He is in regular weekly contact with two of his daughters, one who lives 30 miles away, the other approx. 16 miles away and one of his sons visits 3 or 4 times per week. He is also in contact with another son, but he can be bad tempered if K calls him too often.
- K's main source of support is a care agency for which he has to contribute £51 per week. The carer comes for half an hour in the morning, at lunchtime, and in the evening, mainly to help him prepare meals. They do some cleaning but only very little. He is not particularly happy with the service.

Description of home

- K lives in a ground floor 2 bedroom maisonette that he has lived in for 8 years and rents from the local area's housing association.
- The property is in a postcode area described as type 51 in the ACORN classification scheme, which is commonly populated by single parents and pensioners living in council or housing association properties. With high numbers of single pensioners and single parents, overall income levels are low and unemployment levels are high. This type has the lowest level of qualifications of all ACORN types, which indicates there is little chance of these areas becoming more prosperous.
- K described his neighbours as ok, though he said the person in the flat above him is a known drug dealer so K tries not to bother him as he doesn't want any trouble.
- There are no special adaptations in the flat, though it was built to accommodate wheelchairs so it has a wide corridor and doorways.

Proximity of local mainstream services (e.g. shops, GP, etc)

- Due to K's difficulties with mobility, he is purchasing a motorised wheelchair for travel outside of the home. At the present time, he cannot go out alone to the local shops and relies on the care agency staff to buy groceries and his children to help him collect his pension to pay the care staff.

Visual Impairment

- K has level 5 functional vision (can recognise a friend across a room, but only in good light). He can read large print books, but it is a slow process.
- K has glaucoma and has cataracts in both eyes. He is not sure whether they will be able to operate on them. He was first diagnosed about 12 years ago, and his eyesight has slowly deteriorated since then.
- K is registered as blind and deafblind, but not deaf or disabled as far as he is aware.

Hearing Impairment

- K can hear reasonably well in his right ear, but has no hearing in his left ear. His hearing has deteriorated only fairly recently in the last year.

- He currently has one digital hearing aid but cannot put it in his ear himself; he is hoping to have two new digital hearing aids soon.

Other health problems/disabilities

- K has trouble with his legs and was recently hospitalised as he had suspected blood clots; he didn't have a very good experience whilst in hospital, as the staff were not accommodating to his sensory impairments. He has to wear special tight Velcro stockings on his legs and wear waterproof leggings when he showers.
- K also has an under-active thyroid and was recently diagnosed with arthritis which affects his mobility, and he has to move very slowly around his home to prevent falling over.
- He has to take 21 different tablets a day to help with his health conditions.

Participation in the project

- K took part in one interview for the project.

Participant 8 – Molly

<u>Sex</u>	Female
<u>Date of birth / Age at time of 1st interview</u>	13-03-1919/ 88
<u>Place of birth</u>	UK
<u>Ethnic Group (self-described)</u>	White British
<u>Religion</u>	Methodist

Marital Status

- M is married.

Household composition/Support network

- Margaret lives with her husband of 62 years and her grown up son, who is the main carer for both M and her husband. Her son is not in paid employment which is linked to his condition ME (myalgic encephalomyelitis).
- They have home help visits to do their washing and ironing, which she feels is very expensive at £24 for fortnightly visits. She used to have assistance with personal bathing, but she didn't like it as they never kept to a schedule and they didn't always do a good job. M manages to wash by herself now, though she needs her son to cut her toe nails as she can't see to do it herself.
- Since she was recently referred, M has occasional contact with the deafblind worker employed by social services. She would ideally like some female company, but isn't sure about attending a day centre or group as it might not fit in with her daily routine.

Description of home

- M and her husband live in their son's 4 bedroom terrace house which has a cellar and small backyard; they have lived there for 36 years. Her son owns the house outright.
- A hand rail has been fitted to the stairs and a rail to help her get into the bath.

- M's home is in a postcode area described as type 37 in the ACORN classification scheme, which is commonly populated by very high numbers of young Asian families and students sharing rented accommodation in older terraced housing in major towns and cities. These houses are some of the most crowded in the country. Unemployment levels are higher than average and qualification levels and incomes are low.

Proximity of local mainstream services (e.g. shops, GP, etc)

- There are small shops and stores nearby but M does not go out alone. Neither her son nor her husband drives a car.

Visual Impairment

- M said she has scarring at the back of both of her eyes and a detached retina. She also had cataracts. M said that treatment was delayed because her doctor would not refer her to a consultant until she had a note from her optician, and by the time she was able to visit one, her eyesight had deteriorated too far.
- She has level 3 functional vision (can recognise a friend if close to his/her face), and thinks she was about 80 when she first started getting problems.
- M talked at length about how awful it is when you can't see – that she can't do things for herself, and some days she's depressed about her visual impairment and cries; but most days she tries to "make the best of it" as she says she is looked after and realises that some people have to live on their own.

Hearing Impairment

- M has had difficulty with her hearing since she was in her 50's, when a blood vessel burst in her left ear. She recently started to lose hearing in her right ear, and now struggles to hear someone talk even in a quiet room.
- M wears two hearing aids but they are not working properly at the moment, and she is hoping they will be replaced soon, possibly with digital ones.
- The deafblind worker from social services installed a loop system in her home so she can hear the door bell and telephone ring.

Other health problems/disabilities

- M has angina and suffered a heart attack when she was 71. She also has breast cancer and a lump on her hand that is undergoing tests for cancer. In addition to this, she has Irritable Bowel Syndrome (IBS) and suffers gastric reflux if she takes aspirin.
- M has some difficulty with her mobility and uses a commode downstairs so that she doesn't have to go upstairs to use the bathroom.
- She described herself as being very tired much of the time, and said she never knows from one day to the next how her general state of health will be.

Participation in the project

- M took part in one interview for the project.
- Although she initially agreed to, M was unable to take part in a follow-up interview as she was very poorly at that time; her medical prognosis was unclear.

Participant 9 – Fiona

<u>Sex</u>	Female
<u>Date of birth / Age at time of 1st interview</u>	28-09-1948 / 59
<u>Place of birth</u>	UK, city close to where living now
<u>Ethnic Group (self-described)</u>	White British
<u>Religion</u>	Christian (Non-practicing Catholic)

Marital Status

- F has been married for 33 years.

Household composition/Support network

- F lives with her husband. They have no children.
- F's husband is her main source of support, though she also has a communicator guide visit weekly to take her shopping for "retail therapy" which she describes as "wonderful!"
- She has had mobility training in the past, though she does not go out unless she is accompanied by her husband as she doesn't feel safe due to the combination of her sight and hearing loss.

Description of home

- They live in a 3 bedroom semi-detached house with front and back gardens and an upstairs bathroom. They are buying the house with a mortgage which is almost fully paid, and have lived there for 19 years.
- The area is described as type 39 in the ACORN classification scheme, which is commonly populated by skilled older families living in terraces.
- They have carried out a number of modifications to the house to aid F, some of which have been paid for by social services. They include white painted strips to the garden path steps, installing outside security lights, a handrail up the steps to the house, and a grab rail to help her get in the bath though by the time of the follow-up interview, they had a walk-in shower fitted at their own expense so F could retain her "dignity and independence".

Proximity of local mainstream services (e.g. shops, GP, etc)

- F lives in a village with a variety of small shops, but does not go out without her husband. Her husband has a car which they use regularly for day trips.

Visual Impairment

- F has level 3 functional vision (can recognise a friend if close to their face) and is registered blind.
- F said as far as she knows she is a world's first since she has acquired 3 connective tissue disorders including Sticklers syndrome (diagnosed in 1986), Goldman Fathrey (diagnosed in 2004), and Wagner syndrome (diagnosed in 2007), and yet they can find no history of any of these conditions in her family background.

- She has been told that although she is likely to lose all of her sight and hearing, she will die *with* the conditions, rather than *because* of them which she sees as a “big bonus”. Whilst her conditions have had a terrible effect upon their lives, F and her husband remain positive and try to enjoy life as much as they can while they can.

Hearing Impairment

- F’s hearing loss is due to the Stickler syndrome and possibly the Wagner syndrome, though the effects of the latter are not yet clear.
- She wears two digital hearing aids and has a loop installed in their home so she can still hear conversation when there is background noise. She cannot use an ordinary telephone; they have a big button phone with an amplifier.

Other health problems/disabilities

- All of F’s other health problems are related to the Sticklers syndrome; they include osteo-arthritis which causes F pain ‘24 hours a day, 7 days per week’. F describes this as the most difficult thing for her to cope with even with the medication which merely takes the edge off the pain.
- She is also asthmatic, and has non-specific polyposis (where her body produces warts, polyps and cists – fortunately none so far have been malignant) for which she is occasionally hospitalised.
- She describes the medical care she has received from the very beginning as “wonderful... totally flawless”.

Participation in the project

- F took part in both an initial interview and a follow-up interview.
- Her husband took part in a separate telephone interview after F suggested that we speak to him.

Participant 10 – Pamela

<u>Sex</u>	Female
<u>Date of birth / Age at time of 1st interview</u>	07-04-1921 / 86
<u>Place of birth</u>	UK
<u>Ethnic Group (self-described)</u>	White British
<u>Religion</u>	Christian (Salvation Army)

Marital Status

- P has been widowed for 22 years.

Household composition/Support network

- P lives in a residential home for the elderly, which does not specialise in sensory impairments. She has lived there for 15 years, since she could no longer manage to live by herself in the top-storey flat she shared with her late husband.
- P feels that the standard of care has deteriorated in recent years, and is unhappy with the amount of contact she has with staff, the meals, and other aspects of the service. Although consultation with residents takes place, P feels nothing is ever improved or changed as a result. There is a

high turnover of staff, and the staff have not been trained in issues relating to sensory impairment. However, P does not want to move to a different home as she has been there for so long and knows her surroundings well; this continuity is now even more important as her vision has deteriorated further since the first interview and she has no longer has even light perception (i.e. has level 0 functional vision).

- P has two daughters, one of whom lives close to the residential home. She visits P every Thursday, when the home holds a coffee morning to raise funds, with which she helps out.

Description of home

- P has her own small bedroom with room for a single bed, a television and cupboard, with a small kitchenette area with a sink, microwave and fridge. She also has a small washroom with a sink and toilet. P strip-washes each day, and has a shower once a week in the home's communal bathroom with the help of a carer. She has breakfast and dinner in her room alone, but usually has lunch in the communal dining room though she said she is a bit of a loner and prefers her own company.

Proximity of local mainstream services (e.g. shops, GP, etc)

- P cannot go out alone, and hasn't left the residential home for a long time. Her daughter buys any small purchases she requires with P's money, though P cannot afford many things as she only receives 'pocket money' as her pension is automatically put towards the cost of her stay at the home. Social services pay the rest of the cost.

Visual Impairment

- At the time of the first interview, P had level 2 functional vision (could just about see the shapes of furniture); however, when visited again for a follow-up interview she said her vision had deteriorated drastically and she no longer had even light perception – "everything is dark".
- P has Glaucoma. She first noticed a problem with her sight when she was about 57 years old. She is registered blind, but not as deaf, deafblind or disabled as far as she is aware.

Hearing Impairment

- P started to lose her hearing about 4 or 5 years ago. She has one hearing aid, and was promised a second for her other and better ear but that was 3 years ago.
- She has great difficulty hearing someone talk even in a quiet room, and for this reason she rarely goes down to the common room as she can't hear what others are saying.

Other health problems/disabilities

- P has water retention in her legs which swell to the extent that she cannot walk some days. She has a wheelchair so she can still go down to the dining room, but it isn't wide enough so she is having another one made-to-measure; however, it is a slow process.
- The drops she has to take for her eyes each day causes inflammation on her chest. At the time of the first interview she was taking a course of antibiotics to clear a chest infection.
- There isn't a doctor or nurse on site at the home, but if one is requested before 9 am they will visit the same day. P has to take a lot of tablets and

administers her own medication, and for now is able to tell the tablets apart. She is aware that soon she may need to ask for assistance.

- The staff at the home tell her she is too independent; they say that sometimes they forget she is there at all! Unfortunately, in practice, P often gets forgotten and is not checked upon for hours even though they are supposed to check on residents every 2 hours. She said it would be nice if she had more regular visits as it can be lonely, particularly on the weekends when nothing happens in the home.

Participation in the project

- P took part in both an initial interview and a follow-up interview.

Participant 11 – Colin

<u>Sex</u>	Male
<u>Date of birth / Age at time of 1st interview</u>	17-10-1915 / 92
<u>Place of birth</u>	UK
<u>Ethnic Group (self-described)</u>	White British
<u>Religion</u>	Christian

Marital Status

- C was widowed in January 2005.

Household composition/Support network

- C lives alone; he is supported by both a care agency and his two daughters who live nearby and take it in turns to visit him every day at tea time to prepare his dinner and meals for the following day, and spend some time with him.
- The care agency was put in place by social services after his stroke so C could return to live in his own home; he did not want to live in a residential home, and says he never wants to in the future. The agency provides a carer to help C get out of bed, and to wash and dress. They then prepare his breakfast. He then sits alone and is virtually chair-bound due to the stroke he suffered after his wife's death three years earlier. A different carer then comes at lunchtime to prepare his lunch, which is usually a microwaveable ready-meal or sandwiches prepared the night before by his daughter which he usually enjoys, followed by a pudding. He is reasonably happy with the service though was upset that they stopped one carer visiting him as they were becoming "too close". He wishes the carers would spend more time with him when they come, but they are always in a hurry to go to their next appointment.
- C also has a communicator guide that visits him every week. She works for the social services deafblind team, and as well as providing companionship, she helps arrange things that Colin needs, like home visits from medical staff for check-ups and treatments.

Description of home

- C lives in a 2 bed terrace, with 2 reception rooms downstairs, and a small courtyard rear garden in an area described as type 38 in the ACORN

classification system; in this type of area, family income and the number of degree level qualifications are low. C does not know any of his neighbours anymore.

- He no longer uses the upstairs rooms as he cannot climb the stairs; he now sleeps in the lounge. The bathroom is upstairs so he uses a commode downstairs and has to strip-wash each day with the help of his carer. He said he would love to have a bath again. The 2nd reception room has a kitchenette where his meals are prepared; there is also a chair which C sits in all day, beside a table with a daisy player and radio/CD/tape player. He listens to the radio or to talking books during the day but cannot change the tape or programme himself, so he has to wait for one of the carers to visit.

Proximity of local mainstream services (e.g. shops, GP, etc)

- There are small shops nearby but C never goes out alone, and rarely goes out even when accompanied – he says he hasn't left his home for months.

Visual Impairment

- C has level 1 functional vision (can see the shapes of furniture in a room). However, when visited for a follow-up interview he felt his eyesight had deteriorated further. He is registered as blind.
- Without prompting, C said he had Age-related Macular Degeneration. He first noticed having difficulty with his eyesight when he was 86.

Hearing Impairment

- C first noticed having difficulty with his hearing about 20 years ago, when he had his first hearing aid fitted. He now wears two digital hearing aids.
- He does not know the cause but wonders whether it was due to the gunfire and bomb explosions he experienced as a soldier during the Second World War. He also felt his hearing had deteriorated since my first visit.
- C struggles to have a conversation even in a quiet room; visitors have to sit very close to him so he can hear them. He said he used to love listening to football matches on the radio but cannot hear the commentary anymore over the noise of the crowd.

Other health problems/disabilities

- C had a stroke soon after his wife died which his doctor said was probably due to stress; he is practically confined to his chair all day and finds it difficult to move around his house even with a Zimmer frame. He can just about manage to feed himself with a special fork and spoon, but can only use one of his hands. Due to his immobility, he has a key pad on his front door which his daughters and paid carers have a special code for so he does not have to get up to answer the door.
- At the first interview, C said he was afraid of falling so he has a special panic button around his neck that alerts a company that he needs help; when visited for a follow-up interview, C said he had recently fallen during the night when trying to go to the toilet and although he pressed the panic button it seemed like a long time before anyone came to help; the company called his daughter and she came with her husband and helped him back into bed. C is not particularly happy with the way the service operates, and worries about falling again. He said the service costs over £200 per year.
- C had a pacemaker fitted in 1991 to prevent him experiencing black-outs.

Participation in the project

- C took part in both an initial interview and a follow-up interview.

Participant 12 – Rajat

<u>Sex</u>	Male
<u>Date of birth / Age at time of 1st interview</u>	08-02-1950 / 58
<u>Place of birth</u>	Malawi, Africa – moved to UK to live in 1977. Described English as his first language.
<u>Ethnic Group (self-described)</u>	Indian
<u>Religion</u>	Hindu

Marital Status

- R has been married for 33 years.

Household composition/Support network

- R lives with his mother, his wife and grown up daughter in his son's house; his son also lives in the property.
- His main support network appears to be his wife, though she is ill at the moment (the cause of her illness/prognosis was not clear in the interview).
- R had his larynx removed as a result of cancer, and he can only use speech through an electronic device he holds to his throat. When asked how his cancer and resulting difficulties has affected his family, he said at first they were shocked, but soon adjusted to it; however, he now feels that they are tired of it and can't/won't help him as they are busy with their lives. R seemed quite unhappy during the interview, particularly when talking about the attitudes of his family and friends (as he perceives them), many of whom have stopped visiting him. He does not know why but suspects that they feel uncomfortable due to his condition.

Description of home

- For the past 3 years, R and his wife and grown up daughter have lived in a mid terrace house owned by his son; his son is due to be married later in the year and so R and his mother, wife and daughter will have to move out; they are currently looking for alternative accommodation, but are finding it difficult as accommodation in the area is in short supply and privately rented accommodation is expensive.
- The area is described as type 37 in the ACORN classification system, and is characterised by very high numbers of young Asian families living in older terraced housing. Unemployment levels are much higher than average and qualification levels are low.
- There are no special adaptations to the home.

Proximity of local mainstream services (e.g. shops, GP, etc)

- A high street with many different types of shops is within walking distance.

Visual Impairment

- R has level 5 functional vision (can recognise a friend across a room), though he added that he could recognise a friend across a room only if

they were in his direct line of vision as he does not have any peripheral vision. He is registered partially sighted.

- He does not know the cause of his sight loss, though it happened soon after he had an operation for cancer of the larynx; he suspects that the blood supply to his eye was cut off. He was 56 years old at the time.

Hearing Impairment

- The onset of his hearing loss was also just after his operation when he was 56 years old. He does not know the cause.
- He can hear someone talk in a quiet room but only if there is no background noise.

Other health problems/disabilities

- R has type 2 diabetes for which he takes medication morning and night.
- In 2005 R was diagnosed as having cancer of the larynx; in 2006 he had an operation to remove his larynx and thyroid. As far as he knows he is clear of cancer though he can now only communicate through speech using a Servox digital voice synthesiser that he holds to his throat when he talks.
- R finds speech communication difficult and is reluctant to speak to people as they often have difficulty understanding him; when outside, R carries a writing pad with a message “sorry I can’t talk and have blurred vision” – he says he gets mixed reactions from people that he shows this to.
- When he first came out of hospital his wife helped him to care for himself but now he has come to terms with it and tries to care for himself. He changes the dressings on his throat himself.
- He gets around the house generally but struggles getting upstairs as he starts breathing heavily which makes his throat worse. He has monthly check-ups for his throat to ensure its all working and that the cancer hasn’t returned.

Participation in the project

- R took part in one interview for the project.

Participant 13 – Kulvir

<u>Sex</u>	Male
<u>Date of birth / Age at time of 1st interview</u>	01-01-1928 / 80.
<u>Place of birth</u>	India. Moved to UK in 1972. First language is Punjabi.
<u>Ethnic Group (self-described)</u>	Indian
<u>Religion</u>	Sikh

Marital Status

- K was widowed in December 2002.

Household composition/Support network

- K lives with his son and daughter-in-law who are his main source of daily support; he has another son living nearby (about 1 hour away) plus two other daughters, one who lives 3 hours away and one that lives in the

same neighbourhood. His daughter-in-law has recently stopped working so she can care full time for K.

- K has a panic alarm button for times when he is alone which alerts an agency; details about the agency or how the system operates were unclear.

Description of home

- K lives in a 3 bedroom terrace which he owns outright, and has lived in since 1973.
- The area is described as type 38 in the ACORN classification and is populated by mainly young Asian families in the predominantly terraced streets. There are very few people with qualifications and unemployment levels are high. Incomes are low, and there is low car ownership.
- Social services have installed handrails, a smoke alarm and arranged the panic button service.

Proximity of local mainstream services (e.g. shops, GP, etc)

- There is a high street with a variety of shops and services within walking distance. However, K does not go out often and can not walk unaided as he is weak due to his other disabilities. He describes himself as housebound.

Visual Impairment

- K has level 6 functional vision (can recognise a friend across a road), though he says it depends how far across the road the person is. He has glaucoma (typified by reduced visual field), and described his vision as “foggy”. He was about 67 years old when he first noticed difficulty with his sight.
- K also has a cataract which he says is inoperable as it may affect the remaining sight he has.
- He is registered as partially sighted and can still read normal size print when wearing glasses.

Hearing Impairment

- K does not know the cause of his hearing loss and described how an audiologist couldn't find anything particularly wrong with his hearing. Therefore he does not wear a hearing aid. He first noticed having difficulty with his hearing 4 or 5 years ago.
- Despite this he struggles to hear people even in a quiet room and exhibited some difficulty during the interview. He can hear a doorbell and use an ordinary telephone, however.

Other health problems/disabilities

- K was diagnosed in October 2006 with leukaemia and receives chemotherapy on an ongoing basis. If his blood count is very low he has a blood transfusion, otherwise he takes tablets.
- K appears to be a very relaxed person and feels that his disabilities are “God's will”, and says there is little point in worrying about them as that does not help.

Participation in the project

- K took part in one interview for the project.
- His daughter-in-law was present throughout the interview, and his son took part later in the interview.

Participant 14 – Lionel

<u>Sex</u>	Male
<u>Date of birth / Age at time of 1st interview</u>	03-08-1929 / 78
<u>Place of birth</u>	UK
<u>Ethnic Group (self-described)</u>	White British
<u>Religion</u>	Christian (attends a Free Church)

Marital Status

- L has been married for 22 years to his second wife.

Household composition/Support network

- L lives with his wife, who is his main source of support.
- L and his wife have a grown up daughter who is working abroad; she also has some sight loss. He also has a son and daughter from a previous marriage, neither of whom live nearby.

Description of home

- L and his wife live in an ex-LA 3 bedroom house which they now own outright and have occupied for 20 years.
- The area is described as type 47 in the ACORN classification system, which is characterised by families with low income living in low-rise estates.
- They have had problems with neighbours in the past vandalising their property but fortunately they now have good neighbours.
- Last year they had a stair lift fitted to help L get upstairs, due to his mobility problems.

Proximity of local mainstream services (e.g. shops, GP, etc)

- L's wife does not drive so they rely on public transport and taxis to get around.

Visual Impairment

- L was born with cornea damage, a condition he inherited from his Mum who was also visually impaired. L has level 3 functional vision, and can recognise a friend if very close to his or her face, though it depends on the time of day and lighting. He is registered blind.
- L cannot read any print unless he uses a CCTV and can no longer read braille which he believes is linked to his diabetes and repeated use of a lancet in his fingers to monitor his blood sugar levels.

Hearing Impairment

- L described his hearing loss as gradually occurring over the past 7 years.
- He wears two digital hearing aids, and as a result can now hear conversation even if there is background noise.
- He is registered as deaf.

Other health problems/disabilities

- L has kidney and heart problems (including renal anaemia, chronic obstructive pulmonary failure, and angina), as well as type 2 diabetes,

arthritis and an enlarged prostate. He often gets out of breath when talking and is registered disabled.

- He has had poor mobility for the past 5 years and uses a wheelchair when he goes outside the home. They are unable to use buses with his wheelchair so often use taxis but find them prohibitively expensive.
- L recently went into hospital for 5 weeks as he was hallucinating; it was an unpleasant experience as he was put in a ward where they did not consider his sight and hearing loss; he was not introduced to any of the other patients and he had to find the toilet himself. He sat in silence most of the time as he was unable to communicate with others, even though one patient tried to talk to him without his knowledge.
- L's wife suffers from epilepsy but takes medication to help control it. In the past L worked with people who had epilepsy, so feels able to cope with it when she has an attack.

Participation in the project

- L took part in one interview for the project.
- His wife was present and took part for some of the interview.

Participant 15 – Jeremy

<u>Sex</u>	Male
<u>Date of birth / Age at time of 1st interview</u>	06-12-1927 / 80
<u>Place of birth</u>	UK
<u>Ethnic Group (self-described)</u>	White British
<u>Religion</u>	Church of England

Marital Status

- J has been married for 53 years

Household composition/Support network

- J lives with his wife. They have two daughters and one son who are all married with children and live nearby; they have 14 grandchildren and great-grandchildren in total.
- J feels lucky as all of his family is very supportive, and encourage him to remain as independent as he can.

Description of home

- They live in a 2 bedroom semi-detached ex-LA house that they now own outright, and have lived there since they got married 53 years ago.
- The area is described as type 41 in the ACORN classification scheme commonly inhabited by shopworkers and skilled blue-collar workers employed in manual occupations, with a mixture of singles, couples, families and retired people.

Proximity of local mainstream services (e.g. shops, GP, etc)

- J's wife does not drive so they rely on public transport and family to get around.

Visual Impairment

- J has age related macular degeneration, as well as glaucoma and cataracts.
- He currently has level 3 functional vision (can recognise a friend if very close to his or her face), and thinks he is registered as partially sighted.
- He first noticed having difficulty with his sight in 2003, when he was driving; someone at the hospital told him he could carry on driving but he didn't feel safe so he gave it up.
- With his wife's support, J copes fairly well with his sight loss but does get frustrated at not being able to do the things he did before, for example decorating and gardening.

Hearing Impairment

- When asked about his hearing loss, J felt he doesn't have any hearing loss, and although someone has telephoned him several times asking him to have a hearing test, he has resisted, partly because he doesn't know who they are or what they want. He doesn't wear a hearing aid.
- However, when questioned further about his hearing, J said he had difficulty following a conversation if there was background noise.

Other health problems/disabilities

- J says he has some arthritis in his knee but doesn't feel it holds him back from doing things, though he does get trouble with it if he is bending down when gardening. Otherwise he feels he is fairly healthy, and lucky to still be mobile despite his age. Due to his sight loss, he no longer crosses roads unaccompanied anymore as he doesn't feel safe.

Participation in the project

- J took part in one interview for the project.
- His wife also took part in the interview.

Participant 16 – Emily

<u>Sex</u>	Female
<u>Date of birth / Age at time of 1st interview</u>	06-09-1920 / 87
<u>Place of birth</u>	UK
<u>Ethnic Group (self-described)</u>	White British
<u>Religion</u>	Christian – Church of England

Marital Status

- E was widowed 25 years ago.

Household composition/Support network

- E lives alone. Her son, who was her main source of support, died a few years ago, a loss which E is still trying to come to terms with.
- Her daughter-in-law lives in the same town and drops by or calls E to check she is ok every few days. E doesn't like to ring her too often as she doesn't want to feel she's a burden.
- E's other main source of support is a voluntary organisation for deafblind people based in her town; every two weeks she has the service of a communicator guide who takes E shopping. E has become very close to

her and thinks of her as a friend and looks forward to her fortnightly visit. She is also very grateful that they have a helpline number that E can call whenever she needs someone to talk to. The organisation also organise day trips and holidays that E has taken part in and enjoyed in the past.

- E is fiercely independent, and very keen to stay in her own home for as long as she can, even though at times she feels a bit lonely. She said moving into a residential home would be “dreadful”, due to the loss of independence.
- E’s religious beliefs help her through each day.

Description of home

- For the past 17 years E has lived in a detached 2 bedroom bungalow, with a small garden at the rear, garage and off-road parking. She owns it outright.
- The area is described as type 32 in the ACORN classification system. Most of the people in this type are over 60 and no longer work, and as a result they have modest incomes but are comfortably off. The vast majority of them own their own homes outright. Typically they live in bungalows with two or three bedrooms.

Proximity of local mainstream services (e.g. shops, GP, etc)

- There are a number of small stores at the end of the street E lives on, though the furthest she goes outside of her house when unaccompanied is to the post box a few steps from her home to return her talking books.

Visual Impairment

- E was about 62 when she first noticed difficulty with her sight, around the time her husband died.
- E has some light perception (level one functional vision), though everything she sees is blurry. She did not know the name of her condition but said that the consultant says she has no central vision at all. She is registered blind.
- In the follow up interview, E felt her sight had deteriorated since first meeting the researcher.

Hearing Impairment

- E also first noticed difficulty with her hearing when she was 62; she had an operation to try and improve it but can’t remember the details of the operation or the problem itself. She now wears two hearing aids.
- E can hear someone talk in a quiet room but struggles to follow a conversation when in a group situation. She has an amplifier on her telephone bell so she can hear it ring when she is in the garden. She cannot hear her doorbell if she has her lounge door closed, but friends and family ring her telephone for 3 rings before visiting, so she knows to listen for the doorbell. Otherwise she does not open the door to strangers.

Other health problems/disabilities

- Other than her hearing and sight, E doesn’t have any health problems or disabilities though she does tire easily, especially when she has a very busy day cleaning her home; E likes to keep busy so that she doesn’t have too much time to think and worry about things.

Participation in the project

- E took part in both an initial interview and a follow-up interview.

- The professional contact was present at the first interview as E did not want to be on her own when the researcher visited. She was interviewed on her own for the second interview.
- She agreed to keep a diary, and this was carried out with the support of the professional contact who visited her regularly to record her (spoken) diary using a video recorder.

Participant 17 – Jack

<u>Sex</u>	Male
<u>Date of birth / Age at time of 1st interview</u>	05-10-1924 / 83
<u>Place of birth</u>	UK
<u>Ethnic Group (self-described)</u>	White British
<u>Religion</u>	Christian – Church of England

Marital Status

- J is married, and has been for many years.

Household composition/Support network

- J's main source of support is his wife. They have a grown up daughter who lives some distance away.
- He is in contact with the local deafblind voluntary organisation but he doesn't feel the need to use any of their services regularly. He does take part in the occasional one off events they organise for members, which he enjoys.
- J and his wife are quite independent, and J carries out a number of tasks around the home, though at times his difficulty in carrying out some tasks due to his sight loss frustrates him.

Description of home

- At the time of the first interview, J and his wife lived in a modern flat on a fairly new housing estate; however, they felt there was a lack of community and privacy, and were therefore selling the flat and hoping to move into a bungalow on an established estate nearby.
- They had moved by the time the researcher visited to carry out a follow up interview, and are now much happier living in a large, 2/3 bedroom detached bungalow which they own outright. It is very bright and airy inside, and has a private garden, garage and driveway, and is located in a quiet cul-de-sac.
- The area they now live in is described as type 32 in the ACORN classification system. Most of the people in this type are over 60 and no longer work, and as a result they have modest incomes but are comfortably off. The vast majority of them own their own homes outright. Typically they live in bungalows with two or three bedrooms.

Proximity of local mainstream services (e.g. shops, GP, etc)

- A number of small stores are located within walking distance, and J regularly walks to the shops unaccompanied; J likes to take short, unaccompanied walks outside in order to keep active and independent. His wife worried at first but is reassured as she now realises that he is

quite competent and confident in areas that he knows well. J's wife does not drive so they rely on public transport and taxis to get around.

Visual Impairment

- J has a condition known as 'giant cell arteritis' which is an inflammation of the lining of the blood vessels that carry oxygen-rich blood from the heart to the rest of the body. It frequently causes headaches, jaw pain, and blurred or double vision, and blindness and stroke are the most serious complications.
- J started to have severe headaches about 4 years ago, and following an eye test, his vision deteriorated rapidly before the test results came back.
- For some time he had regular hallucinations; he was very pragmatic and tried not to worry about them, and simply told himself that they were not real. Eventually they stopped happening.
- At the time of the first interview, J had level 2 functional vision (could just about see the shapes of furniture), though by the time of the follow-up interview he felt it had deteriorated further. He is registered as blind.

Hearing Impairment

- J has had difficulty with his hearing since his 20's, which was caused by his experiences of working on torpedo boats during the Second World War.
- He has worn a hearing aid since he was about 35. At the time of the first interview, he had one digital hearing aid, but he felt his hearing was deteriorating and was hoping to have two. By the time of the follow-up interview, he had two digital hearing aids, and although he could hear better, it is a more mechanical sound and so he doesn't enjoy listening to music like he used to and doesn't like the sound of his own voice. It also picks up a lot of background noise that he would rather not hear.
- J said he never considered that he was deaf, and throughout his career he learned to lip read; he feels that one only realises that you are deaf when people tell you so, whereas blindness is much more noticeable.

Other health problems/disabilities

- As a result of his service in the Second World War, J has some difficulty with his nervous system which causes pain in his hands and wrists, causing some difficulty with tasks requiring dexterity. Otherwise, he was healthy though by the follow-up interview he said he was finding walking a bit more difficult.
- J seemed to have a very positive outlook on his life, and tried to be pragmatic about the limitations imposed on him both directly and indirectly by his sight and hearing loss.

Participation in the project

- J took part in both an initial interview and a follow-up interview for the project.
- His wife took part in both of the interviews.
- He originally agreed to keep a diary by email, but later withdrew as his sight had deteriorated and they were busy moving house.

Participant 18 – Lawrence

Sex	Male
Date of birth / Age at time of 1st interview	16-03-1948 / 60
Place of birth	UK
Ethnic Group (self-described)	White British
Religion	Church of England but doesn't attend regularly

Marital Status

- L has been married for 10 years.

Household composition/Support network

- L lives with his wife who is also visually impaired, and has level 2 functional vision (i.e. can see the shapes of furniture).
- L and his wife support each other and live quite independently. He has a brother nearby who helps with jobs around the house.
- They are both members of a voluntary organisation for people who are deafblind, who they got in touch with when they needed a particular computer programme. L says technology has transformed their lives by providing them with information that they could not access beforehand.
- L has also received mobility training in the past from a rehabilitation officer, to learn routes to specific locations in his local home area.

Description of home

- L and his wife live in a 3 bedroom semi-detached house which they rent from the council; it was previously his parents' house. L has lived there for 42 years.
- The property is in an area described as type 45 in the ACORN classification scheme, which is commonly populated by low income, older people living in smaller semi-detached houses few of whom will have mortgages or be educated to degree level.
- L and his wife are nervous of some of the young people in their local area so do not go out at night unless they are picked up by taxi or friends with a car.
- They have handrails and bright lighting installed in the home.

Proximity of local mainstream services (e.g. shops, GP, etc)

- L lives in a small village with a number of small shops and a supermarket within walking distance. Neither L nor his wife drive. His wife has two guide dogs, one of whom is retired.

Visual Impairment

- L has been visually impaired since birth with congenital cataracts. He said his Mum had German measles when she was pregnant. He has been registered blind since childhood.
- He has level 5 functional vision (can recognise a person by sight across a room) and can see well enough to read a newspaper headline but not a large print book.

Hearing Impairment

- L first noticed a difficulty with his hearing about 15 years previously.

- He described his sight loss as severe high-tone loss and moderate to severe mid-tone loss. He said his ‘bass’ was still quite good. He wears two digital hearing aids which he purchased himself.
- When wearing his hearing aids, he has no problem following a conversation even with background noise.

Other health problems/disabilities

- L has labyrinthitis which is an inflammatory disorder of the inner ear or labyrinth which affects balance; L said it affects him 2 or 3 times per week, and does concern him when he goes out of the home as its occurrence is unpredictable.

Participation in the project

- L took part in one interview for the project.
- His wife was present and also took part in the interview.

Participant 19 – Norris

<u>Sex</u>	Male
<u>Date of birth / Age at time of 1st interview</u>	03-06-1919 / 89
<u>Place of birth</u>	UK
<u>Ethnic Group (self-described)</u>	White British
<u>Religion</u>	Church of England

Marital Status

- N has been married for 61 years.

Household composition/Support network

- N lives with his wife. Their daughter used to live next door but she died of cancer 9 years earlier. They have 4 grandchildren, one of whom lives in the same city. His wife is his main source of support.
- He has found social services very helpful; when he was first registered they introduced him to the RNIB and their talking book service.
- N attends a weekly men’s club for people with visual impairment where they discuss current topics, and a monthly club aimed at people with hearing and sight loss which invites speakers to talk on various topics, though N says they are rarely interesting. He also takes part in a 4-way conference telephone call each week with other visually impaired people organised by the RNIB; he was recently given a telephone with an amplifier from a voluntary organisation for deaf people to enable him to take part.

Description of home

- For the past 15 years N has lived with his wife in a large 5 bedroom terraced house, close to the city centre. They own it outright.
- The area is described as type 3 in the ACORN classification system, and is characterised by affluent, well educated professional people employed in senior managerial positions. Residents tend to be older, with fewer children and more retired people, and the housing tends to be spacious, with four or more bedrooms, mostly detached and at the upper end of the

property price ladder. Reflecting the older age profile, more properties are owned outright than being bought on a mortgage.

- Social services installed handrails, and they have tried using bright lighting but the latter hasn't helped N much with reading. He now has two friends who visit and read to him, as he misses being able to read books very much.

Proximity of local mainstream services (e.g. shops, GP, etc)

- N's wife still drives but no longer very far or often; she is having an eye test to check whether she is still safe to drive.

Visual Impairment

- N has glaucoma and macular degeneration which was diagnosed later.
- N has functional vision level 2 (can see the shapes of furniture in a room). He can't read any print at all. He first noticed difficulty with his sight when he was 79 years old.
- He recently had a cataract removed but that has made his sight worse. He is registered as blind.

Hearing Impairment

- N first noticed having difficulty with his hearing about 15 years ago. He does not know the cause of his hearing loss though wonders if it is connected with his service during the Second World War.
- He has difficulty following a conversation if there is background noise, and cannot use an ordinary telephone.
- He normally wears two digital hearing aids which he bought privately but when the researcher visited, one was broken so he struggled to take part in the interview.

Other health problems/disabilities

- N has arthritis in his lower back which makes walking difficult and he takes daily medication for high blood pressure and irregular heart beat.

Participation in the project

- N took part in one interview for the project.
- His wife also took part in the interview.

Participant 20 – Betty

<u>Sex</u>	Female
<u>Date of birth / Age at time of 1st interview</u>	24-06-1921 / 86
<u>Place of birth</u>	UK
<u>Ethnic Group (self-described)</u>	White English
<u>Religion</u>	Church of England

Marital Status

- B has been married for 63 years.

Household composition/Support network

- B lives with her husband. They have 2 daughters and a son, one of whom lives with their family in a village nearby. B and her husband moved nearer to one of their daughters in case they needed support in the future.

- B has not had contact with any support services for her hearing and sight loss. At the present time she does not feel that she needs any.
- B privately employs a lady to help with the household chores 3 times per week, including cleaning, washing and ironing. B and her husband share the tasks involved in preparing their meals each day, and seem to manage very well.

Description of home

- Their home is a large semi-detached cottage in a village location opposite the church which they both regularly attend. They have lived there for over 12 years, and own the property outright.
- The area is described as type 25 in the ACORN classification scheme, characterised by a mixture of young professionals and students in prosperous provincial towns and cities who are well qualified, usually to A-level and degree standard. The older individuals in this type are often already in successful professional and managerial careers.
- B describes the people in the village as very friendly and approachable when she needs help, for example, to find her way home.
- Their home was flooded in the summer of 2007, so they have been living temporarily in the small, 2 bedroom terraced house next door which belongs to an overseas friend whilst waiting for their home to be renovated.
- At the time of the follow-up interview, they were just preparing to move back into their home, almost a year after the flood occurred. Overseeing the renovation of the property has been a long and tiring process for both B and her husband.

Proximity of local mainstream services (e.g. shops, GP, etc)

- There is a wide range of small shops within walking distance, as well as a medium supermarket. B regularly walks to the shops, and crosses the roads with help from passers-by. She walks with a trolley to aid her mobility and balance. She finds people in the village very helpful and understanding, especially when she explains her difficulties.

Visual Impairment

- B has had glaucoma since she was in her 40's; she is blind in one eye, and everything is "shadowy" in the other. She said she could possibly recognise someone by sight across the road if there is very good light (functional vision level 6). She can read a large print book but not ordinary print.
- Occasionally the pressure in her eye increases and her sight deteriorates further. She has been receiving private treatment from an eye specialist for a number of years, and has never been registered as blind or partially sighted as her consultant still hopes to "fix" the problem. She had a cataract removed in the past which gave her good sight for a while.
- However, by the time of the follow-up interview, B said her sight had deteriorated further.

Hearing Impairment

- B said she has familial deafness, several members of her family also had hearing loss; her hearing loss was first noticeable in her 40's, but occurred after her sight loss. She wears two digital hearing aids, both of which she paid for privately. She does not receive NHS treatment for her hearing.

- When wearing her hearing aids, she can follow a TV programme and hear someone speak in a quiet room, but struggles if there is background noise. She doesn't always hear the doorbell or alarm clock ring. She struggles to use a telephone without an amplifier.

Other health problems/disabilities

- B has middle ear problems that cause difficulties with her balance, which is why she uses a stick and a trolley when walking.
- When visited for a follow-up interview, it transpired that B was hospitalised over Christmas with a bladder infection, and whilst there she picked up a bug which was then a recurring problem for both herself and her husband.

Participation in the project

- B took part in both an initial interview and a follow-up interview.
- She agreed to keep a diary, but found it difficult to operate the tape recorder; therefore she dictated notes to her husband who typed them up for the research team.

Findings by Theme

The following section provides a rich description of the views and opinions expressed by the 20 participants who took part in the project. As described in the 'Methods' section, the large amount of data generated from the initial face to face interviews, diaries and follow-up interviews was analysed following a grounded, generative approach in which the data was coded to draw out themes. In all, 11 broad themes were identified including:

- Vision and hearing
- Other health problems or disabilities
- Communication and social interaction
- Accessing information
- Leaving the home and getting out and about
- Activities within and beyond the home
- Daily living and sources of support
- Access to and participation in medical services
- Social and emotional issues
- Residential accommodation
- Views of the participants' families

These broad themes are presented, along with a number of sub-themes within each theme. Additionally, data from the telephone interview and online questionnaire completed by the professionals who helped with the sampling is also presented.

As with other qualitative research methods, the life story interview method is used to obtain rich, detailed descriptions of the participants' lives; in order to demonstrate the breadth of topics and issues that the participants talked about in, examples provided by the participants are presented throughout the following section. Each example is boxed, and where verbatim, the text is *italicised*. In some cases, the examples have been paraphrased by the researcher to limit the length of the report. However, due to the nature of qualitative research, the following section is still, by necessity, very long. It is hoped that the examples provide the reader with a deep insight into the lives of the participants, and a clearer understanding of how they view their circumstances.

As in the previous section, all names used are pseudonyms.

Vision and hearing

Description of participants' sight loss

When asked to describe their sight loss in their own words, many of the participants did not give the name of their condition or know the cause. Whether or not they knew the name of their condition, most of the participants

described their sight loss in terms of their remaining functional vision, or what happened when they were first diagnosed or noticed that they had difficulty with their sight. The description of the case studies in the previous section clearly presents the range of experiences.

Six of the participants said they had macular degeneration, one of whom had to be prompted on the name. Five had glaucoma, and five described having cataracts either at the present time or in the past (three of whom also had cataracts). Judging by the description given by participants who did not know the name of their visual condition, it is likely that many of them had one or more of these conditions also.

Jeremy (80) said he had macular degeneration without any hesitation. He said he also has cataracts and glaucoma, which members of his family have had.

Mary (84) couldn't remember the name of her condition, describing it as a "funny word, everybody knows it". When prompted with 'macular degeneration', she nodded. She said it's like everything she sees is grey.

Colin (92) didn't name a condition, but said that his consultant described his retina as having a 'web' in front of it, which was gradually losing strength and developing big holes taking his sight away. Colin asked the consultant what might have caused it as he felt he'd been "*a clean living sort of bloke*" – the consultant asked him if he'd ever been subjected to extra strong sunlight, to which Colin confirmed that during the second world war he'd spent 3yrs in the desert on patrols in very bright sunshine, with no protection for his eyes.

Two participants who had glaucoma had been told that removal of their cataract was inadvisable since it could impair their sight further, and one participant had recently had the cataract removed, following which his sight had deteriorated further.

Betty (86) has glaucoma and described how her level of sight is variable, depending on the pressure that builds up in her eye. She mentioned that she once had a cataract removed which for a time restored her sight and "made everything glorious, all the colour came out everywhere"; however, subsequent surgery did not help and has left her nervous of further procedures.

Kulvir (80) has Glaucoma and a cataract that he has been told cannot be removed as it might adversely affect the vision he has left.

One participant lost a significant degree of sight in her "good" eye following a stroke whilst another lost their sight quite suddenly a few days after undergoing major surgery for cancer of the larynx. Two of the participants were born with a visual impairment, one with cornea damage and the other with congenital cataracts; for example:

Belinda (82) has only had about 9% of vision in her right eye for most of her life; however, following a stroke she lost the vision in her left (good) eye which she described as “*devastating*”, depriving her of the ability to drive.

Some described less common causes of visual impairment; one described the effects of giant cell arteritis on his daily life, whilst another participant described in detail three connective tissue disorders that she had been diagnosed with, including Sticklers syndrome, Goldman’s Fathrey and Wagner’s syndrome:

Fiona (59) named three separate connective tissue disorders that have caused her sight loss; she gave a very detailed description of each condition, including the times when each was diagnosed, the symptoms and prognosis. Of all the participants, Fiona appeared to have the most detailed medical knowledge about her conditions. This may well be attributable to her age (she was one of the youngest participants), her very outgoing personality, and a desire to gather as much information about her somewhat unusual conditions as possible, both through personal research on the internet as well as through regular contact with medical consultants.

Several of the participants described their own thoughts as to the cause of their sight loss, which wasn’t always based upon what a consultant had told them. For example, one felt that the onset of both her hearing and sight loss was due to the shock of losing her husband, whilst another assumed she had the same condition as her sister who had detached retinas in both her eyes. Five of the participants talked about members of their immediate and extended family that also had visual impairment.

Molly (88) described having scarring at the back of both eyes. She believes she has detached retinas as her sister had that and she couldn’t see. When prompted whether her consultant or doctor had said that, she said “*no*”. She had already had cataracts removed, so thought that was the problem but then found it wasn’t.

Emily (87) said that she had no central vision whatsoever, and everything was blurry if she looked straight ahead. She could still see a little to the side. She felt that the shock of losing her husband was most likely the cause of both her hearing and sight loss.

Others talked at length about what happened at the time of diagnosis; this is discussed later in the section on medical services.

Delia (86) confirmed without hesitation that she had age related macular degeneration. She has been told by her consultant that nothing can be done about it, but she is seeking a second opinion and hopes that there is a treatment that might help her.

Functional vision

We asked the participants whether they could see well enough to read different sizes of print when wearing glasses or contact lenses, *but not using a magnifier of any kind*. Most of the participants (n=12) said that they couldn't read print at all without a magnifier (some of whom said that they couldn't read print even with a magnifier). Five participants could read large print, whilst two could just about read a newspaper headline. One participant said that he could still see well enough to read ordinary newspaper print when wearing his glasses.

As described previously, the participants were asked six questions regarding how much they could see that were used in a number of surveys including the 1991 RNIB Adults Needs Survey (Bruce, McKennell and Walker 1991) and Network 1000 (Douglas, Corcoran and Pavey, 2006). The six questions enabled the 'scoring' of participants' level of functional vision on a seven point scale (0-6); the results below are based upon the best vision score for each participant at the time of the first interview (again demonstrating a large range of vision amongst the participants):

- At the time of the first interview, all of the participants could at the very least tell by the light where the windows were in a room (functional vision level 1); only one participant (registered blind) reported this as their 'best' or highest level of functional vision;
- Six participants reported having, at best, level 2 functional vision, i.e. could see the shapes of furniture in a room; five of these participants were registered blind, the other as partially sighted;
- Three participants had level 3 functional vision, i.e. could recognise a friend if close to their face; two were registered blind, one partially sighted;
- Three participants had level 4 functional vision, i.e. could recognise a friend at arm's length away; one was registered blind, one partially sighted, and the third was registered but did not know the category;
- Five participants had level 5 functional vision, i.e. could recognise a friend across a room; two were registered blind, two as partially sighted, and one was not registered at all;
- Only two participants reported having level 6 functional vision, i.e. could recognise a friend across a road; one was not registered as visually impaired whilst the other did not know if they were registered.

Deterioration of participants' sight loss

Of the nine participants who took part in a follow-up interview, all of them felt that the difficulty they had with their sight was greater than it was when they were first interviewed. Pamela reported a recent visit to her eye consultant who told her she should have contacted him as soon as she had noticed a change in her level of vision, but she had felt it was just down to old age and that nothing could have been done so didn't bother. She now has no light perception at all. This was a common statement in the interviews, where

many assumed that either their sight or hearing loss (or both) was simply due to old age and therefore nothing could be done to help them.

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

- Nine participants reported that it was when they were 75 or older;
- Three reported that they were aged between 65-74;
- Four reported that they were aged between 50-64;
- Two reported onset when they were aged between 30-49;
- Two participants reported that they had visual impairment from birth.

Description of participants' hearing loss

Half of the participants (n=10) said that the onset of their hearing loss occurred before the onset of their visual impairment. Of the others, seven reported the onset of their visual impairment occurring before their hearing impairment, one said they happened concurrently, another participant could not remember which came first but recalled that they both started sometime in her 40's, whilst one participant felt he did not have a hearing impairment at all.

When asked to describe their hearing impairment, many (n=8) stated that they did not know the cause though some speculated that it may have been due to their previous occupations in noisy environments (n=3) or experience of loud explosions during the second world war (n=3); four participants attributed it simply to old age, whilst one participant described it as "familial deafness", describing extended relatives that had also gone deaf in their later years.

The participant with Sticklers syndrome explained how it has affected her hearing as well as her sight and general health; she first started having problems with her hearing 18 months after the syndrome was diagnosed, with a number of infections like glue ear. She is aware that she will eventually lose her hearing completely due to the Sticklers syndrome though she said the medical consultants have no idea how quickly it will happen. Another participant said they lost some of their hearing due to contracting measles during childhood.

In two cases, the hearing impairment had not been confirmed by an audiologist; one participant said that although he struggled to hear people in conversation, the audiologist that tested his hearing said they could find nothing particularly wrong with his hearing and that he was only on the 'borderline' for needing a hearing aid. The other participant didn't believe that he had anything wrong with his hearing, and had resisted going for a hearing test. Interestingly, both of these participants were receiving support from specialist deafblind workers which suggests that they have both been identified by services, albeit informally, as having both hearing and sight loss. Additionally, both of these participants appeared to have difficulty hearing the researcher at some point during the interview.

Functional hearing

The participants were asked a number of questions to ascertain the level of difficulty they have with their hearing, when wearing their hearing aid(s) (if appropriate); the first question asked whether they have any difficulty hearing somebody talk in a quiet room, whilst the second asked whether they have great difficulty following a conversation if there is background noise – e.g. a TV, radio or children playing.

The findings suggest that the majority of the participants have at least some difficulty hearing somebody talk:

- Nine participants said that they had difficulty hearing someone talk even in a quiet room; of these, five wore hearing aids in both ears, three wore one hearing aid, and one participant didn't wear one at all.
- Eight participants said that they would struggle to follow a conversation if there was background noise; 4 of these participants wore two hearing aids, three wore one and the other didn't wear one at all.
- Only three participants said that they had no difficulty hearing someone talk in a room (whether quiet or with background noise); all three wore two hearing aids.

All but two of the participants wore at least one hearing aid, 8 of whom said that they wore two. Of the two participants who did not wear one, one felt they did not have a hearing impairment and refused to have a hearing test and the other was assessed as not yet needing a hearing aid. Experiences of hearing aid use and services relating to audiology are described later, in the section 'Access to and participation in medical services'.

Deterioration of hearing loss

Of the nine participants who took part in a follow-up interview, five participants felt their level of hearing loss was about the same. The remaining four felt that they had greater difficulty with their hearing compared to the time when they were first interviewed, for example:

Fiona (59) has noticed that her hearing is gradually getting worse; she recently had to have an amplifier fitted to the telephone as she couldn't hear it ring anymore and she now listens to the radio using headphones so as not to disturb her husband as she now has to have the volume up very loud.

Participants' self-perceptions about their disabilities

The interviews revealed that many of the participants spent time reflecting upon their hearing and sight loss and what it *means* in a more philosophical way; for example, a number of the participants talked about their 'identity', and whether having sight and hearing loss made them 'disabled':

Betty (86) described how she has pondered her identity. For example, she asked her hearing consultant if wearing a hearing aid meant she was “handicapped”, but he remarked that you’re much more “handicapped” without one! She had also wondered as to whether she is a *disabled* person now: She was going to ask her specialist “*Do you consider I’m disabled?*” because she wanted to cook a recipe that involved a deep frying pan with lots of oil – but she knew she wouldn’t be safe, that she could potentially spill it over herself, and concluded “*I thought to myself, that means you’re disabled doesn’t it? [I] hadn’t thought of myself as being disabled – you adapt, you have to adapt don’t you. You try not to do the things you can’t do*”.

It is particularly interesting that Betty sought the answer from medical professionals rather than elsewhere, which demonstrates the weight that many of the participants give to the opinions of professionals in the medical field.

Another participant differentiated between having ill health and having a disability, and that with ill health there is at least a possibility that one can get better and look forward to a better quality of life:

Colin (92), who is house-bound due to a stroke said: “*If you were poorly you’d look forward to getting better but I’m not poorly, I’m disabled but I’ll never get any better. I shall gradually get worse or at some stage or other I don’t know, I hope not, but I might do, I might lose what bit of use I’ve got in me legs. I’ll be in a mess then but...*”

Another participant also differentiated between having ill health and a disability, but had a more positive interpretation and outlook:

Jack (83) doesn’t look upon himself as deaf – he said you don’t think about it till people tell you that you are deaf. Blindness is different – you notice that. During his working career, without realising it he learnt to lip-read – he would ask his staff to look at him when they spoke to him and enunciate their words clearly. When he went blind he lost all of that – but his attitude was still “*I’m not ill or sick – I have a physical defect, therefore it’s not an illness, it’s a challenge*”.

It is worth noting however that the two participants have quite different circumstances in terms of their home, which may partly explain their different feelings towards their impairments.

Another participant described how her sight loss in particular had affected her confidence to do things independently, and how she has had to accept that she is now disabled and may require help:

Jackie (88) when told there was nothing that could be done in relation to her macular degeneration, said: *“I thought that’s that, but it has made a difference to me as I’m not a confident person, I mean I wouldn’t stride off with chores as I used to, ...can I do it? ...so everything you do you’ve got to think ‘go on, have a go, you can do it’ – it makes this life totally different as you’re not that person you were before, you’re disabled I suppose, you’ve got to, every time you do it, rely on other people which is horrid as I’ve always been an independent person. But I’ve got the strength to do it, I thank God [and says to herself] ‘go on, go forth, go forth, go forth in faith, you’ll do it!’.”*

One of the participants who has been visually impaired since birth remarked that, whilst he was glad his vision has remained stable for some time rather than deteriorated, he is not sure whether he would want to be able to see *more* than he can at present:

Lawrence (60): *“Technology obviously is still moving on, what was that thing I saw the other day? I don’t know something about some new equipment they’ve got for removing cataracts or some other treatment or whatever... and I [said to] myself ‘Hang on, I wonder if that could be used for me?’. Then I think to myself ‘Hold on, if I suddenly gained all this extra vision I would end up in what would be to me a totally alien world’. If you’ve been a sighted person all your life and you’re a more elderly person and your sight starts to go then they suddenly give it back to you again, yes, I think then is the time that people can still handle that, ‘oh yes, that’s how it used to be’, I know that, I can understand that. But, because I’ve been visually impaired all my life and I’ve suddenly been given that extra that would, as I said, it would put me in a totally alien kind of world.*

Other health problems or disabilities

Description of other disabilities and long-term health problems

All but one of the participants said that they had other disabilities and/or long term health problems. These are described for each participant in the previous section, but the following is a brief overview of the impairments and how they affect the lives of the participants:

A number of participants described having problems with their balance (e.g. Betty, 86 and Lawrence, 60) which affected their mobility both in the home and when outside. Previous strokes also affected participants’ mobility and at times caused them embarrassment when eating in public (e.g. Colin, 92; Belinda, 82; Mary, 84).

Common complaints amongst the participants included regularly feeling tired and lacking physical strength, which affected their ability to carry out everyday tasks. Many of the participants described having arthritis, often in the hands or

legs, which also affected everyday tasks requiring dexterity and mobility. Additionally, two participants described having nerve damage and one had water retention in her legs that affected everyday tasks around the home such as getting about, house work, gardening and DIY. Problems with incontinence and bowel trouble due to disease of the colon also affected some of the participants' ability to go out of the home for any length of time.

A few participants described having angina and heart problems, and at least three participants were having or had recently had treatment for cancer.

A number of the participants also had various dietary considerations that included monitoring their salt intake for high blood pressure, sugar levels for those with diabetes, cholesterol levels, and avoidance of particular food types that affected conditions such as irritable bowel syndrome.

Most of the participants described the medication they took for various conditions, with some describing the difficulty they experienced when personally carrying out this task, particularly those who lived alone. For example:

Fiona (59) takes 28 tablets per day, as well as using inhalers for asthma. At first she depended on her husband to make sure she took the right ones at the right time, but she has gradually gotten used to doing it herself now.

Pamela (86) has the staff at the residential home where she lives put out her medication ready, so that she can then administer it herself; she likes to be independent and do it herself although she admits it is becoming more difficult. She says she will ask for more help when it becomes too difficult for her to manage but wants to keep doing it herself for as long as she can. Like many of the participants, she likes her medication to be arranged in her own way and doesn't like anybody to touch it.

Lionel (78) takes lots of medication, approx 17 tablets a day. His wife administers it to him as he says he has lost the use of his remaining useful sight so it's now very difficult for him. His wife felt that he lost the ability to care for himself when he came out of hospital recently, after a particularly difficult stay there.

In some cases, the medication has negative side-effects that affect participants' daily lives:

Betty (86) described how she sometimes falls asleep during breakfast; her doctor says it's a side-effect of the tablets she is taking.

Julie (70) suffers from both rheumatoid and osteoarthritis; she described suffering fatigue and joint pain, particularly in the afternoons, and pain in her hands and hips just about all of the time. She doesn't like taking pain killers too often as she also has diverticulitis, so they upset her stomach.

A few participants said that they took sleeping pills to help them sleep at night; in at least three cases this was to help them sleep following the loss of loved ones.

The effect of these additional health problems and disabilities upon the daily lives of the participants cannot be overestimated; in some cases the participants described their other health problems or disabilities as being unbearable, and more difficult to cope with than their sight and hearing loss:

When Fiona was asked what the most difficult thing was that she has to cope with, she replied: *“This is going to sound pathetic, and you’re definitely going to classify me as a 1st class coward, but it’s the osteoarthritis, it’s with me 24/7. I am on medication and I also have a back massage as most of the pain is in my side, I’ve had osteoarthritis since November 1997, so I’ve lived with it for, what, 10 years, but it doesn’t get any easier. There are days when the pain level is just not funny – I don’t know where to put myself. The medication I’m on takes off the edge of the pain, unless... the only time it doesn’t take the edge off the pain is if I have another problem, like a cold or upset stomach. [Then] it just doesn’t touch the pain at all. That’s the thing that affects me most, the pain level”.*

Mary (84) said that she doesn’t worry so much about her eyes – it’s her lack of physical strength that she finds most troublesome.

Lionel (78): When asked what was most debilitating, he said it was the chronic obstructive pulmonary disease (COPD) he suffers from, which is a lung disease in which the lung is damaged, making it hard to breathe; it makes him short of breath and affects his mobility even around the home. He now has to use a stair lift to get upstairs.

Deterioration of participants’ general health

As described in the Methods section, of the eleven participants who were invited to take part in the follow-up interview in the spring (i.e. were interviewed before Christmas 2007), two did not take part as one was confused and did not seem sure who the researcher was when contacted and another was taken ill. Of the remaining nine participants who were interviewed a second time, some appeared to the researcher to be visibly frailer compared to the time of the first interview, particularly those aged 80+, and almost all of them reported that one or more of their other disabilities and/or health problems had deteriorated since the first interview.

Two of the participants had been taken to hospital, one (Betty, 86) with a bladder infection which had required in-patient care for a number of days over the Christmas period. The other (Belinda, 82) had received out-patient treatment due to a flu and diarrhoea bug just after Christmas; her condition diverticulitis (which is a disease that can cause episodes of pain in the lower abdomen, as well as constipation and diarrhoea) unfortunately made it worse.

Other participants reported more difficulty with getting about; one participant (Colin, 92) explained that he gets tired now more quickly but felt that that's to be expected at his age.

Mobility around the home and falls

A number of the participants described having difficulty getting around their own home; in some cases this was due to their other disabilities or health problems (such as arthritis or the after-effects of a stroke), whilst in others it was due to their sight loss, or a combination of their sight loss and health problems.

Most of the participants were still able to get around their own home, even if at times it was slow and difficult. In one case the participant was unable to get upstairs to use the bedrooms and bathroom in his home and was confined to living in the two downstairs living rooms:

Colin (92) had suffered a stroke which had greatly affected his mobility and he also had very poor sight and hearing. He lives in the two downstairs rooms which include a kitchen-cum-dining room at the back of the house and a front room which was used as a bedroom. In the rear room where he spent most of the day was a small kitchenette, a fireplace, a small sofa, his chair, and two tables - one with wheels that was used at meal times, and another with a telephone, a tape player and a daisy player which he could only listen to once one of his carers put in a tape or CD for him. He described himself as being confined to this chair for most of the day. The other room was used as a bedroom. As he can't use the bathroom upstairs, Colin uses a commode for toileting and his paid carer gives him a daily strip-wash in a special chair; he said he never gets a shower or a bath, but would love to have one.

Several of the participants described their mobility around the home as being very slow, particularly first thing in the morning or when preparing to go to bed. Two participants could only move around their home by using a Zimmer frame. The following are some examples:

Pamela (86) described how, since the first interview, she has experienced more difficulty with her mobility due to her back and legs and has had to be wheeled down to the dining room for lunch on two occasions. She has also found cleaning her room increasingly difficult as she only has the use of two fingers on her right hand – the others are completely numb.

Colin (92), who suffered a stroke and now uses a Zimmer frame, described how he can't walk very far: *"I can only walk a few paces to the door or next room to use the bottle (to go to the toilet), then need a rest – I don't get out of breath to the extent of being in pain, but get puffed"*.

Other participants described having difficulty using upstairs toilets; one

participant wished she had had the foresight to have installed a downstairs toilet in her home before losing her sight, whilst another used a commode to avoid numerous trips upstairs during the day:

Molly (88) said she has a commode to use downstairs during the day to save going up and down the stairs each time.

Jackie (88) explained: *“That was a folly really – you know, when you’re younger you don’t realise when you’re older you might need a little cupboard way into your toilet, I could have done that with what I have outside – it’s a pantry in the kitchen leading into a coal house with an outdoor loo - therefore anyone with some practical common sense would think when you’re old, [you] wouldn’t want to go out to that in all weathers, and the other one is upstairs”*. She doesn’t use the outside toilet in the dark for practical reasons relating to her sight loss.

As well as struggling with mobility due to physical weakness caused by leukaemia and chemotherapy treatment, one participant also found mobility difficult due to his sight loss:

Kulvir (80): *“when I am walking I’ve got to be, for example the steps are there, I’ve got to be very careful with one eye, there’s a little bit of imbalance, I don’t know if the step is there, or there, so got to be a bit careful. If it’s, outside its dark, I have a problem”*.

Kulvir’s daughter-in-law had temporarily given up her job to care for her father-in-law as he needed support around the home:

“Most of the time he just spends up here, he goes downstairs to have his lunch, but when he’s feeling really weak then I bring his food up here, that’s why I had to stop work for a while because his condition was getting quite worse. Because he does like need assistance around the home. [Researcher: “With getting up and things?”] Yes.”

Another participant struggled to go upstairs due to breathing problems related to his cancer treatment:

Rajat (58) gets around the house ok but he only goes upstairs in the evening because he struggles up the stairs and starts breathing heavily which makes the problem with his throat worse – the hole that he breathes through bypasses his nose completely, and took him some time to get used to.

Five participants described having had one or more falls within their homes, which in some cases resulted in hospitalisation. Many described how falls or the thought of falling had made them nervous about getting around:

Colin (92): *“Well, obviously, but I’m frightened of falling, I mean if I... I don’t know, do they operate outside?”* [Researcher: asked him what they mean – he pointed to a button around his neck that called for help if he pressed it] – *a voice would come through and ask “are you having trouble Mr [name]?”* – he said he hasn’t been in trouble but they come on sometimes to test it and make sure it’s working. That’s the only thing he’s got – he isn’t sure whether it would work outside or not. He would worry about falling if he was outside.

However, by the time of the follow-up interview, Colin (who lives alone) had fallen during the night, when he needed to go to the toilet:

Colin (92) felt the Zimmer frame moving on the carpet and was powerless to stop it, and fell onto the floor and couldn’t move. It was in the middle of the night. He pressed his panic button that he wears around his neck, but didn’t hear a voice acknowledge him or ask if he was ok (this may be because he was not wearing his hearing aids). Then some time later, his daughter and son in law turned up – he didn’t know who they were at first. They helped him back into bed. Apparently the panic alarm service called his daughter to come and check on him. Colin is very disappointed with the service, as he thought they would send emergency services out (or someone from the service) rather than call his daughter at 3am in the morning. The panic alarm service said they tried to ring him to see if he was ok but he didn’t hear the phone and wouldn’t have been able to get to the phone anyway as he was unable to move from where he fell. He said the whole matter has distressed him. He has a huge bruise on his right hand side. He said his doctor doesn’t know he fell and would be cross as he said he mustn’t fall, though he obviously didn’t mean to. He is trying to be even more careful than he was beforehand as he doesn’t want to fall again – he said he isn’t afraid, just a little shaken.

Another participant who lived alone described how she had had two bad falls in between the two interviews:

Mary (84) said she had a spasm and couldn’t get up off the sofa – she remembered thinking to herself *“go on your knees [Mary]”* but she couldn’t. The next thing she knew her [volunteer helper] came and found her on the floor; she phoned for an ambulance and Mary was then hospitalised for 8 days. Since her stay in hospital she has had a shower fitted, as she also had a fall in the bathroom, into the bath. She couldn’t get out as she didn’t have the strength, and kept falling backwards – she described it as very frightening. She says she knocked on the wall and cried out for help but she then remembered it wasn’t an adjoining wall so nobody would hear her. Then she realised she could use the taps in the bath to help get herself up, and managed on her 3rd attempt. She said she was so relieved when she got out of the bath, that she decided to get rid of the bath and has recently had a walk-in shower fitted by a relative.

Fiona (59) described how she and her husband had to cancel a trip to a concert in London as she missed her footing when she came out of the toilet and fell down the stairs; she tore her ligaments, sprained an ankle, and jarred her bones.

Belinda (82) said she likes to get out and forces herself to get out and about, but has had a couple of falls lately. She said she finds stairs difficult, but has banisters on both sides which help. She recently went to see her cousin in Jersey; she found it very tiring to get about, even though they had a car. The accommodation where she was staying didn't have a rail down some stone steps, which she thought was bad – one night she fell backwards. She said *“I think when you've had a fall you're inclined to be nervous aren't you?”*; luckily she escaped injury that time but it has knocked her confidence a bit. She said she has fallen forwards before and got black eyes.

Norris (89): Norris' wife described how his doctor was concerned for his welfare after he experienced several falls within the home; his wife said she was unable to pick him up afterwards. Social services recently installed handrails in their home to aid Norris' mobility.

Whilst one participant did not describe actually having had a fall at any point, she said she was very careful when outside, particularly in the winter time when the weather is bad, as she worries about falling and hurting herself as this would burden her family:

Eva (88) *“I wouldn't want to fall down and be a bother to my family, if I broke my arm or whatever, so I've got to be sensible, even though I'd miss going out I say to myself 'No, thank you'.”*

Not all of the participants had such difficulty getting around their homes however; for example, one participant felt lucky that he was still mobile and able to get around his home without too much trouble:

Jeremy (80): *“I always think if I can get out of bed and walk... I mean when I was down [local voluntary organisation for people with sight loss] there was some youngsters and I've seen elderly people, older than me I would imagine, in a wheelchair and they've got sight problems and they can't walk, and I think, well, I'm the lucky one, at least I'm still mobile.”* He said that the only time he struggled at home was if things were moved from their usual place.

Mobility in the home was less of a problem for many of the participants than mobility outside the home as they knew the layout of their home so well:

Lawrence (60) suffers from labyrinthitis which can affect his balance: *“Very often I’ve feared going out... to let the dogs out and things such as that and I’ve suddenly felt like I’m going to go, but it’s only because I know that the proximity of the house and buildings, the things around me sort of thing, I know where they are, I can make a grab and hope that I’ve got it and I’m holding on so that I don’t go down, otherwise if I was to go down outside I could smack my head on the concrete. You know, that would be that.”*

Keith (87): *“But here of course I know where everything is, [in the] minutest detail. I don’t need the lights on at all. Everything is conveniently placed really.”*

Another participant had adaptations carried out in the garden so she could safely navigate the path and steps to her front door:

Fiona (59) has outside security lights that come on when she approaches her front door so she can see where the door handle is, and her husband put a strip of white paint on the edge of the step so she can see it. Social services have also fitted a handrail up the front steps to help her.

A number of participants said that they had handrails installed in their home to aid their mobility; in many cases this had been installed by social services (e.g. Kulvir, Norris, Fiona), though in some cases a member of the participant's family installed them (e.g. Julie, Lawrence).

Sleep

Half of the participants described having trouble sleeping at night, and most said that they rarely slept right through, the most common reason being the need to go to the toilet. Some of the participants appeared to have great difficulty sleeping, and as mentioned previously, three participants said that they took sleeping tablets to help them sleep each night. The following are some examples:

Pamela (86) described herself as a poor sleeper, and rarely sleeps beyond 1 or 2 am. She goes to bed early (around 9.30 pm) as she is normally really tired by then due to waking up so early earlier in the day. This problem has been made worse due to the co-location of one of her neighbours in the residential home who has Alzheimer’s; she regularly bangs on Pamela’s door or rings her door bell during both the day and night. One of the staff come to settle her but a few minutes later she is up again and walking around the corridor distressed, disturbing the other neighbours. Pamela has earphones so she can listen to her talking library books at night without disturbing other residents, when she can’t sleep.

Molly (88) described herself as always feeling tired and lacking energy; she said it affects her daily activities, and because of it she rarely goes out. One day she went to sleep as she sat and had breakfast, and fell asleep again after washing, changing and eating lunch. She often doesn't get out of bed until 11 am and never knows how she is going to be each day. She said she sleeps a lot now, and doesn't get going till the afternoon.

Fiona (59) described how she has always had trouble sleeping through the night, but this has recently been worse due to her husband's recent health problems. She said she gets disorientated in the middle of the night so they have a night light plugged into the landing so she doesn't accidentally fall down the stairs. The nightlight automatically comes on if there is a power cut.

Colin (92) goes to bed at 8.30pm. He is able to get into bed on his own. He doesn't get to sleep straight away, but usually watches the lights on the ceiling of the cars going by on the road outside, and listens to his talking clock counting away the time. He describes himself as having a lot of time to think about things – things in the past, and how he wishes things could have been. He said he can't hear a lot as he doesn't wear his hearing aids in bed. He usually falls asleep around 9.30 pm but wakes up several times in the night. He has stopped having a drink before bedtime as he recently fell when trying to go to the toilet, so he wants to avoid the need to go at night.

Delia (86) often wakes up two or three times in the night to go to the toilet. She said that, at first, she found it difficult to sleep after her husband had died.

Another participant described how anxiety could affect his sleep, but reflected how important he thought marriage was in order to have companionship. This powerful quote leads naturally to the next section which is related to 'Communication and social interaction':

Lawrence (60): *"Do you know the worst part of actually living alone is when you wake up in the middle of the night and you don't feel very well, and you feel you want someone to speak to and there's nobody there. And this, now, I can see is the companionship that when people get married, if you're real, true companions, you can wake your partner up"* [his wife interjected: *"Might get moaned at!"*] *"No, no, but you can wake your partner up and your partner has got that understanding, the other half needs me, the other half is unsure, uncertain, something is not quite right, need that extra little bit of reassurance, need that little conversation. Once that's settled you just both go back to sleep again, no problem. And yet you can wake up in the morning feeling that much more relaxed, that much more happy about life, purely and simply because, just that little bit of conversation in the middle of the night has done the trick."*

Communication and social interaction

Social interaction and loneliness

Not surprisingly, most of the participants talked about social interaction at some point in the interviews, whether in relation to their experiences of mixing with other people or their need for it. For example:

Emily (87) remarked that she can go all week without seeing anybody. But she said that she doesn't worry as she knows she can ring someone if she needs to. However, later in the interview she remarked that she gets a bit lonely and that if she collapsed onto the floor nobody would know or find her for a long time. She added that she sometimes gets a bit "morbid" if she goes for a while without seeing anyone. When feeding back about the interview, Emily said it had made a nice change to have something to talk about (in the interview), *"because you spend hours on your own obviously... it is lonely, but because I have got my church and my faith, I tell myself at least it's still my own home and I can do what I want – because that would be dreadful, if I had to end up in a home – there's no way I could cope, I'm sure I couldn't cope with it."*

It is interesting how Emily initially portrays herself as being able to cope with living on her own with only limited social contact, but later confides that she does get lonely; this contradictory sort of dialogue was not uncommon in the interviews when participants were describing how they felt about their situation.

Many of the other participants (n=10) also commented on how much they had enjoyed doing the interviews, and having the opportunity for conversation, for example:

Jeremy (80) said *"I've enjoyed the company, Sue."*

Pamela (86) remarked *"I've enjoyed it! Really and truly, I'm being truthful, I have enjoyed it!"*

Fiona (59) said it had been an excellent interview, and that she had enjoyed and appreciated every second of it – *"it has been wonderful to talk to someone who isn't emotionally involved. You can get better feedback if the person you're talking to... this sounds awful, but with [husband] loving me, the feedback from him is different – and it's lovely to talk to you."*

Some of the participants talked in the interviews about experiencing feelings of loneliness, even those who did not live alone. For example:

Rajat (58), who lives with his family, described himself as *"being lonely"* when asked what his main worries were.

Others who did live alone talked openly about how lonely they sometimes felt:

Belinda (82) who lives alone described her life as *“a quiet life really... [I’m] fairly happy, but if you’re on your own you’re not sharing it with anyone are you, you need someone really”*.

Colin (92), who lives alone, acknowledged that those who supported him were very kind but commented that they don’t visit him often enough, that he gets very lonely. When asked if he talks to anyone on the phone in the day, he said his friend who he met in the Stroke rehab unit had died recently – he was obviously quite upset about this. He said they would often talk on the phone, sometimes more than once a day. He misses the phone calls with him and their general chit chat and banter, and wasn’t able to go to the funeral as he can’t go outside the house. So now he doesn’t have anyone to call in the daytime. Most of his old friends have passed on – *“that’s the trouble with being 92”*.

Other participants talked about friends that had passed away, and in one case, this had made the participant reluctant to get too friendly with anyone again:

Pamela (86) described her relationship with another lady in the residential home (in which she lives) who was blind: *“we were really good friends, did everything together, and met outside and would go for walks together, and that. But she passed away and you know, it were like losing a sister, and I vowed and declared that I wouldn’t get in close contact with anybody again. It did take me a long time to get over it. [Asked her how long ago that was] “It’ll be about 6 years ago. I vowed and declared that I wouldn’t get friendly with them all, so I wouldn’t be hurt again if I didn’t go before them.”*

Emily (87) described how she is always busy doing something even if it doesn’t need doing – she explained that it’s because she doesn’t get many visitors. But she said that in her age group all her friends and peers have passed away.

Eva (88), when asked if she spoke to someone on the phone most days, replied: *“I’ve got friends. But mind you they’re getting a bit low on the ground because they keep going to heaven like, you know.”*

Many participants coped with being alone by keeping themselves busy during the day and not letting themselves dwell on it:

Jackie (88): When asked if she gets lonely living on her own she replied that she does – but she has to say to herself “*what’s happening today?*” Has lots to keep her busy – doesn’t feel totally alone and desperate as she has lots of friends and God – God gives her something to do and she gets on with her life. “*I think ‘You’re awfully old, what’s going to happen to you?’, and you’re not supposed to think of that, when you’re going to die or anything like that, because he says “visions unto the day” – I have that in my mind. The fact I can walk around without pain – so many people my age couldn’t get around – so I am thankful for so many blessings really. And the sight is made up for by various means and helps, so...*”

Keith (87). “*Most of the time I’m here on my own but I’m not lonely because I have so much to do. One of my biggest [problems] is sheer frustration, you know, I avoid self-pity, that’s the worst thing anybody [could do]*”.

Although many of the participants had daily contact with paid carers, what they lacked was companionship, the opportunity for quality time and conversation with someone; they described how the carers were too busy and could not stay for long, or even if that was seen as part of their job they often didn’t have the skills:

Pamela (86), who lives in a residential home for the elderly, explained: “*I would like a little more company because I’ve found I feel much better after, and I think it’s because I go for days and days and days and just... they’ll come in and [I’ll] tell them what I want for my lunch and tea, then don’t see them again for ages and ages. They’re supposed to give you so much quality time each day but they haven’t got the time, there’s so many people that need caring for and that, they haven’t got the time, and I’m sorry to say it, they’re not carers like they used to be when I first came in. There’s a lot of young ones here for the money... I don’t call ‘em carers, if you come into a job like that you’ve got to be dedicated don’t you? I loved my job, and was sorry when I had to give up. You spend such a long time at your job until you retire don’t you? ... you’ve got to do it right.*”

Keith (87): “*My home care is supplied by a firm called [name of agency] who only pay their carers the minimum wage of £5.30 so what you get, you can’t, you have a conversation in words of one syllable like. That’s my problem I haven’t got nobody to converse with, like, I mean I don’t want to boast about that but that’s important.*”

Colin’s experience linked with the above and also highlighted the delicate balance between professional and personal relationships:

Colin (92) talked about one of his carers from the agency that comes every morning, Monday to Friday at 9 am to help get him out of bed – he said he doesn't want anyone else to come as he likes and knows her well. She doesn't rush like the others, and will take the time to chat to him. He used to have a young carer a couple years ago – they became quite fond of each other and Colin always joked that he would adopt her as a granddaughter! She asked him for advice about things and about how things were back when he was young – was always really interested in what he had to say. But the agency said that they were getting 'too familiar' and stopped her coming. He doesn't know what happened to her. Colin was obviously upset about it, and said he didn't understand why she couldn't come anymore.

Some participants talked about different ways one could engage in social interaction with others; for example, two participants felt that it would be beneficial to have a meeting place for people in similar circumstances so that they could socialise together:

Jack (83) felt there is a need for a meeting place to meet others with sight loss so you can tell them your troubles, and share experiences and successes.

Lawrence (60) suggested that all 20 participants be brought together in one place to share their experiences of having hearing and sight loss with each other, though he understood that, for some, this would be difficult as everybody varied in terms of their health and mobility, and ability to travel.

Another participant (Norris) had started taking part in a weekly conference telephone call with other visually impaired people, while Pamela felt that the simple process of being introduced to people in the residential home would help her overcome her isolation:

Norris (89) described how he takes part in 4-way conference call with others with visual impairment via the RNIB; he was having difficulty hearing the conversation, so a local voluntary organisation for the deaf provided a telephone with an amplifier so that he could take part – he can now hear the conversation very well; his only complaint is that they don't talk about anything of interest to him, like politics for example.

Pamela (86) who lives in a residential home said, "*There are some in here that I don't know! Because I haven't seen them, and our old manager used to introduce them all when they came but this one doesn't at all.*"

Similarly, others commented about the desire to meet people with whom one has things in common to talk about:

Jack (83) said *“I miss sociability to a large degree”*. He likes talking to people, if between you there is something worth talking about. He said he has always liked an association with people who do things, like fishing and farming, but said you can't find it today. He said *“we are at an age where people talk about their ailments! [Both Jack and his wife laugh!]. So we are out of the conversation!”*

Molly (88) lives with her husband and son but craves female company as she feels women are chattier than men and talk about different things; when suggested to her, she said she wasn't keen on attending a day centre, however.

Communication – conversation

A number of participants described the difficulties they had being able to follow group or one-to-one conversation:

Jackie (88) hosts regular meetings in her home for church members but sometimes struggles to participate in the group conversation. She asks them to speak up but as soon as they get excited or engrossed by what they're saying they start talking too quiet again with their heads down. She was given an aid that she has to press when she can't hear, but it doesn't help much so is hoping that better hearing aids, when she gets them, will enable her to hear. She said being in a group is difficult because they don't like to speak in that domineering (loud) way – they like to speak confidentially.

Pamela (86) doesn't go down to the common areas in the residential home as she can't hear all the conversation – she finds it difficult in a group.

Julie (70) finds group conversation difficult, mainly because of the hearing impairment.

Emily (87) said she doesn't like being in groups as she struggles to hear what people are saying.

A number of participants described the difficulty they had to follow a conversation due to their hearing loss, even in a quiet room:

Colin (92): When asked whether he had difficulty hearing someone talk in a quiet room, he unequivocally replied *“yes”* – he said he was straining to hear the researcher talk in the interview, and had to really concentrate. He said *“it's hopeless”*.

Betty (86) described how sometimes she pretends to hear what someone said when actually she didn't: *"you don't want to be a nuisance to other people and sometimes you're very stupid and you pretend you've heard when you haven't. You think you've heard. You shouldn't let them get away with it, you're going to make silly mistakes, it might be dangerous"*.

Kulvir (80): *"Actually it's uncomfortable, actually, nothing but uncomfortable because when somebody's talking to me I say 'What did you say?' - always happen. My daughter-in-law she always tell me 'you always ask twice'."*

Molly described how her sight loss exacerbated the difficulty:

Molly (88): She said it is harder now she can't see – was easier when she could look at people when they talked to her.

Indeed, the researcher found that conversation was at times difficult with a number of the participants as they were unable to pick up on the visual cues that one would normally use to signal that they wanted to speak, particularly if the participant was very chatty.

One participant described an aid that was given to her by the deafblind worker from social services to help her participate in conversation when out and about, for example, in a restaurant:

Fiona (59) has a portable induction loop fitted in her home, so that she can follow conversation when there is background noise; she describes it as *"wonderful!"*

Communication - telephone

The telephone is a vital method of communication for people, particularly those who are more isolated from mainstream society; ten of the participants said they could not hear well enough to use an ordinary telephone, whilst the other nine said that they could. It wasn't clear whether or not the remaining participant could.

Of those who said they couldn't use an ordinary telephone, many had a telephone with an amplifier or one with big buttons or both, for example:

Fiona (59) has a big button telephone with a built-in induction loop, so she can hear the person at the other end of the phone. She tunes her hearing aids into the correct programme. She also has an amplifier fitted to the phone so when it rings she can hear it, as otherwise it's very frustrating.

Another participant felt unable to use a mobile due to the size of the buttons on (standard) models:

Molly (88) said she had no chance of using a mobile phone as the buttons are too small. She said she couldn't use an ordinary telephone either, her telephone has big buttons.

Only one of the participants mentioned that they used a mobile phone; this was one of the younger participants:

Fiona (59) has a mobile phone with a big screen, and a clear display for when you key in numbers; it's a Vodafone "Simply" model.

Some participants could only use the telephone if a member of their family was there to help them:

Delia (86) often speaks to her friends that she met when she was in the Women's Air Force during the war, as well as her sister and brother – she has them programmed in to the memory buttons so can contact them without her son's help; her son has to dial the number for her if the number isn't on a memory button, as she can't see the numbers on the phone even though it is a big button phone.

The hearing or sight loss wasn't always the main cause of difficulty in using a telephone, however. One participant remarked that she didn't call friends and family as much as she would like to as she had to be careful about the cost of the calls she made each month:

Pamela (86) talked about one of her friends who had recently lost a husband; since he died, Pamela has called her every week, just to keep in touch. However, she said she doesn't use the telephone very often, or as often as she would like, as she finds it difficult to dial out easily and she has to pay her own bill at the home; she allows herself £5 per week, as she can't afford to run up a big telephone bill because she only gets a little pocket money from her pension each week after her residential care has been paid for.

Another participant did not use a telephone due to his other disability:

Rajat (58) said that he didn't ever use a phone to speak to anyone because of having to use a voice synthesiser held to his throat to communicate verbally.

Attitudes and awareness of others

A number of examples were given where social interaction was difficult because of people's attitudes or misunderstandings about the participant's sight and hearing loss; for example:

Pamela (86) described how she struggles to hear what's being said by others in the dining room, and wonders if the battery on her hearing aid needs replacing. She said that when she goes to social events in the residential home, people seem afraid to speak to her – she doesn't understand why, but suspects it is because of her visual impairment. Even though she doesn't see anything at all now, she still wears her glasses as she has worn them for years, so she wonders whether people think that she can actually see but is ignoring them. She concluded that *“the trouble is you can't mix when you can't see”*.

Belinda (82) said she can recognise people out on the street if they speak first, but commented that people seem to expect you to speak first – she thinks it's strange that they think like that.

One participant felt that people were intolerant of him due to his additional disability resulting from an operation for cancer of the larynx that took away his ability to speak 'normally'; he now can only speak using a voice synthesiser pressed to the hole in his throat. When asked to describe his life before the operation, he replied:

Rajat (58): *“I had friends”* - but now they don't visit him because he can't talk 'normally'. He said he doesn't know if it's because they feel uncomfortable. When asked whether he thought of finding out about local groups for people with hearing and/or sight loss, he replied *“no”*. He said it's because he can't talk, and couldn't mix with people. When he goes out he takes a writing pad with him that has a message written on it with an explanation of his circumstances – he shows people the pad – it says *“sorry I can't talk and have blurred vision”*. Some people respond ok, some don't. He said people are not interested in him, because of the disability he has (of not being able to speak very well, and his sight loss). He feels that people are ashamed to be associated with a disabled person. Even his direct family makes him feel like that.

Alternative methods of communication

Of the four participants who mentioned that they used a computer, (including Janice, aged 70, John, 83, Frances, 59, and Leslie, 60) one participant described how the use of email was an important method of keeping in touch with others who have similar circumstances:

Fiona (59): *“The next bit of news is that I’m the only adult in the [local] area with Sticklers syndrome – this is why I have a computer with voice recognition software, as the support group for Stickler is in [town far away]. So if I have any problems I just email the members, and they email me back – that’s how I found out about the strobe light... With this “wonderful” disorder being so rare, I’d feel isolated if I didn’t have a support group, and I do, because there’s nobody else of my age with it, and I’m one of these, [name of researcher], that need to talk about things, do you know what I mean? I can’t bottle them in, I need to find somebody. My medical team at [name of hospital] tell me they’ve learnt more about Sticklers from me than they have from anybody else and anywhere else [Researcher: because you talk about it?]... yes.”*

Being able to communicate with others was so important to Fiona that she also decided to learn braille and other communication methods in preparation for the time when she can no longer see or hear at all:

Fiona (59): *“You will have noticed by now I’m a very people-person, and when my sight goes, if I cannot communicate Suzanne, then... [slight pause] it’s the end, I can’t not communicate, I can’t handle not being able to talk to people. I can also use the Deafblind method of communication which is the finger spelling and I can use the block method as well”. [Researcher: can your husband do them?] “Oh yes, he can use the finger spelling and he can just about manage the block, but braille, no, I think it’s too upsetting for him.”*

Accessing information

As described earlier, 12 of the participants said that they couldn’t read print at all without a magnifier (some of whom said that they couldn’t read print even with a magnifier), whilst five participants could read large print, two could just about read a newspaper headline and one could still see well enough to read ordinary newspaper print when wearing his glasses. The majority of participants who could still read print did so using an LVA of some description with varying degrees of success, and some required enhanced lighting. Much less common was the use of braille (mentioned by three participants, but not extensively used to access information), information on tape, and using the internet/computers to access information (used by four participants).

Low vision aids (LVAs) and lighting

Eleven participants said that they had an LVA; they varied from handheld magnifiers with and without lights, to LVAs that plugged in to a computer or TV to enable them to read the enlarged print on the screen. Two of the participants said they had difficulty using the LVA (Jack, 83, and Delia, 86 who needed her husband to plug it in for her), whilst six of them mentioned

that they had difficulty using it due to their degree of sight loss. Here are some of the participants' experiences:

Lawrence (60) said he has not needed to ask for the correspondence from his bank to be in large print or braille, as he can read it using one of his various LVAs; he only has a problem when he is sent reams of information as it takes so long to read it with an LVA.

Jack (83): Said he could not see well enough to read either a large print book or a newspaper headline, unless he uses an LVA; he described an LVA he was given, which looks like a pair of spectacles that covers one eye, and has a lens and light behind the other – he said it can be helpful but it has such a stiff and rigid lead on it that you get fed up trying to use it – if it was cordless and more mobile it would be much better.

Jackie (88) said she can read ordinary newspaper print with a magnifying glass, but has to put it magnifying glass over every word, so the process is very slow; she said she has given up reading the Daily Telegraph newspaper for that reason.

A couple of participants reported having an LVA that they now found didn't work as well as when they first got it (e.g. Jack, 83, Jeremy, 80), suggesting that their eyesight had deteriorated to the extent that they required a further low vision assessment:

Jack (83) got a magnifier with a light from their optician but said it's useless – it has a long lead and plug, which gets in the way when you are trying to use it. In his opinion it is badly designed, it should have rechargeable batteries and a charging unit. He said it needs 'updating' as well, as it suited his level of vision some time ago and his vision has since deteriorated. He also has a monocular but finds that "useless" as well.

Most of the participants acquired their LVAs on a loan basis, but one participant said she purchased one herself as she liked to feel that anything she has belonged to her and that she wouldn't have to give it back at any point; this is despite the fact that she could have got the LVA for free on a 'loan' basis from the local voluntary organisation for the blind. She also described the difficulties she has when trying to use it:

Emily (87) demonstrated an LVA that she has which is a magnifier that plugs into the TV; she described it as being of no help at all, especially when trying to read small print. She said part of the problem is that she isn't very patient, so gets frustrated if she can't read it quickly. Also, one needs to have a steady hand to use it otherwise it jumps across the page and makes the print difficult to read. She said she could have had it on a monthly basis on loan from the local voluntary organisation for the blind, but she purchased it herself for over £100 as she likes to be independent and know that it belongs to her. She attributed this to the ethos she acquired in her upbringing. She said the trouble is, if it goes wrong it's a problem as she would have to pay for it to be repaired.

In terms of lighting, five participants mentioned that they required good lighting, though it was not necessarily said in relation to reading tasks in particular. Two other participants said that they were better off *without* bright lighting, and a further participant said that the special lighting he had in the home didn't seem to help him anymore.

One participant was very concerned about the trend towards the use of energy saving light bulbs which in his experience do not provide enough light for his visual impairment:

Lionel (60): *"we are totally and utterly against these low energy bulbs. What concerns us more than a little is when they decree we've got to use them full stop, no matter what, where...are we going to get the right kind of bulbs that suit our needs because they are just not considering what visually impaired people really need. Only looking at the majority... everybody's got to use low energy but the visually impaired person needs different lighting and if we can't get the bulbs and the right kind of lighting we are going to be scuppered... what are the Government going to do about it?" [His wife:] "They're not, it's as simple as that." [Lionel]: What kind of pressure can we apply to the Government to say 'look, you've really got to consider the needs of the visually impaired person because their needs for lighting is much, much more differing to the ordinary, every day person'. So I think if Pocklington want to do something of real good, [they need to] pressure... the Government."*

Braille

Only three participants said that they read braille; two were visually impaired since birth (Lionel, 78 and Lawrence, 60), whilst the other was learning braille in preparation for the time when her sight deteriorates to the extent that she can't read print anymore (Fiona, 59).

Fiona had recently taken a third exam in braille having already passed two previously, and appeared to be reading braille every now and then in order to access information on the rare occasions it was available, for example a braille menu in restaurants. Due to the use of lancets in his fingers for his

diabetes, Lionel finds reading braille more difficult but tries to persevere. Lawrence did not mention any sort of information that he accesses in braille, and felt that its use was diminishing due to the growing use of technology:

Lawrence (60): "Technology is a positive but you've got to be able to know how to use it and find the right kind of people who can help to teach you the technology... you can't read the instructions, if we had the luxury of being able to say that all equipment that is sold is privy to braille, right, to be able to read it, so we have the chance to read it and understand it just the same as anybody else, fair enough, you wouldn't want a great deal more to be honest. The trouble of it is... because of technology, because of computers and things such as that, then the element of braille is being dropped, is gradually being dropped in lots of different directions, it really is and it's a shame."

Information on tape

One participant mentioned that he received a regular talking newsletter from the council, that details "what's going on" for elderly people; Keith (87) was not clear whether the information was about available services or activities, but said it contained news from both local and national government and gave information about carers. Other participants also received talking newspapers on tape with news from their local area; for example, Pamela (86) who enjoys regularly listening to the three different tapes that are delivered personally by a very friendly gentleman who stops with her for a cup of tea before going on his way.

Computer use and the internet

A number of participants talked about the difficulties of accessing information, and ways that they have overcome it. Learning to use a computer to enable access to the internet was one that several participants described; for example, one participant used a computer to search the internet for information about the conditions that are causing her visual and hearing impairments

Fiona (59) said that at first she was absolutely devastated as so little was known about her condition [...] "that's when I first got a computer, to help find information". She said back then (in the 1980's) it was very early days for the internet, whereas today there is more information available online. However, one of her syndromes, the Wagner syndrome, is so rare that she has not been able to find much information on the internet about it.

Another participant used the internet for internet banking, so that he can keep an eye on his finances; he felt that access to the internet has enabled him to access information as well as the sighted population:

Lawrence (60): *“That’s the one thing I do like my computer for because obviously I do use the internet banking. I check that every day. People say to me ‘What do you do it every day for?’ I say ‘Well, hang about, you look at how many people have money stolen from their accounts’. Because they don’t check it every day and they’re not putting in the necessary safeguards and that, if anything goes wrong what are they going to do about it, they could end up being the losers, now if I find there is something wrong, immediately, my first step is ‘phone [his bank], and if I think there’s something wrong I say to them ‘Right, what are we going to do about this, because I don’t think this is right, I need it looking into’.”*

Others used the internet for shopping, or to access books that aren’t available as talking books and keeping a daily diary:

Julie (70) uses the internet to get all of her shopping online and then delivered to her home. She also uses it as an important method of communication with other volunteers involved in a charitable organisation. She says she is happy to use a computer for a couple of hours at most as she gets tired easily.

Jack (83) uses the internet to access books that he can no longer read in print; he tries to limit the amount of time he spends on it in the day as he said time can run away without you realising it. He writes his daily diary and then listens to a couple of chapters of a book, such as ‘Huckleberry Finn’, which he downloads off the internet – he said recently he has been downloading books that he read when he was at school and finds he is enjoying it now as much as he did then.

One participant described how she would have struggled to learn how to use a computer with her sight loss, if she had not had the support of her son:

Julie (70) has a computer that was built and adapted for her by her son. She learnt all she knows about computers from her son who lives at home, and feels she wouldn’t have done it had he not been around. She would have liked to go to a computer course but said she would have had to sit at the front of the class, and wouldn’t have been able to hear either. As far as she knows the local voluntary organisation for people with sight loss don’t offer computer courses.

Some of the participants who were using computers on a regular basis had specialist software on their computers to enable them to access information and keep in touch with others:

Fiona (59) explained *“I’m the only adult in the [local] area with Sticklers syndrome – this is why I have a computer with voice recognition software as the support group for Stickler is in [far away town]. So if I have any problems I just email the members, and they email me back – that’s how I found out about the strobe light.”* She also has a webcam for conversing with other members.

Another participant would like to purchase specialist software to enhance his experience of using a computer, but says it is difficult to get hold of the equipment:

Jack (83) uses font of point size 72 on his computer screen which he describes as very cumbersome and tedious at times. He is hoping to go to the QAC Sight Village exhibition in Birmingham in July to look at the different technology available, if [local voluntary organisation] is able to set up transport.

Another participant (Lawrence, 60) found it difficult to purchase specialist software as it is so expensive, and although he was aware that he could get the software on loan for free, he preferred to own it himself:

Lawrence (60): *“you can go into things like the Sight Village that they have. They’ve got all this absolutely wonderful equipment, beautiful stuff, yes, if I could lay my hands on a lot of this stuff life could be a whole lot easier, however, it boils down to one thing and one thing only – money, the price of this material is absolutely horrendous... So where do you go to get funding, this is the other thing. You’ve then got to find places to get funding. A lot of them turn round and say ‘Oh yes, we’ll fund you for this, but as long as you stay in that particular place that equipment’s yours, you move somewhere else, wherever, that equipment actually belongs to us’. I like things to be ‘my’ things; I want them to belong to me, not to Tom, Dick and Harry.”*

He bought the equipment that he has with the help of the deafblind worker he is in contact with who found an organisation that gave him a grant towards the costs.

Lawrence described how technology, and computers in particular, had really enhanced his ability as a visually impaired person to access information as much as sighted people can:

Lawrence (60), who has been visually impaired since birth, said: *“The huge loss of information that we’ve had in our lives, now it is obviously enhanced a great deal because of the use of computers and technology and things such as that. We are now beginning to pick up on so much information.”*

Accessing information about support services and entitlements

Knowing who to turn to for help was obviously very important to many of the participants; there were some instances where people were not aware of support that was available, or where they could get it from. For example, one participant was not aware that she could get help with her shopping:

Jackie (88): *“A friend helps, but she is Indian and is off to India for two months in November... it’s an awful bind to give people lists every week.”* She said it’s too difficult for her to go to the supermarket due to the large numbers of people around, and aisles that appear to stretch to infinity so she’s no good whatsoever in supermarkets, so when her friend goes to India she will have to ask somebody else. She said she didn’t think anyone in SSD or [the local voluntary organization for people with sight loss] helped with that, thinks you have to get help yourself in that way.

Fortunately she later approached the local voluntary organisation for people with sight loss who agreed to try and help her get a more long term solution (see also ‘Shopping’ in the earlier section about independent living skills).

Some participants (e.g. Jack, 83, Julie, 70, Fiona, 59, Jackie, 88) had attended courses hosted by voluntary organisations for people with sight loss that covered many different aspects of living with sight loss, and the support services that are available to help them; it is clear that the participants who were fortunate enough to go on a course found them to be very helpful:

Fiona (59) When asked whether she has ever received advice about benefits: *“Yes – [SSD Deafblind service] and the RNIB organised an amazing course called ‘Finding Your Feet’, for those of us recently registered blind. [It] was at the Windermere Manor Hotel at the Lake District. We have been back to the hotel about 11 times since! Was a wonderful course, it really helped – was for me and for [husband], for partners as well – to help them come to terms with what happened and also to know what’s out there and available.”*

Jackie (88) described how she attends a weekly group that she was introduced to by the local voluntary organization for people with sight loss: *“I’m very happy to meet these other people and find out how they are coping”*. But she said she isn’t sure about going to the next session as it is about careers, but most people in the group are pensioners like her. The course runs for 8 weeks and had sessions on counselling, rehabilitation, holidays, Age Concern, etc. She said they are given refreshments and provided with a taxi to get there and back.

Jack (83) described how he used to go to the blind centre who *“were helpful in lots of little ways, things like how to handle money, by holding the notes in certain ways so you knew which was which, used to be quite amusing some of it. But it was helpful. They had us in for about 6 classes.”* Jack also found about the local voluntary organisation for people with sensory loss, which has been a source of help for many things, from attending this course.

A few participants mentioned that they received benefits like Attendance Allowance for their sight and hearing loss or other disabilities and health problems, or Carers Allowance, which their spouses claimed for the care they provide to them; in some cases they only found out about these benefits and their entitlement to them through contact with services. For example:

Julie (70) said she receives Attendance Allowance, and found out about that via the deafblind worker at the local VO for people with sight loss; she was pleased as she didn't think she was eligible for anything like that.

The wife of another participant described at length the process they had to go through so she could receive carer's allowance for the care she provides to the participant, and was very unhappy about the questions they were asked which she felt were too personal. She concluded that she wished they hadn't bothered to apply for it, though the deafblind worker from the local voluntary organisation for people with sight loss insisted they applied as she felt they needed it.

Leaving the home and getting out and about

Most of the participants said that they left their home at some point to go out, even if only occasionally. Three participants however (Colin, 92 who lives alone; Pamela, 86 who lives in a residential home; and Kulvir, 80 who lives with his son and daughter-in-law) were largely housebound and only ever left their home on rare occasions, for example when they needed to access medical treatment which could not be provided by a health visitor visiting them in their home.

One of these participants, Colin, described how he had gone on one outing in recent times with his family to see where his late wife was buried; his description of the outing clearly illustrates how difficult mobility is for him:

Colin (92) described how he hadn't been beyond his front door for over 3 years, except on one occasion: *"that was when they took me to... I have a wheelchair, but, er, can't get out, I can walk with Zimmer (frame) to door, but that's it, I can't go any farther without somebody helping. And I can use my Zimmer and there'll be one [person] each side of me and help me along. They've [daughters and family] taken me out in their car, and last year or this year earlier on they took me to crematorium so I could see where my wife was but I couldn't see it, I couldn't see it. But both my son-in-laws are big strapping lads, and, have you seen a duck trying to fly? They picked me up and I was stretching my legs out so I could bend down [he started to get upset again] and just touch it. But otherwise I haven't been out since then, it's difficult."*

When asked whether he would like to go out more often, he said he would but was too afraid to try:

Colin (92): *“Well, obviously [I would], but I’m frightened of falling, I mean if I... I don’t know, do they operate outside? [asked him what he meant – he showed me a button around his neck that signalled he needed help if he pressed it] – a voice would come through and ask ‘are you having trouble Mr [Colin’s surname]?’.* He said he hasn’t been in trouble yet but they come on sometimes to test it and make sure it’s working. That’s the only thing he’s got as a safety net and he isn’t sure whether the service would work outside or not.

Kulvir (80) rarely goes outside of his home even for religious activities as he is very weak due to leukaemia and the regular treatment he receives; he has to be careful when mixing with other people as he is very vulnerable to picking up infections that could be dangerous for him: *“I’m not supposed to go in a crowd, I’m not supposed to go in any infectious places, if anybody has got a flu or something he shouldn’t come here... so that’s why I can’t go out, but I haven’t got enough energy to attend these sorts of meetings or anything, I don’t go nowhere actually.”*

Many participants described the difficulties they face when out and about and why some of them never go out unaccompanied:

Fiona (59): Due to the Sticklers syndrome, Fiona loses her vision completely several times a day. It is like a roller blind, starting at the top and working its way down to the bottom. If she is in the house she says to her husband *“the roller blinds are coming down again, so take me to the nearest chair, and I’ll sit down until it clears”*. It can take anything from 5 minutes to 10 hours. If it happens when they’re outside, her husband will take her to the side of a wall so others can get past her. She says that she can’t go out alone as she cannot cross roads unaided or use local transport as she can’t read bus destinations or train timetables. The Sticklers has caused her to lose her depth awareness and spatial awareness. *“I’m like two different people – here [home] I’m confident because we’ve lived here for so long, outside I am not at all. My stick has helped a lot but it’s not given me back all I did have.”*

Belinda (82): When asked if she goes out often, she replied “not a lot” – she still goes to the local shops but doesn’t go to shows anymore as she finds the steps difficult and confusing. She used to enjoy going to see plays in the city centre.

Emily (87) said that if she ever goes out she always telephones her daughter-in-law so she knows not to worry about whether she is ok, since she would worry if she didn’t answer the phone as she is always at home. The only time she goes out is to post one of her cassettes (talking books), otherwise she would run out of them. She only does this when the children are at school as they aren’t careful around older people, *“they just knock you over, they don’t have any respect for older people”*. Other than these short trips, she never goes out alone, and she doesn’t go out if it is windy or wet.

Another participant talked about concerns for his personal safety and that of his wife, who was also partially sighted, to the extent that they no longer go out at night unless they travel by car or taxi:

Lawrence (60): *"No, we don't venture very far, not unless we are actually physically taken. [His wife: "Not being funny Sue but it's not safe."]*
[Researcher: In what way? Because you can't see or because of people?]
"We can't see who's about. Because of the culture of youngsters today you feel that much distrust of them. Every little noise and thing that you hear, especially when it's dark, you'll think to yourself, 'Who is that, where is that?'"

One participant described how she coped with the sudden deterioration of her sight by trying not to panic and think logically about how she could get home:

Betty (86): *"A fortnight ago, I was walking along the high street and it was getting dark, and it got darker and darker, and I stopped a strange woman on the street and I said "is it very dark everywhere, is it very misty?" and she said "No, it's not, it's very clear, I'm afraid it's your eyes". The wretched thing had got blocked up again, more scar tissue. I was very worried about how I was going to get home because I was on my own, and I got into a bit of a panic. Then I thought 'Oh, I'm near the bookshop, they know me there and my telephone number and where I live and everything, I'll get someone to take me to the bookshop as I can't see at all', then the panic receded, and when I stopped panicking I could see better, and I did manage to get myself home on a very familiar journey."*

Another participant, who appears to be quite a confident person, described how he copes when he is out alone, despite having poor sight:

Jack (83): He and his wife had a 'tiff' one day, so to prove he could do it by himself, he pinched his bus pass out of her purse and went to town and a café on his own, and then went home. He feels he is quite capable of doing that despite the deterioration of his sight and hearing. He said if he gets lost, he'll ask for help. He regularly goes to the shops at the top of road by himself, and can't read what's on the bottles so just asks somebody. On the money side he has no idea what small change he has, so he just holds it out and tells them to help themselves. He said he doesn't think for one minute that anybody would rob him.

Jack and his wife moved to a new home in a different area after the first interview; when asked how he will get to know the new area once they move, he replied *"by experiment, exploring around. I have a good memory."*

A few participants said that they used a wheelchair to get around when venturing away from home, for example Keith (87), Pamela (86) and Colin (92) (though Pamela and Colin rarely left their home), and Lionel (78). One participant mentioned the high cost of purchasing a wheelchair and how one company had tried, in their opinion, to sell them a highly over-priced wheelchair:

Lionel (78) uses a wheelchair much more often now when he goes outside the home, due to his heart problems and difficulty in walking; he described an occasion when a salesman visited their home and tried to sell him a wheelchair for over £1000. He did not have an actual wheelchair to show them, just a photo of one, and wanted his old wheelchair as part-exchange; but Lionel and his wife thought it was too expensive, especially when they couldn't see what they were buying. They eventually bought one for £299 which had better features than the one the salesman had been trying to sell them.

As well as wheelchairs, the participants described using other aids to help them with their mobility when they go out, for example long canes, symbol canes and walking frames; here is a selection of their experiences when using them:

Keith (87) described how the walking aid he was given was useful in the home but no good when out and about: *"They gave me a walking frame, did I tell you? I was in hospital, the occupational therapist, it's all very well on a nice flat surface like this but as soon as you go outside with all the different inclines and curves to get up and down, [it's] not very good."*

Emily (87) uses a folding white symbol cane when she is out shopping with her communicator-guide so people know why she (the guide) is telling her things; she said she would otherwise be worried that people would think she's "barmy". She said she preferred a plain white one rather than a red and white banded one, as she would worry about being too conspicuous. She said she has found the symbol cane useful when out and about.

Lionel (78) and his wife do not have a car, and due to his mobility gradually getting worse he has to use a wheelchair when going out; if they travel any distance they have to use taxis which he described as a *"costly job but necessary."* They have to order the large taxis that have the loader to load the wheelchair in and out of the car. They used to use public buses but found they were *"a nightmare"* as they didn't have enough space to take a big wheelchair with a person in it. They used to use the local 'dial-a-ride' service for people with disabilities, but like other participants, found it to be inflexible as you had to order it 24 hours in advance and he doesn't always know if he will be well enough the next day to be able to go out.

Fiona (59) walks with the aid of a mobility cane with a revolving base [long cane], which tells her what material she is walking on, i.e. whether cobbles, grass or tarmac. The rehabilitation officer from social services gave her an 8 week course on using the cane; Fiona described this as: *“it’s wonderful – everyone comments on the improvement on my confidence. Really is wonderful, would be lost without it.”* However, she still doesn’t feel confident enough to go out alone and only goes out if her husband is with her: *“My stick has helped a lot but it’s not given me back all I did have”. “And I just object to the fact I can’t cross the road and I just can’t go out by myself, because I’m not safe either for me or anybody else [Researcher: Is that mainly because of your VI?] “Yes, and of course cause of my hearing [Researcher: because you can’t hear traffic?] no [said in agreement] “and I’m fed up of bicycles on pavements, it gets me mad. And I object to coming out the house and we’ve got workmen who forget to put barriers round holes or signs up or you don’t even know they’re there or how long they’ll be there. They must think everyone round here is built like Arnold Schwarzenegger, you know? There is no way I can go out by myself, no way!”*

Only one other participant mentioned that they had received mobility training outside of the home; like Fiona, this participant (Lawrence, 60) was fairly young in comparison with the other participants and talked very positively about the training he received from the social services rehabilitation officer.

Some of the participants talked about the different seasons and how different times of the year affected how often they go out; for example:

Belinda (82) said the weather affects how often she goes out, as she finds it difficult when it is darker earlier. She said that lately she has been going out less often.

Fiona (59) said she has fewer outings in both the daytime and the evenings during the winter as the weather affects her confidence – she said when there is frost or snow on the ground she makes Jane Torvill [the famous skater] look like an amateur! Because she is not safe she rarely goes out during the winter, even with her husband. Because he knows she is not safe, he is terrified she will fall. Fiona doesn’t go out with her Communicator-Guide if there is frost or snow on the ground either, as it’s too big a responsibility for both of them. She said she is virtually house-bound in the winter.

Many of the participants had to rely on public transport or upon friends and family members who had a car, since nobody in their immediate family (e.g. their spouse) had access to a private car. This reflects the fact that many of the spouses were themselves elderly and thus were no longer driving. Experiences of using public transport were mixed, with some having no problems whilst others experienced practical difficulties in using them, or financial difficulties particularly when taxis were used:

Molly (88) said she has “*given up*” on her eyes. She was given a ‘white stick’ but said she can’t go out on her own. She said that they (i.e. her and her husband and son) mostly use taxis, sometimes buses. She talked at length about the high cost of taxis – thinks it’s a lot when they know they use them a lot and that they’re pensioners. She said she has to pay £4 each way to go to the Doctors. She talked about the transport that collects people with mobility problems, for hospital appointments – but said it wasn’t reliable, and in the past didn’t turn up when it was supposed to. She said her son couldn’t afford to buy and run a car, he bought the house they all live in instead – she said she wishes he did have a car though.

Jack (83) tries to go out every day, but feels he is very limited in terms of not seeing anything. He said there is a real difficulty when you don’t have a car, and have to rely on the buses. He mentioned that the new bus pass is much less restrictive now, as you don’t have to wait till after 9.30am to get free travel. Jack and his wife try to go into the town centre once per week, and choose to go in early as it’s not so crowded then. They have been farther afield on the bus but not often.

Belinda (82) described how she gets the bus outside her house down to the local shops or to a large, fairly local shopping centre on her own. She sometimes has difficulty seeing the bus numbers even though they have enlarged them recently. She said the bus drivers don’t consider their passengers and jerk the bus – she said it’s a struggle when you have aches and pains. She remarked that she gets free travel on the buses and that her niece sometimes takes her in the car instead.

Delia (86) explained that she did not have the use of a private car as her husband, who was 87 at the time of the first interview, was too old to drive; instead, they relied on friends to offer lifts for shopping and visiting her sister, or taxis. She said they were not planning any holidays at the moment as her bowel trouble made any long distance travelling difficult; therefore they were planning to spend any money they have on taxis instead of holidays, so she could see her siblings every now and then. She said that she had used the ‘Ring & Ride’ service 3 times in the past, but didn’t like it as it was inflexible.

Jackie (88): When asked her about her mobility, she said *“it is good, but the world’s a funny place – I’m not happy out shopping at all, I’m really quite glad to get back because when your sight’s only partial it’s not a real world, it’s really funny, you go along, and on the bus, the houses go along. I got on the outer circle at [name of area] I thought, and I thought, ‘well this is a time getting to [name] Road!’, and said ‘where are we?’ And they said [different name] Road so I’d got on the 82 or something [laughs], I thought “ooh, I don’t know [name] Road” so she had to get off the bus and ask the staff in a cake shop to ring a taxi for her as she didn’t know where she was. She said the problem with being on the bus is “you don’t know where you are and you have to stand up a good time before you want to get off so you don’t miss your stop”.* Jackie said that she found the bus drivers to be helpful. However, she feels that she is a nuisance to people when she is out and about and feels silly when she asks for directions only to find the place she is looking for is right beside her! She finds most people she comes across are very good, and help her to cross the roads.

Similarly, another participant talked about how kind and helpful people often were when she is out and about:

Eva (88): *“I try to go out every day for an hour... I’ve only got to walk down that slope... and it’s on the straight to the bus stop and I’ve got two or three different buses that’ll take me to, to get another bus to [local area], because all the girls and the lads in the shops and the supermarkets, I know such a lot of them, if I’m looking around they’ll say ‘Come on, what you after then?’, lovely! [Researcher: That’s nice. You feel people are quite helpful and friendly then?] “And I mean the bus stop, being as I got me white stick, people will say ‘Right...’, a lot of them have got to know me, ‘This ain’t your bus [Eva]’, because they ask me my name and that. So, you only hear about the rotten people, you don’t hear about the nice people. And then when I come into [local area] and I want the 84, folks will say ‘Sit down and we’ll tell you when your 84 comes’. Nice things.” [Researcher: And how do you find the bus drivers, are they OK?] “They’re lovely. I carry a bag of sweets with me, they call me the ‘Sweet Lady’, and I give them out, you know, to kind people.”*

Some of the participants (e.g. Keith, 87) described how transport was provided to and from activities and group meetings that they attended, saving them the expense of paying for a taxi or relying on family or friends to give them a lift.

Activities within and beyond the home

Leisure activities in the home

Participants talked about a number of leisure activities in their home. Often they talked about how they enjoyed them, sometimes about barriers and

difficulties they faced, as well as reflections upon things they used to do but now find difficult. The following were discussed by the participants:

- Listening to talking books/magazines, etc
- Reading print
- Listening to the radio
- Watching/listening to the television
- Visitors to the home
- Other activities
- Leisure activities that participants were unable to do.

- *Listening to talking books/magazines, etc*

The participants spoke at length about how they spent their day. Not surprisingly, reading was a popular pastime amongst the participants, with listening to talking books/newspapers/newsletters/magazines on either tape or CD being the most popular way of reading (mentioned by half of the participants):

Belinda (82) said she sits down and listens to a talking book for an hour or so, as they are really very good for people like her who can't see very well. She gets them from her local library but they only have a limited range of books on offer; she had not heard of organisations like Calibre.

Jack (83) said that he gets talking books regularly – but wasn't sure from where – he said you don't choose what you get, you just state your preferences in terms of topic and they send you a selection of titles you might like. He said it isn't the same as reading in print, and many of the sorts of books he used to read aren't available as talking books; he used to love to read poetry and literature, and used to read a lot in French and Portuguese – he really misses that.

Most of the participants got the talking books or newspapers on loan either from the RNIB, Calibre or their local library or talking newspaper organisation (though some did not know where they came from); a couple participants (Fiona, 59 and Belinda, 82) mentioned that they purchased some or all of their talking books, so that they were theirs to keep.

Some participants described the difficulty they had in using talking books; for example:

Colin (92) finds it difficult to hold things due to a stroke that affected his hands; because of this he cannot change the CD's in his CD player, turn over the tape of his Talking Book or use his daisy player; rather, he has to wait till someone visits him. He is not sure where the Talking Books come from but when he is finished with one, another is sent as soon as you post back the other one, which is free.

Delia (86) enjoys listening to a review paper that she gets from St Dunstons on DVD (she may have meant 'CD') but she can only play that if her son is present as she can't see to use the DVD player on her own.

However, two participants said they did not want talking books:

Eva (88) was not interested in talking books even though they were suggested by her deafblind worker; she did not say why.

Molly (88) refused to have talking books even though suggested by her deafblind worker, as it would involve too much "*messing about*" for her son (who lives with her and her husband), as he would have to put them in the tape player and play them for her; she said "*he gets fed-up*" with all of the responsibility he has in caring for her.

- *Reading print*

Few participants said that their vision was good enough to read print, and of those who could, only one (Kulvir, 80, whose functional vision was still quite good) mentioned that he regularly read books. One of the participants, whose eyesight was good enough that they could read print, didn't read large print books due to her other health problems:

Fiona (59) explained that she has a collection of audio books as she cannot read large print because of her joint problem – she can't lift the books as they are too heavy.

Two participants who could no longer read print themselves mentioned that they had someone who regularly read to them, including Norris (89) who had friends that read to him when they visited, and Delia (86):

Delia (86): Her son, who lives with her, often reads her excerpts from the 'People's Friend' magazine and the monthly magazine from her local church. He also helps her with her bible reading and notes.

- *Listening to the radio*

Listening to the radio was also a popular activity with nine participants mentioning that they passed the time this way. Many explained that they enjoyed listening to the programmes about sport, politics or discussion as much as the music programmes:

Eva (88): "*I love my radio, I love that, I have it on when I get up until I go to bed practically. There's nothing on the telly.*"

Jeremy (80) *“my best friend now is the radio. Pull my leg about that, I’m awkward about an old battered radio and I’ve got one here and I suppose it’s my best friend; when I want a bit of sport, even talk shows or ‘phone-ins, I’ll listen to those, especially sport.”*

Norris (89): *“I don’t watch the TV which is quite true, but I do turn the TV on, on Sunday mornings at 09:00 to watch this programme by Andrew Marr, they have a series of interviews and so forth, which is interesting, but I listen to it rather than watch it. I use the television set for that, but otherwise its radio that helps me a lot... It’s Radio 4 mostly, but there’s also Radio 5 Live and the BBC World Service. [Researcher: You prefer stations where it’s more talk rather than music?] “Absolutely, yes.”*

One participant found the background noise on some radio shows to be a problem, however:

Colin (92) listens to the radio but said it’s no good when they put music on in the background when they are talking – this is also a problem on some Talking Books. When this happens, he turns it off and just sits quietly instead, as he just cannot hear what they are saying. He said he has always been a sports fan, particularly football, and likes to listen to match reports on the radio but finds it difficult due to the cheering in the background – *“they call it atmosphere but I can’t hear anything due to noise in the background”*.

- *Watching/listening to the television*

Most of the participants had a television, though many said that they had difficulty watching it due to their sight loss and in some cases, their hearing loss. Fifteen participants said that they would have the TV on at some point in the day, but often only for short periods or to listen to shows that didn’t require you to see, for example some game shows or discussion shows. Three participants said they never, or very rarely, watched or listened to the television. The following are some examples:

Emily (87): When asked if she could follow a TV programme with the volume turned up, she replied *“Yes but that’s where trouble comes in as I have to sit so close to hear and see it.”* She said that normally just sits on her reclining chair and listens to the TV. She can’t sit too close for long as her vision goes “fuzzy”. She tries to watch the soaps but has no idea what is happening most of the time.

Belinda (82) said she watches a bit of TV in the evening; at the time of the follow-up interview, one of her hearing aids was broken and she remarked that she misses her 2nd hearing aid as it balances out the sound.

Eva (88): *“I can listen and follow [the TV] more or less that way; I couldn’t watch a film through. Too much, but the half hours are lovely. I like the Weakest Link, that’s for parts of an hour and I can follow that like.”*

- *Visitors to the home*

A number of participants mentioned that they have visitors come to their home, the frequency of which varied from one participant to another; some participants had family visit several times per week whilst for others it wasn't a very frequent or regular occurrence at all. For example:

Jackie (88), who lives alone, meets with a group of friends from her church every Tuesday evening at her house; it's a bible group, in which they discuss passages from the bible and their different troubles.

- *Other activities*

A number of other daily or regular activities within the home were mentioned; for example, many participants said that they often passed the time by talking to a friend or family member on the phone, though in some cases this was difficult due to their sight or hearing loss (e.g. difficulties dialling out without help, with using an ordinary telephone without an amplifier, or cost implications) and many mentioned that the friends they used to keep in touch with had passed away. Contact with people via the telephone is discussed in more detail in the earlier section 'Communication and social interaction'.

Listening to music was also enjoyed by some (n=5), though two participants (Molly and Jack), one of whom had stopped listening to music, complained that the sound of the music was affected by the use of a hearing aid, and was thus not so enjoyable as it was previously; for example:

Molly (88) said that her son keeps going on about getting her a radio, but she says she couldn't see to turn it on. She went on to say that music doesn't sound right now with her hearing impairment. She used to love music, and used to sing whilst they were dancing. But she doesn't bother anymore as she would have to have it on so loud to hear it. She described it as a bit frustrating at times.

As described in the section on 'communication', four participants regularly used a computer; this was predominantly, though not exclusively, for activities such as keeping a diary (e.g. Jack, 83), downloading and listening to/reading books (e.g. Jack, 83), email (e.g. Fiona, 59 and Julie, 70), and the internet (e.g. Fiona, 59 to search for information; Julie, 70 for shopping; and Lawrence, 60 for online banking and searching for information). Another participant was trying to write his biography with some difficulty because he was unable to use a computer:

Keith (87) has been making notes for his biography by hand; he would rather word-process them but is unable to use a laptop as he can't manipulate the keys. He said one of the deafblind workers he is in contact with said she would help him type up his notes, but that was some time ago and he has never heard back from her about it. He feels it is because she has too much other work to do.

Keith also enjoyed exercising on an exercise bike in his home and painting; his flat was adorned with his artwork. He still manages to do some painting despite the severity of his sight loss and problems with his dexterity, by using acrylic paint in bright colours.

Three participants (all male) mentioned that they enjoyed doing some gardening, though all experienced some difficulty due to either their sight loss (e.g. Jack, 83 and Norris, 89) or arthritis (e.g. Jeremy, 80). Another three participants, all female, said they passed the time of day by doing housework, though this wasn't really seen as an enjoyable leisure activity; rather, it was one that participants carried out in order to maintain their independence and to keep themselves busy so they didn't have time to think about (and get upset about) their situation.

One participant described how she enjoys knitting whilst listening to a story (one of her talking books), though this is a little more difficult due to deterioration of her sight:

Pamela (86) said she likes to be doing things, to keep busy. Up until recently when her sight got worse she had been knitting teddies for orphans in Romania – she had knitted 375 – but she can't tell the colours now, so has resigned herself to knitting dish-clothes. She said it gives her something to pick up and do when she is listening to a story.

Other activities mentioned were doing crosswords and puzzles, which Eva (88) still managed to do using a magnifier, and playing card games using cards designed for people with sight loss; Molly (88) said playing the game 'Patience' kept her from "going mad".

- *Leisure activities that participants were unable to do*

A number of participants talked about favourite leisure activities within the home that they could no longer do, mostly because of their visual impairment. This included reading books in print, which some preferred to listening to talking books, doing crosswords, baking, painting, and doing cross-stitch, tapestry and sewing.

Leisure activities - outside the home

Participants described a number of different activities that they took part in, including:

- Day trips
- Walking
- Shopping for pleasure
- Eating out
- Going to place of worship / religious activities
- Day centres and group meetings
- Holidays
- Voluntary work
- Leisure activities outside the home that participants were unable to do.

- *Day trips*

Most of the participants described going on day trips, though it varied from one participant to another as to how regular they were. The participants who lived with a spouse were more likely to enjoy regular day trips than those who lived alone; for example:

Jack (83) and his wife described how they sometimes do a day trip to the nearby lake area where it's pleasant to walk and chat with other walkers, or they go to [city] centre. Jack said he particularly enjoys the markets, as he likes to browse and haggle! They try to do something like that a couple of times per week.

Fiona (59) and her husband try to go for a drive somewhere as often as they can, particularly in the summer months when the weather is better.

- *Walking*

Some participants went out for a walk regularly, often unaccompanied; for example:

Rajat (58): When asked about leisure activities outside the home, Rajat replied that he doesn't do anything other than go for a walk each day. He can go out unaccompanied to places that he knew before he lost his sight, but struggles in new places. He said he feels confident using the buses as he can tell by the sights as they go by where he is and if he's near his stop. When the weather is good he goes to the local park and he sits there for a bit, to pass time.

Jack (83) regularly goes for a walk down to his local shops unaccompanied, as he likes to retain some independence.

- *Shopping for pleasure*

Some participants said that they went shopping for pleasure (rather than for essentials), as a way of passing the day. Most went only if they were accompanied by someone:

Jack (83) and his wife regularly go to Marks and Spencer's together; he says that he feels he sometimes holds her back, so he sits down and lets her look around and shop.

Fiona (59): *"I have a communicator-guide who comes to collect me. She comes once a week for three hours, and its retail therapy and it's wonderful. I don't buy..., when we go out for retail therapy, it's not for food, it's for if we need something for our home. That's my responsibility. [Husband's responsibility] is the food and the stuff for the home is me. And it's also, I love [husband] dearly and I wouldn't send him back and I wouldn't swap him for anything, but its lovely being in the company of another woman as she can talk more. It does [husband] good when I go out for these 3 hours as it's a break from me as I am a big responsibility. Even not looking at it from the point of view that it's good for me to spend time with another woman, I am a big responsibility."*

- *Eating out*

Some of the participants enjoyed going out for meals, but once again the regularity varied between the participants. For example:

Jeremy (80) enjoys going out for a meal with his family, and tends to have things like fish and chips that he can eat easily; his wife commented that he does really well and never drops any of his food. His family are very supportive and encourage him to go to the bar and order drinks as he did before his sight loss.

Some were too embarrassed to eat out as they felt self-conscious eating in front of other people; for example:

Pamela (86) described having a birthday recently; her two daughters visited her in the residential home and had lunch with her there. She doesn't like to go out to eat as she can't eat properly because of the problems she has with her hands.

- *Going to place of worship / religious activities*

Many of the participants were religious and enjoyed attending church; some explained that they could not go unless they were given a lift to and from the

church:

Emily (87) only goes to church if someone collects her; she doesn't go on Sundays as a rule, but attends on a Wednesday morning once a month. She described a recent attendance on a Sunday for the Harvest Festival: *"it was an absolute change – I sat there and went through the service, was a buffet type thing – [a friend] said 'I'll leave you here [Emily] and I'll go and fetch you something or other, and she hadn't been gone two minutes when somebody patted me on the back and I turned round and he said 'it is nice to see you [Emily]!' – I recognised his voice, and his wife was there and she came over, and when they went somebody else came and Jean was stood at the back watching, and she said I wasn't left 5 minutes on my own – was people that I hadn't seen because of not going on a Sunday. And even the vicar came over and patted me on the back and said 'what are you doing here?!'. Everyone was so friendly so I thought, 'they don't forget you'. It was really nice."* She said she stayed an hour and a half longer than she'd anticipated as she enjoyed herself so much.

Jackie (88) described a number of activities related to her church that she took part in regularly; one group was suggested by the Reverend to get older people together for *"activities, recreation, inspiration, services and education"*. They meet twice a month at the church for a coffee, and sometimes have a speaker. She also goes to a group at the local Methodist church that she has attended since approx. 1980; she described it as a nice, friendly little group that does various activities like discussing how hymns are inspired by passages in the bible. Both of the groups meeting places are within walking distance of Jackie's home.

Lionel (78) *"I go to church most Sundays, but it's not to a Church of England. It's a sort of free church, there's only about 20 of us all together. I'm picked up and taken to church every Sunday, I've just had to give up going up for bible studies things like that."* [Researcher: Why have you given that up?] *"I've got kidney problems. Heart failure they call it nowadays and I can't see to read books and I can't read them in Braille now because of the sticking pins in [...] my fingers because of Diabetes."*

- *Holidays*

Some of the participants talked about holidays that they had recently been on, or holidays in the past; some of the participants were well travelled, and enjoyed reminiscing in the interviews about the many places they had visited and people they had met. Others talked about the difficulties they encountered whilst on holiday due to their sight and hearing loss. Here are some of their experiences:

Jack (83) and his wife stayed in a hotel for 3 days over Christmas; whilst they enjoyed seeing their daughter, Jack felt the hotel and travel was expensive and too much trouble at their age. He found getting around the hotel okay as he said he never lets his visual impairment become a hindrance. He said he is *“not one for going away now”* as it upsets him that his wife has to do all of the packing and unpacking and laundry upon their return (due to his sight loss). They may go to Switzerland again, as it’s the only place Jack would like to return to now; they had lovely experiences there in the past.

Fiona (59) went away for a weekend with her husband for a military police reunion. She described it as a bit of a disaster as the hotel wasn’t run very well and the facilities for disabled people weren’t very good, even though they were allocated a room that was meant to be for disabled people. She said it was an exhausting trip which she wouldn’t want to repeat.

Rajat (59) said he doesn’t ever take any holidays because of his disabilities and the prohibitive cost of them.

Some of the participants wanted to go on holiday but had difficulties organising travel insurance due to their disabilities, especially if they weren’t very common:

Jack (83) described how one or two firms for travel insurance won’t accept you if you have the form of blindness that he suffers from; he said he doesn’t know why.

Fiona (59) and her husband go abroad once a year. They always tell the airline about her conditions and have to choose hotels that *“can cope with my problems”* – so a lot more planning is involved. She said trying to get holiday insurance when you have three disorders nobody has heard of is almost impossible. Luckily they got insurance this year via the Police, as her husband is currently working for them; this was the first time in 20 years of trying that she was given holiday insurance for existing conditions for a long-haul flight.

Some participants described experiences where plane travel had been difficult or unpleasant:

Jack (83) and his wife enjoyed their holidays in Italy but talked about the hassle involved when going abroad, particularly the plane travel; they upgrade their flights to make things as easy as possible, but *“then they treat you like a little child! [laughs]”*.

Jeremy (80) and his wife went on holiday and flew from their local airport; they were supposed to have additional support due to Jeremy’s visual impairment, but this was not available on the day and the trip was very stressful.

Lionel (78) said he would like to go to Belgium for a holiday to see family; he will have to go by ferry as he is not allowed to fly due to his health problems

At least three participants had been on holidays organised by voluntary organisations for visually impaired people or people with sensory loss; they all thoroughly enjoyed the experience, and felt they were well supported:

Emily (87) recalled a holiday that she went on that was organised by a voluntary organisation for deafblind people; the deafblind worker explained that she was the oldest lady there, and yet the last to go to bed! Emily said she hadn't gone on holiday for years and had really enjoyed the company. The deafblind worker remarked that she was amazed how Emily managed all the stairs and walking; Emily attributed this to her upbringing, and the ethic that you can do anything you want to if you try.

Pamela (86) used to go to the [name of] 'blind' home with her husband; he wasn't very keen but accompanied her so that she could go, and then when he died, you could still go if you could find someone to go with you. If you were unable to find anyone, you had to go on what they called a 'no-guide' week. So Pamela went with a lady who hadn't been before; she had a nice week, and went for two or three years after, but then it shut down. The only place Pamela said she would like to go to now is down South to visit her friend, but she said this is unlikely now as she wouldn't be able to travel by train anymore due to her sight loss and mobility problems caused by her other health problems.

Lionel (78) and his wife recently went on a group holiday to Blackpool arranged by a voluntary organisation for people with sensory loss; the group consisted of four other holiday makers and a number of volunteers, which gave his wife some respite from the responsibility of caring for Lionel. It was a lovely holiday and they hope to go again in the future.

Two other participants have been invited to go on an organised holiday for people with sight loss by a national voluntary organisation for ex-Service men and women with sight loss, but one is unsure whether she will be able to go as her health problem makes travelling difficult:

Delia (86) said that the national voluntary organisation St Dunstons have asked her if she would like to go to Brighton for a holiday, but she is not sure whether or not she will go as she is worried about the journey; the last time she went away she was poorly due to her bowel problems.

Keith (87) is hoping to go on an activity week that offers activities such as swimming, dancing and horse riding, which he is very keen to do.

Not all participants said that they wanted to go out and take part in activities however; some were reluctant to try activities that older people commonly took part in or seemed content with their lives as they were; for example:

Molly (88) said she doesn't like Bingo, as it 'drives her mad': *"surely there's more to life than just crossing numbers off! Boring in't it, you want a bit of a challenge, that's why I used to like doing me crosswords, getting the brain active, y'know"*.

Eva (88) who lives alone: *"When I was younger and [husband] had died there used to be a place down there, warden controlled, and I knew one or two in there, [so] now and again if there was a day's outing going they'd ask me if I wanted to go, and I did then, I enjoyed it, but I've done it all, I'm happy doing my own little thing. They're [her family] always asking me to go abroad with them, I mean our [name of daughter] [has] got her own place in Calpe - they don't ask me now, because they've asked me that many times to go and I've said 'No, I ain't bothered'... I ain't bothered I don't want to go, I'm an awkward little wotsit aren't I?!"*

Delia (86): *"I don't go out ever without my husband, and, um, we've got no real social activities."* [Researcher: Is that because of your disabilities?] *"Well, it is really. I used to go to church, he [husband] goes to church morning and evening on Sundays and they fetch him and bring him back, and I used to go with him but I can't go now. So really I'm quite happy because I'm not the type of person, at my age any rate, that craves to do anything. When I was younger I was dancing, swimming, skating, the lot y'know. In later years since I've not been a hundred per cent I've been quite content really to sit in."*

However, after Delia lost her husband (between the first and follow-up interview), taking part in activities beyond the home with friends became more important, as she described in the follow-up interview:

Delia (86) explained that they used to get fewer visitors when her husband was alive as she didn't really need the company as much. Now that she does not have her husband for company every day, Delia has friends from church that are very kind and either visit her or take her out on various days of the week when her son is working.

Another participant wasn't keen to go on holidays or short breaks away from home as he didn't see the point as he felt that he wouldn't be able to see anything or take part in activities that sighted people do:

Norris (89): When asked if he and his wife missed going on holidays: [Wife: *"Well, yes, I think we do, yes. I miss that, because it makes a change and you're always pleased to get home, that sort of thing."*] Norris: *"The problem with going away is you've got to get away somehow or other, transport problem, and when you get there, what do you do?"* [Researcher *"You feel restricted in the activities you can do?"*] *"I mean, for instance, we had a visit from one of [wife's] cousins the other day with her daughter and they were all going up to stay at Blakeley on the Norfolk coast and we'd been there, but if we went up to Blakeley, if we got there what would we do, what would I do?"* [Wife to Norris: *"I could walk a bit, but the thing is you couldn't really could you?"*] Norris: *"No."*

- *Day centres / group meetings*

Only one of the participants regularly attended a group for people with dual sensory loss or sight loss; in fact, he was a member of two different groups that met locally:

Norris (89): *“I’ve got a number of interests which keep me occupied, I belong, I’m a member of the [city] blind society and they have what is called a men’s club and I’m the vice-chairman of the men’s club; we meet every Wednesday morning, usually with a speaker, if we don’t have a speaker then we discuss current topics and so on, you know”*. Norris also belongs to a club that meets on the first Thursday of every month in the afternoon: *“they have various activities but mainly speakers to entertain us. The club is aimed at people who are both deaf and blind. Mainly the members are elderly women. There are four or five men but there are about 20 women I think.”* [Researcher: *Tell me a little bit about that club then, what sort of speakers do they have?*] *“A variety of speakers about people who, not very good speakers actually.”* [Researcher: *‘Not very good’ as in not very good at speaking?*] *“The subjects are not all that thrilling. Occasionally we get a very good speaker but mostly they are not.”*

Some of the other participants had gone to a day centre or group meeting for people with sight loss or sensory loss in order to ‘try it out’. Many of the participants gave their thoughts on attending day centres, including those aimed at elderly people generally as well as day centres aimed at people with sensory loss; many said it wasn’t really the sort of thing they enjoyed:

Belinda (82) described how the local voluntary organisation for the blind told her about a nearby day centre for people who were retired, which enabled people to meet up with others, play bingo and have a meal; she attended once but didn’t like it *“because it isn’t my scene really, I only went the once”*. She said that she didn’t like the fact there were a lot of “disturbed” people there, and *“if you stepped outside people ran after you thinking you were ‘mental’”*. When asked if she would like to go to a different type of group, she said no, it wasn’t her scene and she couldn’t think of anything else she’d like to go to.

Jack (83) described some coffee mornings that were organised by a local voluntary organisation for deafblind people, which he and his wife went to one time; unfortunately they found that everyone sat in ‘cliques’, and they were told *“you can’t sit there, that’s so-in-so’s seat”!* He said that neither he nor his wife feel they are ones for clubs or groups anyway.

Mary (84), when asked if she ever thought about going to day centre, replied that it would bring back bad memories of when her late husband was in a day centre type of setting: *“no, and I’ll tell you why, and people understand, I used to go see [husband at one] on the [name of road], and there they are, they all sit, and in another room, they all sit, no, it would bring back.. I don’t want that”.*

Lawrence (60) described how he did not want to go to a group of any kind as he did not like doing ‘crafty type things’; he had encouraged his wife, who is also visually impaired, to go to one as he feels it is important for women to have the company of other women, and they otherwise spent so much time together.

Rajat (58) who speaks using a voice synthesiser said he would not attend any local groups for people with sight and/or hearing loss because he can’t talk very well, and couldn’t mix with people.

Keith (87) described a meeting that was organised by a voluntary organisation for ex-Service men and women that he recently attended; he was pleased that they provided transport to and from the meetings as *“otherwise I’d have to pay a taxi or somebody to take me”*. He didn’t comment on whether he would attend meetings again in the future.

Keith also mentioned that he regularly attends a local group for elderly people in his community; once again, he was provided with transport to and from the meetings but said that the conversation was at times limited:

Keith (87): *“That’s on the Tuesday, you get a meal, you pay £6, what was it last time I went? Shepherd’s Pie or Cottage Pie, a sweet, I also bought a big jar of some lady’s marmalade. I guarantee this, she said, as being made from Seville oranges. Cakes as well. Homemade cakes. There again you see it’s nearly all elderly ladies... Difficult to get them talking, they’re sitting there and looking at me, so I say ‘Has anybody got a funny story to say?’ or something like that. Something to get them going, still looking at me. They’ve been conditioned the poor darlings. One means of communicating, when they get there they can’t communicate, talking in words of one syllable, like ‘Nice day?’, ‘Nice’. Somebody came up with a funny story that got them going a bit. ‘I’ve got a conundrum for you, this is a play on words, if the ark was made of wood what was Joan made of?’ Maid of Orleans! It’s a play on words you see, made as in ‘m-a-d-e’ and maid ‘m-a-i-d’ of Orleans. That got them going a bit.”* [Researcher: Did they get it?] *“They did get it once I’d explained it to them. That was the sole topic of conversation for a long while.”*

Norris (89), along with his wife, also attended monthly meetings of a book club, which attracted many speakers, some of whom were well known authors who came to talk about their work. The group provides transport to both Norris and his wife to get to the meetings which was very much appreciated, as his wife no longer likes to drive.

- *Voluntary work*

One of the participants described voluntary work that she is involved in which takes up a lot of her free time since she retired, with a local restoration committee and the management committee of a nursery that she used to work in:

Julie (70), who still has some useful sight and hearing, said her hearing and sight loss hasn't overly affected her life compared to how it was beforehand. She likes getting involved in things and spends her days as a volunteer for the local restoration society and gets involved in a lot of work with them including organising tour guides and fund raising. She can't use their computers as the fonts are too small, so uses her own computer at home that her son adapted for her sight loss. She is also on the management committee of a children's nursery on a nearby estate that she used to run before she retired.

- *Leisure activities outside the home that participants were unable to do*

As with activities in the home, many of the participants talked about leisure activities outside of the home that they used to enjoy but no longer took part in; the following are some examples:

Fiona (59) explained that she no longer went to the cinema as after about 30mins, the screen just blurs into a total mess and she doesn't know what she is doing or what she is seeing, and she can't always hear. She does go to shows (musicals) as they have an interval – but she has to check if they have strobe lights as with the particular disorder she has the strobe light bypasses the optic nerve and hits the "vomit nerve" and that's exactly what she does – she had no idea about this until she went to see the Lord of the Dance and started vomiting due to the strobe lights! So she has to ring ahead now and check.

Julie (70) undertook courses at University on archaeology as she has always had an interest in history; however, she hasn't been on any digs because of her eyesight and arthritis, as when you're on a dig they expect you to do anything and everything.

Some participants felt that activities like shopping were pointless when you can't see very well:

Jackie (88) described the difficulties she encountered when shopping as she couldn't see the aisles or items on the shelves. The researcher asked her if she preferred to stay at home than go out; she replied "*well, it is a bit like that... [I] used to love to go to town and Marks and Spencer's but it's a bit too much now to go round the shops and things, and if you can't see what's the point?*" She feels she has to force herself to go shopping now.

Other activities beyond the home that participants described no longer

participating in due mainly to their visual impairment, included: dancing (e.g. Molly, 88 and Mary, 84); singing (Mary, 84); going to shows due to difficulties negotiating the steps to the theatre (Belinda, 82); playing the piano (Mary, 82 and Betty, 86); and fishing, volley-ball and soft-ball (Rajat, 59).

Daily living and sources of support

Sources and levels of support

In terms of their support network, the participants' circumstances varied widely, from receiving support from family members only, to support from both family members and statutory agencies, voluntary organisations and/or privately paid help; a detailed description of each participant's support network is included in the individual case by case descriptions presented earlier in the report, but in summary:

- The main source of support was a member of their family, usually a spouse, for the 12 participants who lived with someone;
- For those who lived alone, the main source of support was often a mix of family members living nearby (2 participants), friends (one participant), help from voluntary organisations (1 participant), statutory agencies (2 participants) or support from privately run care agencies (2 participants)
- The remaining participant who lived in residential accommodation received most of her support from the care staff at the home, though she also received occasional visits once or twice a year from the social services deafblind worker.

As well as variance in terms of who offered support, the *level* of support varied from occasional support provided once or twice a month through to a high level of support provided every day.

Dependence and independence

In most cases, maintaining some level of independence was only possible through the support that the participants received from family, friends, and support services. The majority of the participants spoke about issues relating to independence, whether about the loss of their independence or how important maintaining their independence was to them. For example:

Emily (87), throughout the interview, repeatedly stated how much she wanted to stay living independently in her own home; this became more difficult when her only son, who had been her main source of support, died a few years ago. She described how important the local branch of a national voluntary organisation (VO) for people with sensory loss had become in helping her retain her independence and stay in her own home: *“Gives you that independence, I can still feel that I’m coping on my own... I just hope that I can carry on as I am doing, I would dread having to give up my home and go into a home and see..., I don’t even think about it, I daren’t. While I’m here and I’m coping and it’s me’ own, and I can lock my front door, I’m alright, I’ll cope, with the help of [name of VO].”*

One participant described how, at the time she had a stroke which caused her sight loss, losing her independence was her main concern:

Belinda (82): When asked how she felt when she was having the stroke, she said she was frightened and worried about losing her independence – that was foremost in her mind at the time. She said she doesn’t receive any help (in terms of daily living) at the moment – she would ask for help if she could no longer do things, but whilst she still can, she’d rather do it herself. She feels she is managing ok at the moment.

When asked what the most important thing in his life was now, one participant replied:

Colin (92): *“Now? [pause] well, the most important thing in my life now is that I can’t do anything really. You can’t do owt at all.”*

However, even though he now required help to do most things, Colin, like the other participants, was still eager to retain a little independence as he explained earlier in the interview:

Colin (92) explained that he still gets ready for bed on his own even though he finds it physically difficult. He uses his Zimmer frame to get to the bed and sit on the side, takes his hearing aids out, and then undresses himself from a sitting position. Although it’s difficult, he wants to keep getting himself ready for bed for as long as he can in order to retain that little bit of independence. He is unable to get himself out of bed in the morning, wash and dress himself, or prepare any of his meals, and has staff from a care agency visit every day to help him.

Another participant described how hard it is to lose the independence she once had and to instead have to rely on her family:

Delia (86) described how she would like to be able to walk down to [nearby road] and back to feel she’s done something each day, as she has always been a bit independent, but her husband and son were reluctant to let her: *“I find it hard to have to depend upon them”.*

As described earlier, Emily repeatedly talked about her desire to remain independent throughout the interview; like other participants (e.g. Pamela) she attributed it to her upbringing where she was brought up to expect to do things for yourself rather than ask for help:

Emily (87): *“I’ve had a lot of hard things to cope with in one sense, but I suppose that’s why, as [daughter-in-law] says, ‘you’re strong and you cope on your own’ – she always knows that if I ring it must be desperate because I don’t in ordinary ways ring her for anything, but there again I guess that’s how I was brought up, stand on your own two feet, if you got some time off from school ‘right, you can help with that’... so it’s automatic I’m alright doing housework and cleaning!”* She always says to herself *“do it right the first time Emily and you wont have to do it again”*, like her mum used to tell her! *“It’s something that is there – you don’t ask, you get on and do it yourself.”*

Pamela concisely summed up what she felt people with hearing and sight loss need from others:

Pamela (86): *“You don’t make them soft but have a bit of feeling for them, have some sympathy but encourage them to do for themselves, that there are other ways – sometimes you think ‘they could have done that for me’ but then you think ‘you can do it yourself, why ask somebody else?’ Can do it yourself.”* As an example, she described how sometimes she might lose something and can’t find it; she might decide to wait till a member of staff comes in and spots it for her, but then after a while she decides to look again herself and finds it - she then feels like she has achieved something.

Family relationships and support

Clearly the support received from family members was very important to the majority of the participants. For example:

Betty (86): *“He’s [her husband] terribly good at helping me with any problems. He said yesterday ‘what will happen to you if I get knocked off my perch?’ And I tell him ‘I have 3 wonderful children, they’ll see me right!’... He does help me a lot.”*

Regardless of the level of support that they received, many of the participants expressed concern about being or becoming a burden upon their families; for example Eva (88) who no longer plans to visit her daughter at Christmas as she does not want to feel a burden. Other examples:

Keith (87) lives alone and sometimes struggles with aspects of daily living; one of his sons is bad tempered if he calls him too often for help or whilst he is working, and he is reluctant to call his daughter if she is at work as he feels a burden.

Colin (92): *“I keep telling daughters its time that I popped my clogs but they do get cross, they tell me ‘don’t be so daft Dad’. Ah, lovely lasses they are. Their mother was the best, as I say, I’m a funny sort of a fella, I brought ‘em up proper and I don’t want them, I don’t want to be [dependent on] them and have them mucking about, I had that with my mother and father, and I didn’t want anybody to have to do it to me. [pause] Difficult Sue, life is so very, very difficult. If you examine it properly...”*

One participant was concerned about being a burden to her daughter-in-law as she herself has a daughter to care for who is in a wheelchair and has heart problems; she felt that it is easier to ask your own son or daughter for help, but not so easy when it is a daughter or son-in-law. That’s why she appreciates the help and support that she receives from a voluntary organisation for people with sensory loss, who provided her with a communicator guide to take her shopping every week and a friendly voice at the end of the telephone line whenever she needed to talk to someone:

Emily (87) *“that’s what I’ve been trying to say about them – that they’re so friendly and definitely a company to help but you don’t feel you’re being a bother to them because none of them make you feel like that.”*

Not all participants felt they were a burden to their family; one participant explained the very positive relationship he had with his family, who both supported and encouraged him to be independent:

Jeremy (80) feels very lucky as all of his family are supportive and encourage him to remain as independent as he can be; for example, when he goes out for a meal with them, his daughter encourages him to go to the bar to order the drinks, just like he used to do before his sight loss. He lives with his wife, and his children and grandchildren all live locally.

Contact with specialist support services

Most of the participants were in contact with at least one service that catered for people with sight loss or dual sensory loss; only one participant was not in contact with any statutory or voluntary support services:

Betty (86) said she doesn’t have any “specialists” that come to her home, and has had no contact with social services. She is not registered as visually impaired. In terms of support, she felt that she gets enough from her husband and the lady who they employ privately to do some housework for them around the house. She has been working for them for 11 years, and is as much a friend as an employee now.

Some participants were unsure as to whether they had ever been visited by anyone from social services following their registration as blind or partially sighted, or if they had, whether that had received services or support as a result. One of the participants was a little confused about the services that

she had been in contact with, and at first said she had not had contact with a specialist worker for deafblind people nor a rehabilitation worker/specialist worker for people with sight loss; this may be due to confusion about the role of the professionals she had been in contact with and the purpose of their visit:

Belinda (82) said that she doesn't receive any help at the moment and that she doesn't need any. She was registered about a year before the first interview took place, so the researcher asked her if she'd ever seen a specialist worker for visual impairment, like a rehab worker: she said 'no'. She said she hadn't ever seen a specialist deafblind worker either. When asked more directly if she'd ever seen anyone from social services, she said someone came to her home and started to assess her but nothing ever came from it. She wasn't sure why they had visited her but supposed that they were assessing her eligibility for attendance allowance. When asked how she had come into contact with the deafblind worker of the local voluntary organisation (VO) for people with sight loss (who had referred her to the project), she said she came to see her after she was registered. When asked what support the VO gave her – she said she didn't really know, though they had told her about a talking watch she could use during the night for checking the time and about the day centre which she tried out but didn't like.

Other participants also reported that since being registered partially sighted, she had not received any support from social services:

Delia (86): When she was registered she had a telephone call from 'the Blind', which she assumes was statutory services as it was arranged via the hospital, to see if they could come and visit her – an appointment was made twice but nobody has ever turned up. She hasn't heard from 'the Blind' since, and yet [she was] at home when they were supposed to come. They have a clear door bell, so she would have heard them if they had come to the door.

Jackie (88) when asked if she had ever been visited by anyone from social services, like a rehab officer or social worker, said she thinks she had a nurse visit about her 'water works' and that she may have had someone come from social services, but she said nothing ever came of it.

The degree of contact with and support received from support services varied immensely between participants from occasional contact once or twice a year (e.g. Belinda, 82, mentioned earlier) to very regular support. One participant said that he had been waiting for someone from social services to contact him for over 7 months:

Kulvir (80) explained that he was visited by someone from social services over 7 months ago and promised a telephone with big buttons, as he struggles to use the phone he has at the moment to dial out; he does not know why they are taking so long to come back to him, and says he doesn't have a telephone number to contact them on.

Three participants (Emily, 87, Fiona, 59 and Colin, 92) received regular support from a communicator guide that worked for a deafblind service; all of them praised highly the service they provided:

Colin (92) sees his communicator-guide every Tuesday morning at 11 am. When asked what she does when she visits, he replied: *“Just talks, just talks and asks me what I want, anything I want doing, she’s ever so..., she’s marvellous, will do it for me”*.

Emily (87), who lives alone, has a communicator-guide visit her once a fortnight. When asked how long she comes for, she said they don’t count the time! Comes at 10am, unless something comes up in which case she comes at 11am. They often stop and have a cup of tea or snack before going shopping. She explained that she is so thoughtful that if she sees something that Emily needs when she is out doing her own shopping, she will get it for her. Emily said she doesn’t think of [name of Comm-Guide] as a stranger, she comes into the kitchen and knows where everything is, and treats the place like her own home – she said it’s like having your own daughter or sister.

Another participant (Mary, 84) received help with household chores and shopping from a volunteer worker from a local VO for elderly people, and once again praised the service she provided, describing her as a friend and companion.

One participant, who was unhappy with the quality of support that he received from a care agency, expressed a desire for a paid carer that he could employ himself, with the aid of government funding:

Keith (87): *“If I had a carer, it could either be my daughter, well it could be anybody really, and they are paid by the government aren’t they carers? It’s just been increased a lot. It doesn’t have to be a relative it can be anybody, the carer, but that’s what I’m really looking for, a carer. A carer, a carer as in helper, these are helpers like, the carer is paid quite a good wage obviously. [Researcher: Would they live with you or not?] “They wouldn’t live in, they would be probably on duty about 10 hours a day, probably help me to get, when I wake and I got dressed and had a shower, it takes me three hours.”*

Some participants mentioned they had attended courses after they were registered or diagnosed with sight loss, that were organised by different support services for people with sight loss; these are described in more detail in the section on ‘Accessing information’ earlier in the report.

Support provided by care agencies

Two participants said that they had daily support from staff members of a care agency that come into their home to prepare their meals and help them with other tasks:

Colin (92) said his support was arranged by social services after he came out of hospital following his stroke, with the aim of helping him remain in his own home rather than have to go into residential care. His two daughters had to agree to provide as much support as they could, so they do all of the cleaning and shop for and prepare his meals ready for the carers to give to him the following day. He was reasonably happy with the service though he wished that the carers could spend more time with him when they came to do his meals or get him out of bed, rather than rushing about before leaving; he pointed out that they are supposed to be carers and caring involves more than popping in and feeding him. But he assumes they aren't allowed to stay any longer. He said they also empty the commode and turn over his tape (talking book) for him if required, before they leave.

The other participant was not very happy with the service he received at all, since the care workers were supposed to spend half an hour preparing his meals and cleaning the flat twice per day:

Keith (87) said the agency care worker *“comes in, supposed to do half an hour but does about 15 minutes. She’s falsifying the account, she puts it down in there but I keep a record of the time. She does it, but she does it quickly, I’d rather she done the full time – half an hour.”*

He also said that one of the previous care workers he had was fired from the agency as he believed she had been stealing things from him, including some of his paintings; he said he has never been able to recover any of them.

Another participant had care staff put in place to support him and his wife temporarily when he was released from a five week hospital stay; they described how it simply did not help their situation and was rather uncoordinated:

Lionel's (78) wife explained: "he could do nothing for himself and he was really very disorientated and they said 'Oh we're sending carers', never mind about what I needed or what I wanted, I mean it became very clear from just after he came home, [that] I realised that instead of having carers during the day I wanted one overnight just to really sit with him and be there so I could get some sleep because I need my sleep because I've got epilepsy" Lionel: "I was wandering about in the night." [Researcher: So... did you have a carer come in or not?] Lionel: "About 20 a week, all different [people]." Lionel's wife: "4 times a day, and you see, we tried to get continuity but when you consider that they have days off and some of them don't work Sundays, so the weekends you've got different people coming in, so we had about 17 different people traipsing in. It made me feel redundant and it confused him totally, [so we stopped it]. [Researcher: What was their role?] Lionel's wife: "Well, they were coming in to get him up, one didn't turn up until half past nine one morning, any way they were supposed to come at half past eight, so they did, and then again at lunch time, one o'clock... but one came in and said 'Where's his medication?', well seeing as I've been told they were in blister packs and I was told 'Leave it to the carers to do', so... I said 'I don't know, where they put it', and she wasn't very happy. This is the thing, there were too many people coming in and really I didn't need it during the day because I could cope with him during the day, but they won't put anybody in overnight."

Other services

Many of the participants employed people privately to help with various aspects of daily living, for example gardeners to help with gardening (e.g. Jackie, 88, Norris, 89, Delia, 86, Emily, 87, Eva, 88, and Mary, 84). A few participants mentioned that they employed someone to do housework, including Betty (86) who employed a lady to come and do various household chores, Jackie (88), and Molly (88) who said they had "home-help", though it wasn't clear if this was a service that was privately paid for or part paid for by her family and arranged by social services.

A few participants including Keith (87) and Colin (92), who both lived alone, and Lionel (78), who lived with his wife, and Kulvir (80), who lived with his son and daughter-in-law, said that they subscribed to a panic alarm system, which involved wearing a panic button around their neck that they could press in times of emergency to alert that they needed help. The participants were a little sketchy regarding the precise details about who provided the service or quite how it worked, though one of the participants did have an understanding of how he *thought* it worked, and later, experience of using it:

Colin (92) subscribed to a panic alarm system run by an independent company, which social services put him onto. At the time of the first interview, he had never had reason to use it but said that if he pressed the button they would be with you in 5 minutes so they must have places or homes with people on standby, so that they can get in touch with and get to you straight away. He said it gives you that bit of confidence that you know you can get in touch with somebody if something happens. He has to pay for the service which he said is expensive at over £200 per year, but thought it was well organised. However, by the follow-up interview, Colin had fallen and used the panic button (see earlier section 'Falls' for details about the fall); Colin was very disappointed with the service, as he thought they would send emergency services out (or someone from the service) rather than call his daughter at 3 am in the morning. He said the whole matter has distressed him. The service is not what he had expected at all.

Mainstream services

A few participants described their experiences of access to mainstream services, most of which were positive. For example:

Pamela (86) used to travel by train to visit her friends down South. She described one journey where she paid a bit extra and had a seat by the guard and the buffet and was met at the station and looked after every bit of the way on both the outward and return journeys: *"In fact they pestered me to death with drinks, more than I wanted! In finish up I had to go to the toilet and he said 'don't lock the door, I'll stand outside door', and he did. And then when I got there, my friends were there to meet me, but had to show some identity before they'd hand me over!"* She hasn't been since as she said she couldn't afford it now, even though her friend would have her tomorrow if she could go.

Norris (89) *"I still manage to do some shopping, for instance, yesterday I was down at Marks & Spencer's. I go down there in a taxi and I go in and I go to the Customer Services desk and they know me very well there, and they provide me with one of those staff members, usually an attractive girl, and I give this girl my order and she goes and collects it and comes back, they bag it and I pay for it and they take it up to what we call the car services and then I go upstairs and order a taxi and the taxi comes into the car services and puts the bags of stuff I've purchased into the back of his taxi."*

One of the (younger) participants was very aware of her 'rights' as a disabled person, and described in detail the services she had received or could receive if necessary:

Fiona (59) said that under the terms of the DDA [Disability Discrimination Act], utility providers must provide a 'helping hand' service for the customers who are registered deaf, blind or wheelchair bound; if they don't they are breaking the law. When you ring them, they will send you a form to complete in your required format (e.g. braille, large print or tape) and within 7 working days of receiving confirmation from your doctor they will send you a large printed letter telling you you're now registered with the Helping Hands Service. So for example, if you lose your water supply, instead of having to go to a standpipe, they would bring the water to you, and if the phone lines went down, you would be the first to be connected again; she confirmed that the service works as they were reconnected straight away following repairs to a telephone line. They also give you £1 per day towards your mobile phone bill expenses if you need to use that in the meantime, and divert your calls to your mobile for no extra charge.

Demonstrating how proactive Fiona is in terms of her disability and ensuring she has access to information and services as much as sighted/hearing people, she described how she had recently translated menus into braille for three of the local restaurants that they regularly go to:

Fiona (59) asked the staff for a menu in braille to which they all apologised and said they didn't have one. She then offered to translate them into braille for them, and when asked how much she would charge, she said she would do it for a free meal for her and her husband. Apparently the restaurant owners are all thrilled! One is a part of a chain and they are very happy that they are the first restaurant to get their menu put into braille.

Fiona also mentioned that the stationery chain 'Staples' offers a service to people with visual impairment where, for a fee, they produce a signature stamp with your signature, so that you can use the stamp instead of having to sign things; she added that this is 'authorised' within the Data Protection Act.

Another (again younger) participant and his wife, both of whom are visually impaired, were involved in campaigning for the rights of disabled people with the aim of improving the infrastructure for people with sight loss and other disabilities:

Lawrence (60) and his wife participate in three different forums that work to improve access in their local area, town and region. For example, they would try to improve access to buildings that have dangerous steps, or road crossings that have big puddles. He said that they work closely with a building control officer on the forum who ensures that both new and old buildings have the correct depth and widths of steps, widths of doors, heights of doors, appropriate lighting, and good access with ramps, etc.

Examples of the support that participants required and received relating to particular aspects of their support and care are presented below in the relevant independent living skill area.

Independent living skills (ILS)

The participants talked at length about a number of different aspects of daily living that they found difficult due to their sight and hearing loss (but mainly their sight loss), and other disabilities and health problems. This included: personal care tasks such as washing, dressing, toileting and general grooming such as cutting their nails; housework; preparing a meal; dealing with paperwork and other tasks involved in running their home and affairs; DIY and gardening; shopping; mobility around the home and managing and dispensing their medication (both of which are not described here - see earlier section on 'Other health problems or disabilities'). Many of the participants described the support they received to carry out these tasks, as well as ways that they had learned to overcome or work around their difficulties.

- *Personal care*

Many participants found difficulty with aspects of their personal care, and in many cases had to rely on family to help them; for example:

Molly (88) talked about how awful it is when you can't see; she said she can't do things for herself anymore. For example, she can't cut her nails so her son has to do it. She said that when you grow old you start growing hair on your face, so her son shaves her with an electric razor – she can't see the button to press. She used to have people from 'home help' come to help her wash and dress but she didn't like it, as they would come at different, sometimes inconvenient, times and they didn't always do a very good job.

Other participants had found solutions to their difficulties by fitting special equipment or adaptations; in some cases this was carried out by social services, for example: Delia, 86, had a handle fitted across the bath and a seat so she can shower more easily by herself; Norris (89) had handrails fitted to the stairs by social services to aid his mobility around the home. In other cases (e.g. walk-in showers fitted for Mary, 84, and Fiona, 59), the participants paid for the adaptations or special equipment themselves:

Mary (84) was given a seat by social services so she could have a shower more easily in her bath; she described the lady from social services as someone who "comes a couple of times a year to ask 'how are you?', and that's about it". Mary later fell whilst in the bath (see earlier section on 'falls') so had a walk-in shower fitted by a relative.

Fiona (59): At the time of the first interview, she explained that she could not have a bath due to her osteo-arthritis that made it difficult to get in and out; she said she would like a walk-in shower but explained “we haven’t won the lottery”, so made do with a grab rail fitted on the bathroom wall which social services had fitted. However, by the follow-up interview, they’d had a walk-in shower fitted as she felt she was losing her dignity. It was supplied and fitted by a company that deals with bathroom components for people with disabilities. Fiona and her husband have been really pleased with it, both in the installation by the contractors who were very professional, courteous and helpful, and the end product. They paid for it themselves but she said it was worth the money.

Some of the participants said that getting out of bed and the associated tasks of getting washed and dressed for the day took them a long time; for example, Keith (87), who lived alone said it took him 3 hours due to both his sight loss and physical difficulties with mobility; Delia (86) said that showering and dressing takes her around 45 minutes, and Betty (86) said it takes much longer than it used to.

- *Housework*

The majority of participants, particularly the female participants, still did most of the housework themselves, and in some cases said that it helped to pass the time of day (see earlier section on ‘Activities within the home’) and made them feel that they still retained some independence. As described earlier, a few participants paid for people to help with the housework. One participant said they had ‘home help’ come to clean the house, though it’s unclear whether this was arranged by social services or paid for privately by her and her family:

Molly (88), who lives with her husband and son, said they have ‘home help’ to clean their house and do the washing and ironing; she described it as very expensive as they have to pay £24 once a fortnight when they come.

The two male participants who lived alone did not do much housework; in the case of Colin (92), his two daughters cleaned his home, whilst Keith (87) had some cleaning carried out by the care agency staff though he did not feel it was sufficient or very thorough. Most of the male participants who lived with a spouse did not do very much housework, perhaps reflecting a more traditional division of work in the home as well as difficulty in carrying out the tasks. Some said that they tried to help out with any tasks they were still able to do, e.g. vacuuming or polishing:

Jack (83) often does the vacuuming which is a job he likes and still feels able to do, and washes the breakfast dishes. He mentioned that he often gets up at 3am (as he can’t sleep anyway) to turn on the dishwasher or washing machine as it’s more economical to run at night.

Of the five female participants that lived with family, all but one (Molly, 88) still did some, if not all, of the household chores; most admitted to experiencing difficulty with some of the tasks, and said they received help from their family with tasks that they found difficult whilst some had devised their own ways of working to get jobs done. For example:

Eva (88) said she does the little jobs around the house, like polishing and the vacuuming; then, when her daughter visits her every month, she will pull out all the furniture and clean things more thoroughly for Eva with a Dyson vacuum cleaner. She also does the 'big' jobs like taking down the net curtains and washing them, and scrubbing the floors on her hands and knees, which Eva wouldn't risk doing as *"I can't get down there, I might not get up so I don't chance it."*

Fiona (59) has a two-sided linen basket which her husband puts the dirty washing in that separates out the colours so she doesn't inadvertently mix them in the machine. She said doing the clothes washing takes her most of the day. She recalled how recently she realised she had turned the machine on but failed to put the clothes in first, which was very frustrating though she did see the funny side of it afterwards and joked that at least she knows she has a clean machine now!

The participant who lived in residential care was also very keen to continue to do housework even though the staff at the home would do the jobs for her if she asked them to:

Pamela (86), who lives in residential care, has a set daily routine to keep her washroom and bedroom clean even though they have paid carers to clean the rooms. To do the dishes, she places them on a tray and takes them to her washroom, runs the water and puts the pots in. She then sits down on the toilet seat to dry them as she can't stand for long periods of time on her legs. Then she washes the worktop and drawers where she puts the tray. Then she changes her cloth, and cleans the toilet. Later she tidies her room. Each day she dusts everything, except once a week when she moves everything and cleans more thoroughly. She has a carpet sweeper but now she can't see anything she misses bits so the home's domestic cleaners vacuum for her once a week. She said one of them does a good job, but another is in and out very quickly and says it's been done, and Pamela can't argue with her as she can't see whether it has been done properly or not.

Many of the participants mentioned that they used special equipment or had made adaptations to help them carry out household tasks; for example, putting 'bump-ons' on their washing machine so they could select the right programme for washes and using gadgets to keep pairs of socks together:

Fiona (59) said that she and her husband were always on the look out for gadgets that would help her to carry out tasks around the home more easily; she showed the researcher some 'sock locks' that keep pairs of socks together in the wash.

- *Preparing a meal*

A number of participants struggled to prepare meals as they had done before losing their sight; in some cases, their other disabilities also affected their ability to carry out tasks that required dexterity, e.g. Betty, 86, who could not hold heavy pans and Julie (70) who often spilt things due to her sight loss and arthritis. Many of the participants who lived with family were still able to prepare meals with their support; for example Betty (86) and Delia (86):

Delia (86): When asked what her plans were for Christmas, she said they would spend it at home, just the three of them; this is totally different to how it used to be – until three years ago she would have as many as 16 people for dinner on Christmas day. She said she couldn't cope with all the work now. She used to prepare the food weeks beforehand and enjoyed the cooking, but can't do it now. Her husband has to help her with certain tasks, for example chopping and peeling vegetables, and serving up the food as she can't see so ends up putting the food on top of each other; she said he still thanks her for every meal, even though he now has to help prepare them.

Some of the participants who lived with a spouse, had most, if not all, of their meals prepared by their spouse; this was particularly the case for the male participants, which perhaps partly reflects the traditions of this older age group where women would traditionally prepare all the meals anyway, rather than just being due to having sight loss.

Other participants managed to prepare meals on their own, some of whom extolled the virtues of special equipment that they used to help them prepare their meals independently; for example:

Emily (87) explained that she got a talking microwave so she could still do her own meals without any help from others; it was expensive but her late son told her that she had to have the right equipment to help with her sight loss. She eats mostly frozen or chilled meals that can be reheated in the microwave – her communicator guide tells her the choices available when she takes her shopping. She is not sure that she particularly enjoys the ready-meals, as she used to be a good cook and enjoyed cooking, so it's a bit of a let down, but said you have to have something! She said she couldn't bear to get 'meals on wheels'.

Special equipment, such as liquid level indicators to help make hot drinks safely, as well as adaptations like bump-ons on cooker controls were also popular amongst the participants:

Julie (70) said that when the deafblind worker from the local VO for people with sight loss visited she gave her bump-ons for the cooker so she knows what level of heat is turned on.

Keith (87) described a big timer he was given for the kitchen and things to put on the shelves within the oven to stop things sliding off the shelf, though he said the latter didn't work very well; both items were provided by a VO for people with sight loss.

Another participant (Fiona, 59) purchased a tin opener for £20 that, although not designed necessarily for people with sight loss or a disability, had really helped her when preparing meals.

Many of the participants who lived alone ate mainly frozen or chilled ready-meals that were reheated in the microwave rather than preparing meals from raw or fresh ingredients that were more difficult for them to prepare; for example Mary (84), Colin (92) who had his meals heated and served every day by care staff, and Emily (87). Another participant, Delia (86) said she uses frozen vegetables now rather than fresh as she finds it difficult to clean and prepare the vegetables due to her sight loss and the fact her husband is no longer around to help her. However, whilst some participants said they missed eating things that they could no longer prepare, this did not necessarily mean that they didn't enjoy the ready meals that they had instead; for example:

Colin (92) said he ate ready-made meals, from M&S – he said he could recommend them. He used to get Asda and Tesco ones but they weren't half as nice. M&S are a lot dearer but he said money doesn't come into it; he said he enjoys every meal that he has.

Nobody mentioned that they received a meals-on-wheels service from social services.

- *Dealing with mail, paperwork, and running the home*

Few participants talked about how they managed to deal with mail and others tasks involved in running the home and their daily affairs. One participant said that she struggled to read the post and so had to leave it for her son to read once he got home from work:

Delia (86) said she can't see to deal with the post; during the follow-up interview she asked the researcher to see whether anything was addressed to her late husband. Otherwise, she waits for her son to get home from work, to open and read the mail to her.

Eva (88) cannot read any of her mail or sort out her correspondence so has to wait for her daughter to sort things out when she visits once a month.

Others managed to read their post with the use of an LVA; for example:

Fiona (59) uses an LVA to read bills and letters that the social services deafblind service gave her; it's a 'Bionic-Mono-Mouse' that plugs into the TV and scans the text, displaying it on the TV screen. She said she also has one for the computer. Her husband calls it "Mighty Mouse" as it makes a remarkable difference to the size of the font! She also has a cheque template to help her sign cheques, but she said she doesn't use it often.

Belinda (82) said she can read post and things with a magnifying glass, but has to read very slowly.

- *DIY/gardening*

A number of participants talked about home improvements and work that they had either carried out or needed to do on their property. Two participants spoke of the difficulty of finding tradesmen or women to do the work for them for a fair price and to do a good job. One of them felt that this was a service that was lacking for people in his situation, i.e. with sight and hearing loss:

Jack (83): Since moving into their new home, Jack and his wife have planned and carried out a lot of home improvements, e.g. installing new UPVC windows and fitting an ensuite bathroom and new condensing boiler. Jack felt that it's difficult to know who to turn to when you need things done. They described having had bad experiences with tradesmen in the past even though they asked Age Concern for the details of reputable trades-people. He feels there is a need for some sort of service where you can get reliable help. He said he doesn't expect anything for free and doesn't mind paying for a job well done. He also thinks it would be good if there could be a service that visits you in your home to carry out a 'survey' following diagnosis of your sight impairment, that would suggest improvements and adaptations that might help you. He said they haven't yet asked the local voluntary organisation for people with sensory loss about reputable tradesmen, as they are not sure whether they can help with that sort of thing.

Many of the participants had to rely on the help of family with DIY tasks that they were no longer able to do:

Jack (83) feels they are lucky to have a cousin that helps them with some of the smaller DIY tasks – whenever he visits he brings a boot full of tools!

Jeremy (80) said his son in law helps with any jobs around the house that he can no longer manage due to his sight loss. He used to really enjoy painting and decorating, and really misses doing that.

Lawrence (60) has a brother who helps with any maintenance tasks around the home whenever he visits them.

As described previously in the section on 'Leisure activities in the home', three participants still carried out some gardening tasks, though all expressed difficulty in doing so due to their sight loss and/or other disabilities, e.g. arthritis. Many of the other participants who had a garden paid for someone to tend to it for them.

- *Shopping*

Some of the participants still went shopping for food and everyday essentials themselves; for example Julie (70) who was the only participant who mentioned she used the internet to get her shopping and have it delivered, and Belinda (82), Betty (86), and Eva (88), all of whom still went to the local shops by themselves for their shopping:

Eva (88) goes shopping for everyday essentials each day, but relies on her daughter, who visits once a month from up country, to buy anything that's big and bulky or heavy like toilet rolls. She feels she has friends that she could ask for help with shopping if she needed it, but prefers to remain independent.

Other participants had to rely upon friends or family to help them get most, if not all, of their shopping; for some, this arrangement worked, for others it was more problematic:

Jackie (88), who lives alone, gets help from friends with her shopping as she struggles to do it on her own. She is aware that she could get a taxi to the shops and ask the assistant in Marks and Spencer's to help but doesn't like to expect them to do it. She said she is not totally confident in these situations, so if someone (i.e. a friend) can do it for her she's happier. She described her friends as very good, since she doesn't have family nearby or anybody to support her. However, when Jackie was visited a second time, she explained that relying on her friends had become problematic as they were unable to do her shopping on a regular basis and Jackie was concerned it was a burden on them; therefore she had approached the local voluntary organisation for help with shopping each week.

Delia (86), who at the time of the first interview lived with her husband and son, explained that she has a friend from the church help take her to the shops every fortnight. She said her husband is very good and goes to the shops most days, but there are things he forgets, so her friend takes her to Sainsbury's every fortnight. Her friend does it voluntarily but she always tries to make it up to her (didn't say how). She also gets quite a lot from Iceland as they then deliver it to her house.

One participant who relied on the care agency to get his shopping for him was not particularly pleased with the service as they didn't always come on time and left him concerned that he would have to go without essentials; he

experienced difficulty getting his shopping whilst the researcher was at his home interviewing him:

Keith (87) is supposed to draw out money from his bank before the carer visits to go and get his shopping; unfortunately he had a new debit card but did not know the PIN and the bank refused to tell him over the phone. The carer said she wasn't allowed to take a blank cheque from him, so he would have to get one of his children to take him to the bank later that day and sort out his debit card so he can withdraw money for another carer to get his shopping the next day (she announced that she was quitting the job so Keith wouldn't see her again). Keith was obviously distressed about the situation and unsure who to turn to for help, as his children all worked full time and some were not very approachable.

Access to and participation in medical services

Identification as visually impaired and hearing impaired

The participants were asked whether or not they knew if they were registered as visually impaired, deaf, and deafblind; most of the participants were aware as to whether they were registered as visually impaired (with 10 stating they were registered blind, 7 as partially sighted, 2 not registered, and one participant who said she was registered but did not know the category); one of the participants was a little confused about his registration as he had not received the card to say he was registered partially sighted. There was much less awareness about being registered as deaf and deafblind, possibly because it is a less formal process. Registration as a deaf or hard of hearing person was less common, with only two participants saying they were registered, 11 stating they were not, and seven being unsure. Similarly, ten participants said they were not registered as deafblind, 4 said they were (but in two cases this was confirmed only because the deafblind worker was present in the interviews), and the remaining six didn't know.

In terms of having been identified by support services for their sight and hearing loss, the majority of participants were known to a voluntary organisation for people with sight loss, and in some cases, they had been referred to the deafblind worker employed by that service. Eight people were definitely known to a statutory service for people with sight loss as they had been referred to the project by the deafblind worker working for social services; interestingly, only four of these participants were aware they were recorded as deafblind, one of whom only found out when the deafblind worker who was present during the interview told her. Of the four social services departments that were involved in recruiting people to the project, all held a register of people who were deafblind so it is likely that all eight of the participants referred to the project through them were recorded on it, though only 3 participants were aware that they were. Whilst two of the registers were described as live databases that were either updated following each

instance of contact with a person or were linked to the council's Client Index System, the others were described as more informal lists that the deafblind worker compiled themselves.

In terms of services for deaf people, the picture is much less clear; the majority of participants who wore a hearing aid appeared to have contact with audiology services to the extent they had been given hearing aids, though in some cases the hearing aid had been brought from a private company, and only one participant mentioned receiving support from a voluntary organisation for deaf people (i.e. Norris, 89, who was given a telephone with an amplifier by the local VO for people with hearing loss, so he could take part in a conference call with other people with sight loss, organised by the RNIB). Of course, a number of participants had been given support for their hearing loss via the deafblind worker they were in contact with.

In terms of identification as sight and hearing impaired, it is interesting to note participants' relatively low awareness of their registration status as deafblind (in contrast to a clearer understanding of their registration as blind or partially sighted). This may be partly explained by the fact that the statutory requirement for deafblind registers is relatively recent, and also the process of registration may feel less formal or important (and therefore less memorable) to people because it does not involve medical staff.

Reasons for low registration as a deaf or hard of hearing person (or certainly lower awareness of it) are even more speculative. We are confident that many of the sample were *not* registered perhaps reflecting that our sample contained people with relatively less impaired hearing (compared with sight) – for example there were no people with profound hearing loss in the sample. Also fewer people in the population as a whole are registered as deaf or hard of hearing compared with blind or partially sighted.

Of the two participants who said they were not registered as visually impaired, one (Julie, 70) had experienced difficulty with her eyesight for over 20 years, but the rate of deterioration has been very slow and she still has quite a lot of functional vision. She had an upcoming appointment with her eye consultant and said that if registration was suggested, she would accept it, and added that perhaps that would mean that she would get more help. The other participant, who described her level of sight as being very variable, was diagnosed with glaucoma and hearing loss almost 40 years ago:

Betty (86) has had glaucoma for almost 40 years; she is not registered as visually impaired as her private consultant feels he may yet "cure" her sight problem; she does not feel she needs to be registered in order to receive any support services as she feels that she and her husband cope quite well. She also receives private treatment for her hearing impairment which also began when she was in her 40's, and is not registered as deaf or hard of hearing.

Access to medical treatment

Not surprisingly, many of the participants had frequent contact with doctors, eye consultants, audiology services and hospital staff; some of the participants described their experiences. Often they focussed upon medical aspects of their conditions which were inevitably linked with emotions of losing their sight or hearing. They also discussed some of the interactions with staff and confusions and frustrations about their treatments, the hospital systems, and communication.

- *Consultations with eye consultants and treatment*

A few participants talked about the time of diagnosis of their sight loss, and how they hadn't received a very good service either at the time or since diagnosis:

Molly (88) talked at length about the time her sight problem was first diagnosed; a woman (possibly the eye consultant but Molly was unsure) asked her when she had noticed her sight had deteriorated and she replied it was when she was watching TV, as it went all 'wavy'. The consultant told her that if it happened to the other eye she should visit straight away, day or night, as if she came in time they could save it. So when it happened to the other eye she didn't at first think much about it, but went to hospital the next morning as instructed – but they then told her that she couldn't come without a doctor's note, so they rang their doctor and he said "I can't give you a note till you go to optician" – so by time all this had finished, she said she was ready to collapse and couldn't go to the hospital – by the time she went it was too late. She complained about how she had been treated at the hospital, but when they asked for the name of the nurse that had initially sent her away, she didn't want to get anyone into trouble so pretended she didn't know. She said the hospital seemed frightened they were going to sue but they said they wouldn't "so that was that!"

Norris (89): "when I started this eye sight problem I went to an eye doctor privately, but then sometime ago I decided that I needed some other help and I heard about the low vision unit in the hospital so I went to them and it was through them some 3 years or so ago that I was put into the National Health system to treat my eyes, but I don't think that they've done it very well because at the beginning one would have thought they would have assessed your eyesight and then developed a programme for you, but I mean it's been up and down, there have been intervals of some months before they see you again and so on."

When asked whether the eye consultant he recently saw explained the various tests and treatments to him clearly, both Norris and his wife felt they had little continuity in terms of the consultant they saw and the information they were given:

Norris (89): When asked whether the consultant explained things relating to his condition and possible treatments very well, Norris' wife replied: *"You get such a variety of doctors, really."* [Researcher: "You rarely see the same doctor?"] Wife: [No] *It's confusing. Because you have to have the notes there's nothing sort of personal about it."* Norris: *"I would say that [in terms of] having explanations, I don't think I would give the service a plus at all."*

Another participant described having to self-diagnose that she had a problem with her sight following a stroke, as they didn't assess her eyesight:

Belinda (82) said that following the stroke, she didn't get any on-going support. They told her she would be driving again in a month, but she never drove again because she couldn't see well enough. When she had the stroke they never tested her eye sight, so the problem wasn't diagnosed – she told her doctor that there was a problem *"but they never really said too much, they don't unless you keep asking, you know."*

Another participant was told that he could keep on driving when his sight problem was first diagnosed, but he felt it was unsafe so made the decision himself to quit driving:

Jeremy (80): When asked how old he was when he first realised that his sight problem was affecting every day things, Jeremy replied: *"when I had to give up driving. Yes, I had to give up driving in 2001 because I said to the wife 'I could see a shadow on the left, that's that eye more or less dead', and I said 'You'll have to tell me' [if anything was coming when he was driving] and from then on I packed it in. The hospital said 'Carry on' but I said 'No'."* [Researcher: "The hospital said you could carry on [driving] did they, but you didn't feel you could?"] *"One person said 'You're alright to drive' I said 'No, it's not fair', your life could be lost or two lives. I wouldn't risk it."*

One participant was currently paying for private treatment but hoped she could get NHS treatment, as she was likely to need ongoing medical care since her eye condition was degenerative:

Jackie (88) said she currently goes to an eye consultant privately for treatment. However, as it is quite expensive she is planning to ask him if she can join the [local] hospital eye clinic – she said she may get the 'city registrar' and not him, but the consultations are expensive and as her condition is degenerative it will go on and on. People have told her *"you're silly, you should go on the NHS"*, so she thinks perhaps she will next time.

A number of participants spoke of eye treatments including surgery, which they had had in the past; in some cases the surgery had not been successful, and had made their sight worse. Here are some of their experiences:

Emily (87) *"No, I did lose it suddenly yeah. And that was another thing, [late husband] said 'let's go privately, don't mess about – go privately you'll get to*

the bottom of it straight away'. I had some laser treatment to start with because things were getting a bit blurred, and he said we'll try laser treatment on it. But the laser treatment made it worse. And gradually, that's it, everything's a blur now. I don't think they do so much laser treatment now as they did. Treatment [was] just coming out back then... went back the next week, and 'good God!' he said – so I knew that was it then, there was nothing else they could do."

Norris (89): *"So my eyesight was disappearing, and it wasn't so much glaucoma as macular degeneration, I had an operation on my left eye for the glaucoma which would cure it but glaucoma remains in the right eye which was, I think that when I was treated for what was glaucoma in the hospital in [city abroad] they used the laser and they made not a particularly good job of it. It damaged the right eye so the right eye is damaged but it does provide looking at things, the right eye provides light, the left eye provides the seeing."*

In one case, the unsuccessful surgery she had some years ago had made her nervous about having further treatment:

Betty (86) said *"they didn't have the knowledge and instruments they have now, so perhaps why surgery didn't work."* When asked if she was given a choice about having surgery, she said she was but in reality there wasn't any choice as her sight was getting worse. The surgery helped the first eye but didn't help the second eye – following surgery she had tunnel vision and it closed up, was definitely worse afterwards. However she has had lots of surgery since (i.e. draining the eye), and "needling" which gets rid of the scar tissue that closes up the drainage system. She has a bit of a fear of surgery on the eye because of what happened before – but the consultant she has now understands and explains things to her.

Some participants talked about treatment that they were either hoping to have or had hoped to have until recently, when they were told it wasn't suitable or was too risky:

Delia (86) said her consultant had told her about an injection which isn't in England yet, but she could potentially have it privately (not on NHS) once it arrived – she was told it would cost £1000 per injection and that she would have to have several. Her [late] husband was with her and said the expense didn't matter, *"if she needs it and it will give her sight, will you put her name down for it."* But consultant said he would have to consult with others first and then she got a letter in the post that stated the treatment wouldn't "suit her"; so she said she just has to live with it. [Asked her if she was really disappointed] she said *"yes, but if it is to be, it is to be – can't do anything about it"*.

Belinda (82): At the time of the first interview, Belinda said her consultant had mentioned that she could perhaps have an operation to help her sight; she said she had to have a scan before a decision could be made and that she would be having the scan in November. When asked if they had explained the

surgery to her, she seemed to know a little about the process, and said they told her there was a risk her eye haemorrhage whilst they're doing it, in which case she might lose the sight she has left in her better eye. She said it's not like having sight in two eyes – she might lose the sight in the one eye she's got, her left eye – that would be the one they do the surgery on. In the follow-up interview, the researcher asked her about her appointment in November and whether the possibility of surgery had been discussed, but Belinda seemed confused and said nobody had suggested surgery.

Kulvir (80): *"I spoke to a doctor, the eye doctor... she said there's a cataract over it, they cannot remove the cataract because there's a risk of secondary glaucoma. What you are going to gain?... She said 'no, leave it'. Then for my own satisfaction she said we'd do a different consultant to make for a second opinion, and he also told me the same thing, he said 'Leave it as it is'."*

- *Audiology and experience of hearing aids*

As described earlier, all but two of the participants wore at least one hearing aid and 8 participants said that they wore two. Some participants knew little about their hearing aids and information was possibly not accurate. For example, there was evidence that some confused 'in ear' aids with 'digital' aids. It is perhaps not surprising that this group, who were hearing impaired, and who clearly presented with difficulties in communication and information had difficulty in accessing information about hearing aids, in particular about recent technological advances in hearing aids. At least 13 participants described their hearing aids as digital rather than analogue.

A number of participants said that they had bought one or both of their hearing aids privately. In some cases this was because digital aids were not available through the NHS at the time, but in some cases the participants had simply been unaware that they could have got one via the NHS. Whilst two participants said that they could afford to buy them privately, most of the others said that they found the cost prohibitive, and were hoping to get a more up to date aid via the NHS.

It is also worth noting that wearing one hearing aid provides access to amplified sound but having two hearing aids for many people will aid listening in noisier environments. Having only one aid may inhibit this.

The following are some examples of the participants' thoughts and experiences:

Belinda (82) has two digital aids, one bought privately and one acquired more recently via the NHS. When she bought the first aid privately her hearing impairment hadn't been diagnosed by her doctor, rather she identified it herself. When someone came to the house selling hearing aids, she filled out a form to find out more information and then two people came to visit from a private company. She hadn't previously had any idea about how much hearing aids cost, and was shocked to find that a digital one cost £4000. She was eventually referred for a digital hearing aid under the NHS, as her doctor said she had a problem with both ears. She said she had told them but they never seemed to want to know. She remarked that she didn't ever really get any help: *"you can struggle along on your own without knowing these things, whilst other people appear to get lots of help and drain the NHS"*.

Julie (70) doesn't always wear her hearing aid as she finds it uncomfortable. It is a digital one for her right ear that she bought privately. She is hoping to get referred by her doctor to see a specialist to see whether she can get any improvement. She bought her hearing aid privately as, at the time, she didn't fancy one that went over her ear; she said that she is aware that the NHS now gives out digital hearing aids.

Lawrence (60) described how his two digital hearing aids have made a huge difference to his life – with them, he feels he is no longer hearing impaired. He bought them privately as he was not prepared to wait a long time for aids on the NHS and he felt that the digital aids offered by the NHS were of an inferior quality to those bought privately.

One participant was hoping to exchange her analogue hearing aids for digital ones, and had heard that this might be possible if she made a 'case' for why she needed them:

Jackie (88) has hearing aids that need cleaning; however, she wants to see if she can get a better type now, as she has had them a long time. She said that she is going to the hearing centre to see the audiologist and mention her partial sight. As she can't see or hear cars when crossing the road, she has been told she can make a case to get two digital hearing aids as they are the best that you can have when you have to cope with sight and hearing loss.

Few participants talked about appointments they had had with an audiologist regarding their hearing (compared with the number talking about experiences at eye clinics), focusing instead on their sight loss and treatment they had had in relation to that; a couple of participants did share their experiences however:

Mary (84) described an appointment she had with a nurse after she experienced *"a very loud bang in my ear, just like someone was turning a screwdriver"*; Mary said *"they have a lot to learn"*, as he simply stood near her and kept saying 'can you hear me, can you hear me' and that was it! She wasn't at all happy with how they assessed her hearing.

Another participant felt the long waiting list for digital hearing aids on the NHS was unacceptable for people who were in his position, with severe sight loss in addition to hearing loss, and that the support available was inadequate:

Jack (83): When asked if anyone visits to help with his hearing aid, he said no: *“it’s quite interesting – what can you do to maintain your hearing aid? Have to go to the hospital and queue up. I would have thought being a blind and deaf person there should be someone who can help or a facility to go to”*; he said there isn’t one as far as he knows.

However, despite the difficulties in acquiring aids, it was clear that the use of digital hearing aids greatly benefited the participants who wore them:

Belinda (82) said that the digital hearing aids have made a big difference to what she can hear, though some days she still can’t hear certain things. She felt that it depends on “how you feel” each day. At the time of the follow-up interview, she said that one of her hearing aids was broken and needed to be repaired; she remarked that she misses her second hearing aid as it balances out the sound when watching TV.

Colin (92) described how he gradually lost his hearing to the point that he couldn’t hear a thing; if he takes his hearing aids out now he said he can’t hear anything at all.

Fiona (59) has been prescribed two digital hearing aids and the deafblind service installed a loop in her home so she can hear conversation even when there is background noise. She also has a portable loop for when she goes out to a restaurant, etc.

However, the use of hearing aids was not without its problems; many of the participants didn’t wear their hearing aids all of the time, as they picked up on unwanted noises or were themselves noisy, whilst another participant remarked that they altered the way that music and voices sounded to him:

Jack (83): By the time of the follow-up interview, Jack was wearing two hearing aids rather than one at the time of the first interview. He described having two aids as “a mixed blessing”. Whilst he can hear better than with just one, he says he doesn’t like the sound of his own voice as through the hearing aids it has a more mechanical, rather than lyrical, sound. Another consequence is that he doesn’t enjoy listening to opera music as he once did. He has been told they are not adjustable. He also said that they pick up every little noise so when he is outside he hears noises you wouldn’t perhaps want to hear. They are also whistling a bit so he is going back to have them adjusted.

Belinda (82) doesn't wear her hearing aids all the time as she lives alone and it picks up a lot of unwanted noise like dogs barking - her neighbours both have dogs that bark a lot. She generally doesn't wear them unless she's expecting a phone call or a visit from someone.

Rajat (58) only wears his hearing aid – which he thinks is analogue – when he really needs to, as it picks up outside sounds and other unwanted noises. When he goes outside of his home, he carries it in his pocket as it picks up too much background noise.

Additionally, many participants said that their aids were broken or in need of repair, and others experienced difficulty maintaining, fitting or wearing their hearing aids; the following are just some examples:

Keith (87) has a digital aid but cannot put it into his ear by himself; he is hoping they will replace it with two digital hearing aids that are easier to fit.

Mary (84): The latest hearing aid that Mary has been given keeps making a noise. Although she has two, she only wears one in her right ear as the other is rather heavy. She commented that she struggles to put them in but said that she doesn't have anyone come to help her. Mary lives alone.

Delia (86): By the follow-up interview, Delia still wore hearing aids but described them as being a different style; she had difficulty putting them in at first but she applies a little Vaseline so manages okay now.

Colin (92) is unable to put his hearing aids in himself, so has to wait for his paid carer to come in the morning and do it for him, before she helps him to wash and dress.

Pamela (86) struggles to hear what's being said in the dining room when she has lunch in the residential home, and wonders if the battery on her hearing aid needs replacing. Due to her sight loss she is unable to do this by herself. She was told she would be given one for her other ear as her hearing in that one "wouldn't last long"; however, that was 3 years ago and she is still waiting. She doesn't like to complain as she feels there are others in more need and she at least has one. However, Pamela has great difficulty hearing someone speak even in a quiet room and particularly struggles to hear people in group conversation, and this hinders her participation in activities in the residential home where she lives.

Most participants said that they didn't wear their hearing aids in bed, though one participant wore hers so she could hear her husband during the night and check whether he was okay.

- *Treatment for their general health*

A couple of the participants remarked that they don't like to bother their doctors or other medical practitioners unless they really have to; for example:

Emily (87) said she has to be at *"rock bottom"* before she asks for help regarding her hearing aids, as she likes to be independent.

Emily also said that she doesn't need to go to the doctor's surgery for general monitoring of her health as they provide a service where they visit her annually in the home:

Emily (87) described how a nurse visits her home once a year to give her a general health check – she came in November and did a blood and urine test, and gave her the flu jab. She said she doesn't go to the doctors unless she really has to as she feels she might catch germs whilst waiting in the surgery waiting room – she said you have to be careful when you're older.

Other participants talked about the difficulty they experienced trying to access treatment. For example, one participant described how his daughter had been having difficulty arranging for him to have a flu injection, yet his communicator guide, who he describes as *"marvellous"*, managed to arrange it at very short notice; this suggests that even participants who have family that support them require the help of professionals at times to ensure they access the services they need:

Colin (92): *"She's a lovely girl, she is, is [name], she'd do 'owt for me. She's done it this morning for me again"* – he then described how his daughter has been trying to get him the flu jab as there has been a scare in the papers about it; she had been ringing the doctor's surgery for about a month but they kept telling her to bring him in, so *"she told them 'how many times do I have to tell you, he can't walk out of front door"*. But still nobody came till [communicator guide] came this morning and when he told her what had happened she got straight on the phone and they had visited him and given him the flu jab within an hour!

Julie (70) ended up being referred to a specialist for her Sjogren's syndrome via her dentist; she said they had to completely bypass her doctor, and doesn't understand why her doctor didn't refer her in the first place. She described him as useless, that doctors seem to *"just write a prescription and then pass you off"*. She said it has been the same with regards to her hearing loss; her doctor simply said it's just part of old age so she has had to motivate herself in terms of getting help. Her doctor has never suggested she get a hearing aid despite the fact she has spoken to him about it, but now her hearing is deteriorating she feels she will have to go and insist that she be referred for more help.

Another participant felt she didn't get any ongoing rehabilitation or support after her stroke:

Belinda (82): When asked whether she had undergone any rehabilitation since the stroke, she said a speech therapist came but said there wasn't a lot she could do for her, and that she was doing very well on her own. She apparently told her some long words to practice saying, then she left, and hasn't heard from her since. Belinda mentioned that she still has problems in her right leg and that since the stroke she's never walked the same as her coordination was affected; but she pointed out that she had never been told that, rather it is her own self-diagnosis.

One participant described how she has regularly had to call for the doctor and go to the hospital due to her heart trouble; she has found difficulty accessing services at times, and her experiences in hospital have left her frightened about being readmitted:

Molly (88) said she is always in and out of hospital, which she described as "awful"; she said she tends to get panic attacks a lot, and when she gets indigestion she is never sure if it's simply indigestion or her heart. Her son tried to help her diagnose it – she takes a Rennie to see if it helps. If the pain doesn't go away following that and the use of a spray she has, she knows she has to see her doctor; however, she says you can't get one at the weekend. She said the emergency doctors aren't very good as they come hours after you call as they're so busy. She then told the researcher about a time she was in hospital in a ward with people who were all dying; she said she saw things she should never have seen (though she felt unable to describe them) – she was only in overnight, but was desperate to get out of there, and so dreads going now. She said it was a very scary experience. She said she never used to be bothered about going to hospital, but when you get so many things wrong with you "it affects your nerves".

Attitudes and awareness of medical staff about their sight and hearing loss

Many of the participants described having regular contact with the medical profession; some had quite negative experiences in how they were treated in terms of their hearing and sight loss.

For example, some of the participants who signalled to medical staff that they were having difficulties with a particular aspect of their condition or treatment were often met with quite negative responses:

Belinda (82), who had a stroke that affected her sight and dexterity, has to administer eye drops several times a day for her condition; her consultant was unsympathetic when she explained she had difficulty administering them herself. Belinda lives alone.

Another described the remarks of a nurse regarding her hearing loss:

Betty (86) described a hospital appointment she had where the Sister said something to her as she walked out of the room: *"When she came back she said very crossly 'You didn't do what I asked you to do!' to which [Betty] replied, 'I'm very sorry but I did not hear as you were walking out of the room and I am deaf', and she turned to me very crossly indeed and said 'Well, you do not look deaf!'"* which Betty felt was a rather ridiculous remark.

A number of participants described their experiences when being admitted to hospital; unfortunately, their experiences were somewhat negative. For example, one participant was recently hospitalised for 5 weeks; he felt the staff in the ward did not consider his needs in relation to his sight and hearing loss:

Lionel (78): *"I'd been put in the old men's ward but nobody had told me who was who or which was which, I had to go out and find people to ask them where the loo was. That was the one particular ward in the hospital, the rest of the hospital [was] fine, absolutely fine... They knew I had hearing aids, they knew I couldn't see. [Wife: "But they did nothing about it, I mean they left him with one broken hearing aid and one that wouldn't work anyway and they just left him there for 5 weeks."] [Lionel] "I was in silence most of the week, most of the time... [my wife] came in and she said 'There's a man over there trying to talk to you' and that was the first I knew about it."*

Mary (84) said she *"hated"* her recent stay in hospital following a fall at home; she said she couldn't see what she was eating and nobody helped her to chop her food up. She felt as if she was a nuisance to everybody.

Another participant recently had a hospital stay, and described the attitude of one of the nurses when he asked for a glass of water:

Keith (87) described why he had a bad fall whilst in hospital recently: *"I was parched, I was asking for water and I know the people were, one of the nurses, a male nurse, [said] 'you can't have any water because you'll spill it', this is about 10 o'clock at night, everything's in darkness, one or two lights over the bed like, [and] in my desperation to get some water, I fell over the side of the bed, fell on my back and it's causing me a problem and I think I'm going to ask for compensation really because it's not getting any better and I could do without that."* He added that he was thinking about applying to become a governor at the hospital so he could try and change their attitudes and practices towards patients.

Not all participants reported such negative experiences of hospital treatment however; one participant described being on 'first name terms' with the nurses and doctors at her local hospital as she was such a frequent visitor for various treatments:

Fiona (59) has had ongoing, regular medical care due to three connective tissue disorders, and describes it as *“Wonderful! My medical care is amazing [..], totally flawless, I can’t fault it, not any way at all... and because of my hearing and sight difficulties and mobility problems, they’re just wonderful, I just can’t [fault them]”*.

Fiona also praised her consultant ophthalmologist, who runs a Stickler clinic, whom she has a close relationship with due to her 3 conditions which he carefully monitors. She visits him in his clinic which is a journey several hours away from where Fiona lives, at least once a year; to date, Fiona and her husband have had to pay for their travel, accommodation and food, but her consultant is trying to get funding to pay for Fiona to visit the clinic in order to save them this expense.

Social and emotional issues

General perceptions about their life

When asked how they viewed their life, many of the participants were quite downbeat and even depressed, both about their current life and their prospects for the future. Those who lived alone seemed most likely to feel negative about their life, though not exclusively; the following are examples:

Emily (87), who lives alone: *“I was only 62 when [husband] died. I sometimes sit and think, where have the years gone and how have I managed, and how have I coped? You take each day as it comes and hope for the best and that’s it.” “You can’t afford to get down when you’re on your own, you get miserable anyway at different times when you’re listening to something or something reminds you [that] you did something when you were married, different things come back to you and you think poor old soul, on your own!”*

Molly (88), who lives with her husband and her son, said that she tends to live in the past a bit now. She said the best years of her life were when she used to go dancing, and when she was healthy. She said you have to appreciate your life while you have it. She sometimes cries about her situation.

Despite struggling with their feelings of loneliness and coping with the difficulties they face daily, many of the participants still said they were thankful for every day that they managed to get through; for example:

Mary (84): When asked about the previous day, she replied *“Yes, it was a good day.”* She said that every night when she gets into bed she thanks God for another day that she’s been here.

Some of the participants were asked how they would describe themselves at this point in their life; one participant described herself as a ‘survivor’ whilst

others said that they take each day as it comes:

Fiona (59) described herself as someone who has been through a lot, but due to the support of her husband, her medical care and the support she receives from social services, she has survived. She said she looks upon herself as a survivor; she tries to be as positive and proactive as she can. She said she doesn't want to sound big-headed or like a martyr, but has been through a lot and is aware that she still has a lot to come ahead of her. She said the three syndromes she has been diagnosed with have had "a terrible effect" upon the lives of both her and her husband, and she feels that she is living with a time bomb as her consultant cannot tell her when she will lose her remaining sight and hearing, which is inevitable.

Jack (83): *"I take life as it comes – that's the basic thing."*

Norris (89): *"How would I describe myself? I don't know, it's just goes day by day."* [Researcher: You mean you take it day by day?] *"I've got a number of interests which keep me occupied."*

Mary (84) replied: *"I try not to think about myself very much, I said to [volunteer helper] the other day, 'I think I must be boring'. She said '[Mary], you can be so many things but that ain't one of them!', we were only having a laugh!". "It gets so boring, [so I] think of somebody else and what they're doing! I admit sometimes you get a friend on the phone, and they'll say 'I've just been shopping' or seen some relation or something, and you do think 'I wish!', I can't do some of the things they do, but, so what! [shrugs]"*

We asked the participants what was the most important thing in their life; many replied that it was their family, or being able to remain independent. Others seemed unable to answer the question, or seemed so depressed about their life that they couldn't think of anything that was important anymore nor of anything that could improve their life:

Colin (92), who lives alone: *"Now? [pause] well, the most important thing in my life now is that I can't do anything really. You can't do owt at all. All you could put down is to see me daughters and grandchildren. But honestly Sue, there's nothing, no enjoyment. After you've gone it will be just like a morgue again, if you put it that way, you know, quiet and I sometimes get news on wireless and listen to that, but I shall be in bed by half past eight. I just lay in me bed, and I can get in where I can't get out, but I have what they call wheelers by side of bed so I can get hold of them and pull myself, drag myself on, and once I've got on there it's nice – like I say, you can go and have a look – watching then, all cars that come, all lights go on ceiling, it just keeps you thinking. And that's all you do, you just think of what might have been, or think of what did happen and where've you been. Whereas years ago you used to plan and think 'oh, we'll do this next week or we'll do that in a months time', or 'we'll book and go there and do this and do that', but now there's nothing to do, you can't do that."*

Rajat (59), who lives with 3 generations of his family, answered “*nothing*”. The researcher then asked him how he would like his life to change, what he would like to do – he shrugged and replied that he didn’t think there was anything that he could do or anything that could be done to improve his life.

Reactions to diagnosis of sight and hearing loss

Many of the participants spoke about the time of diagnosis of their visual impairment, and how it affected them emotionally:

Jack (83): For anyone going blind there is an element of shock – he said it’s a challenge, so he just has to find a way around it. He suggests that people who have just gone blind need something to prevent the shock – they need to be given something to help them cope with it, to get “*the right attitude of mind towards it*”.

Betty (86): “*I was very frightened when I was told about the glaucoma... he didn’t take me in gently [the consultant said] ‘if not dealt with you will lose your sight!’*” She recalled that “*it was very frightening. He did not quite explain enough to me at the time, but this is not the man I am seeing at all now. So that was alarming but I have been well-treated ever since.*” Interestingly, Betty seemed to think that this ‘direct approach’ was a good thing as it made her use the eye drops.

Fiona (59) described how she and her husband were both very shocked when her first connective tissue disorder was diagnosed. What helped her to get through was the amazing support she received from medical staff. She said they knew it was very much “*un-chartered waters*”, and so “*they knew they had to be there for me*”. She described herself as a very proactive person, a “*fighter*”, who will ask lots of questions; she says she doesn’t care how long she is in for when with a consultant, she does not leave until she is happy that she understands what they are telling her since it affects not only her life but her husband’s as well.

Mary (84): [Researcher: How did you feel about losing sight, were you worried about it?] “*That’s a funny sort of question really. You can’t say you’re happy about it, I have to tell myself there are people a lot, lot worse. I try not to let my eyes get to me too much, it’s just that I wish I had more energy, I get so tired doing so little, and I think “you stupid woman!”, I’m always telling myself off!*”.

Jeremy (70): [Researcher: How did you feel when you were diagnosed with it, how did it make you feel?] “*Rotten. I thought I was going to lose everything, you know. Even with the family it’s, sort of, think I’ve got to rely on those now, but I didn’t want it to happen, [but] I get by on most things I think.*”

In some cases the level of sight loss and speed of deterioration seemed to

make a difference to how people reacted when their sight loss was diagnosed:

Julie (70) agreed it wasn't so much of a shock when her visual impairment was first diagnosed as she has had time to adjust as the deterioration has been slow. Before she lost any of her sight she had assumed that losing her sight would have made her feel as though she wanted to die; but instead she has coped with it due to the slow rate of deterioration. She said she felt like she shouldn't have attended an information course run by the local voluntary organisation for people recently diagnosed with sight loss, as other people on the course appeared to have far worse sight loss than she did.

Some participants (mostly male) took a pragmatic approach and described trying not to panic at the time of diagnosis of their sight loss; for example:

Norris (89) said: *"I think I took it all fairly well, in my stride, I accept this as an event and a fact of life. I'm not sort of moaning over it."*

Interestingly, most of the participants focused upon the time when their visual impairment was diagnosed, rather than when their hearing impairment was diagnosed. This suggests that losing their sight was more traumatic than losing their hearing for these people; indeed, many participants explained that the loss of their sight loss is much more difficult to bear than losing their hearing; for example:

Emily (87) when prompted said that her sight loss was the worst of the two – she said *"you can wear hearing aids that help but can't do anything with the sight."*

Jackie (88) when asked which she found more difficult said *"Sight, yes, it always affects you, definitely. I didn't lose confidence through not being able to hear, but you do when you can't see where you're going."*

Pamela (86): When asked what was more difficult, her sight or hearing loss, she replied *"my sight – there would be a lot I could do if I could see. Could put up with the deafness if I could see. If you feel a bit off colour and down, and you're looking for something, you seem to drop more and make mistakes more. I suppose you don't but it's you that thinks so, and sometimes I do get frustrated, I'll sit in chair and have a weep, and I think 'you silly thing'"*

A number of participants talked about how their sight loss had affected their confidence, particularly in terms of how others see them; for example:

Emily (87) wears glasses to look as "normal" as possible, though they are now purely for cosmetic reasons as they don't improve her sight: *"I put my glasses on and I think I get the confidence that I don't look all that funny, I feel I look queer when I've got my glasses off. Being self conscious about things again but there you go"*.

Throughout the interview, Emily, in particular, showed a lack of confidence in herself and her life; she was reluctant to keep a diary for the project as she couldn't see what anyone would find interesting about her life:

Emily (87) felt she wouldn't do anything that was interesting enough for people to read about, as she doesn't go out. She said she has never thought about the day – just gets up in the morning and fills it somehow or other and that's it! Emily asked the deafblind worker who was present during the interview whether she thought she could talk about anything that would be of interest. Even though she replied, wholeheartedly, 'yes', Emily was still very reluctant to take part and reiterated that she couldn't believe that what she does would be of any interest to anybody: *"When you can't see and you can't hear, I just can't see that what I do is of interest"*.

Depression and bereavement

A number of participants described feeling depressed about their sight and hearing loss:

Delia (86): before losing her husband, Delia spoke about how he helped her to cope with her depression over her sight loss: *"I get a bit depressed, not when I'm in the home and I've got my husband. But I can't see to put the microwave on, but he can, and between us we can get our meals and that. But I do get a bit depressed when I go out and I go into a shop or perhaps want to buy a present for somebody and I can't see what I'm buying. I'm alright in the shop but as soon as I get out I burst into tears. I just can't see things. I'll get over it [sighs, but smiles]"*. When asked whether she was still coming to terms with her sight loss, she said that she was slowly coming to terms with it.

Sadly, Delia's husband passed away a few months after the first interview. Along with Delia, a number of participants described their bereavement after losing a spouse or one of their children:

Delia (86) lost her husband suddenly just after Christmas, four months before the follow-up interview; in the follow-up interview, Delia seemed keen to talk about the circumstances of his death even though she was visibly upset, as if talking about it provided her with some form of therapy. She said her husband was her main source of companionship and support, though her son still lives with her and has taken over the caring role that his father had carried out.

Colin (92) described his late wife as “a lovely girl” – he said it was taking him a long time to come to terms with losing her. He said “*you never know what’s going to happen*”; they certainly never expected that their lives would turn out as they had. He described how when she became ill she only lasted 5 days before she died: “*I blame it all on my eyes, I couldn’t see how she was suffering and she wouldn’t give in, she wanted to look after me all the time*”. He said he blames himself, and couldn’t help doing so. Colin was visibly upset at this point but reassured the researcher that he could continue with the interview, but said he might “*have a catch in his voice*” now and again. He said his wife was wonderful, that there was nobody like her – she was his best friend.

Another participant described how she has been helped through the bereavement she experienced following the loss of her son via support from a communicator-guide working for a local branch of a national voluntary organisation that supports deafblind people:

Emily (87) was depressed after the death of her son, who was her main source of support since losing her husband – she said “*I just thought that was the end*”; she was referred by her concerned daughter-in-law to a voluntary organisation that supports people with hearing and sight loss, which assigned her a communicator guide who has helped Emily to remain independent by taking her shopping, providing some companionship and building her confidence.

Personal ‘strategies’ for coping with their circumstances

It became apparent in the interviews that the participants had a number of different strategies to help them cope with their circumstances; these included positive thinking whenever they started to feel sad or low, support from family and friends, making and keeping contact with others with similar circumstances, and their religious beliefs. The following are some examples:

Fiona (59) has tried to come to terms with her sight and hearing loss by keeping in touch with others with the same conditions by email, and searching for information online.

Kulvir (80) is a very relaxed person and feels that his disabilities are “God’s will” so there is no point in worrying about them. He has a very supportive family, particularly from his son and daughter-in-law who live with him.

Pamela (86): *“Sometimes I do get frustrated, I’ll sit in chair and have a weep, and I think ‘you silly thing’, and then I say a prayer to my picture up there – I can hardly see it now, it’s what you call a 3D picture, you see Jesus one way and look another and he’s in a different place... it gives you something to cling to, to keep you going. And I think, ‘well, aren’t I lucky, what do I have to be down for?’ Two daughters and family, and I’m here, I’m warm, I’m safe, they’ll fetch and carry me if I want to be like that.”* She said she has a lot to be grateful for and she is grateful.

Emily (87) said that at the end of each day she always thanks the good Lord for having gotten through another day.

Molly (88) often cries about her visual impairment but reminds herself she is lucky to have a family that supports her; she lives with her husband and her son.

Jack (83) keeps a diary on his computer at the end of every day – he finds it a good way to ‘get things off his chest’. Jack described how he has had a very wide range of experiences in his life, therefore whatever comes in the future he feels capable of facing it. That is how he deals with his disabilities.

Suggesting the importance of having a partner, some of the participants who were married talked about supporting each other and working as a ‘team’, a ‘strategy’ used by participants to help them lead their lives successfully; for example:

Lionel (60): *“Most things that we do we do together as a team. Not just as husband and wife, not just as two friends, we are a team; we are a working, bonded team. When she goes anywhere with her guide dog to do things we work as a team. Whatever it is we do, I keep [wife] informed, [wife] keeps me informed.”*

Betty (86) described how she and her husband worked together to get jobs done around the house; for example, she described how they managed to prepare meals between them by sharing the tasks as some were difficult for Betty due to her sight loss.

Fiona (59) explained how she and her husband supported each other as he has also had health problems: *“He [her husband] says to me [Fiona], our wedding vows said ‘in sickness and in health’, when do we get the health bit?!”* He has had two heart attacks you see, so we’re like carers for each other.”

In one case, the participant expressed dismay that he could not help his wife when she was in need as he would like to have been able to, due to his health problems:

Jack (83) described how his wife had a fall recently when they were walking near their home; his wife explained that she was so concerned to see where Jack was walking that she missed a step up onto the kerb and fell flat on her face – there was blood everywhere, and she struggled to get up, but luckily two people passing by stopped to help. Jack said he felt useless when she fell as he couldn't pick her up because he is now physically too weak. He said *“when things go wrong like this you realise your lack of strength.”*

Many of the participants talked at length about their memories of the past and how important those memories were to them now:

Delia (86): The researcher commented that she had many good memories from her life, to which Delia said *“[yes] that’s what I think now”*. Later in the interview, she remarked again that she has happy memories to look back upon.

Emily (87), who lost her son a few years ago, showed the researcher some photographs of her two granddaughters and her recently deceased son when he was young. She said *“so they’re always with me, I don’t feel it’s an empty life if you know what I mean. It’s hard work but I can pick them up [the photographs] and it’s all memories, they help me get through the day”*.

Thoughts about the future

The participants were asked about their thoughts for the future; some explained that they didn't think about the future or at least tried not to, but rather tried to take each day as it comes:

Belinda (82): When asked how she sees her future, she replied *“Day by day.”* The researcher then asked her whether she had any hopes for the future – she replied *“No”*. When asked if she had any fears or worries about the future, she simply replied *“My eyes.”*

Delia (86), before her husband passed away, said *“I just don’t think about the future”*. When asked if she has any worries for the future, she replied: *“Only the worry that my sight will go completely, but I try not to think about that. I think what I’ve got day to day, and at my age, I’ve had a good life, I’ve been blessed with a wonderful husband who would do anything for me. I’ve got a good son. So, I’ve always had a good life from a child really.”*

Jack (83): When asked whether he thinks about the future at all, he said he doesn't; rather, he takes each day as it comes and only thinks about the future in terms of establishing that he and his wife will have enough to manage on.

Molly (88) said *“I try not to think about it too much as there’s not much to look forward to, is there? Nothing much happens really.”*

Mary (84): *"I try not to think of it too much, and when the time comes, if I'm going I'm going!"* When asked if she was hoping to stay in her own home, she replied: *"What can you do, if you've got to face up to things, what can you do but make the best of it? Especially when people are trying to be kind to you."*

Pamela (86) said: *"Not a right lot love, no different, but I'm happy and content, until the good Lord takes me, to carry on as I am. I would like a little more company because I've found I feel much better after, and I think it's because I go for days and days and days [without company]."*

Jeremy (80): [Researcher: Do you think much about the future? Do you plan things?] *"No, we come to accept life as it comes now"*. Researcher: *Have you got any particular hopes for the future or anything?* *"I just hope for good health and happiness, you know. The way I look at life now because, I get about, it doesn't hurt me to get about, and I don't think I'm a hindrance to any of them [family], when I do go out with them, I'm alright."*

Other participants focussed upon a particular goal (returning to her home after a flood) or were more philosophical in their answers:

Betty (86) said that nobody can see into the future, but they have tried to make the best provisions that they can for themselves. She said she will probably end up in a home, but will cope with whatever comes her way. Following the flooding of her home and its subsequent renovation, she said she was hoping to move back into [name of their cottage] and live there as long as she and her husband can. She said they have made it a lovely home. She remarked that she was just hoping that they will live long enough to move back in [then she laughed].

Keith (87): [Researcher: How do you see your future?] *"I see it as a challenge. Anything that's worth doing is difficult, anything that's worth doing at all, whether your painting or whatever you're doing, if you have to do it thoroughly and properly it's not easy is it, it's difficult, it's a challenge, yes."*

Lionel (78): When asked if he had any particular hopes or fears about the future, he replied: *"No fears, God will take me when he wants to. I have hopes that it won't be for another 10 years."*

Many participants, as already illustrated, were concerned about further deterioration of their sight:

Fiona (59), when asked what her main worries for the future were, replied that she feels she is living with a time bomb as doesn't know when her sight is going to go for good; she is aware that one day it will suddenly go and wont come back – she said *"I know that's the end then... I try to put it on the back burner but it isn't easy [name of researcher], that's my big thing"*. When asked whether she still plans ahead for things in the future, she said *"I try to, because I try to be positive, I try to, which is why the time bomb, as I call it, I try to put it to the back but it isn't easy."*

Julie (70), who is not registered and still has some useful vision, said her main concern is how she would cope if her sight went completely – she doesn't know yet if that will happen. She is hoping that her consultant can tell her what's wrong, the prospects for the future and whether anything can be done to improve her sight at her upcoming appointment. In terms of hopes for the future, she said *"if it doesn't get any worse than now I'll be quite happy!"*

Many of the participants expressed the desire to stay in their own homes for as long as possible; for example:

Jackie (88) prays that her sight will just last her out so she doesn't become totally blind. She said that otherwise she would have to move into accommodation for the blind (and mentioned a local voluntary organisation that provides such accommodation). When asked if she hoped to stay living in her home in the future, she replied: *"Yes – I have to face things because people have to... If I can just go on with my pension, but I don't want anything desperately done structurally to the house, so I would like to, if it's the right thing, stay here for as long as I can, as it's such an upheaval for people to sell all their goods and chattels and all that they've got".*

Lawrence (60): *"The only way they are going to take me out of this damned house is in a flipping box, I'll tell you that now!... That's not going to be for several years yet I'll tell you now. I don't plan on giving up that easy I tell you, I'm not giving anybody the satisfaction"* (laughs).

Many of the participants said they hoped they would not have to go into residential care in the future, and that they would rather stay living in their homes; these views are described later in the section on 'Residential accommodation'.

Some of the participants had more pragmatic thoughts about their immediate future; for example:

Rajat (58) explained that his son is getting married soon, so Rajat and his wife, mother and daughter have to move out as they're isn't enough space for everyone – it is his son's house and there is only one double bedroom. They are trying to find somewhere to live nearby, but privately rented accommodation is very expensive. He said he has spoken with a lot of agents and there isn't much in the area at the moment. He said that finding somewhere to live is quite a pressing worry. When asked whether he had any hopes for the future – he said *"I don't know"*.

Residential accommodation

Only one of the participants was living in a residential home at the time of the interview; her experiences of living in a home for over 15 years are described below. Other participants talked about residential care in the interviews,

expressing their views on the possibility that they might one day move into one.

Case study: Pamela's experiences in a residential home for the elderly

- *Description of Pamela's accommodation*

Pamela (86) has lived in the residential home that caters for elderly people for over 15 years; she moved in to the home after her husband died, as she was struggling to live independently in their top storey flat that didn't have lift access. She said she was "going mad" living in the flat on her own due to the isolation she felt, as she never went anywhere or saw anybody. So her daughter approached the home to see whether they would provide her with accommodation, and she was invited to visit for a day to see whether she would like it. She said it seemed okay, so they said they would let her know when a flat became free. She was on the waiting list for 18 months before she was offered a place.

Pamela has her own small room with a single bed, a TV, a kitchenette area with a sink, microwave and a fridge, and her own washroom which has a toilet and sink (there is no shower or bath, she has to go to the home's shared bathroom for a shower with the assistance of one of the care staff). The flat is furnished with her own furniture except for the microwave and fridge. She said that she can do what she likes in her own room, and she can leave the home whenever she wants to, so she feels she has "plenty of freedom"; however, Pamela very rarely leaves the home unless she needs to go for medical treatment that cannot be administered by the doctor who visits the home, or the very rare occasions when she goes on a day's outing laid on by the home. She does not visit her family as neither of her daughters have a downstairs' toilet, and she cannot climb the stairs anymore due to her sight loss and mobility problems caused by the water retention in her legs whereby they swell to the extent that she cannot walk easily.

Whilst she can still prepare basic meals in her flat, Pamela tends to have lunch and dinner prepared by the home's catering staff; however, she does not particularly like the food as she says they use poor quality ingredients and the cook is not a very good one, though she notes she is young and still 'learning on the job'. Pamela buys her own bread and washing up liquid as she likes to buy better quality than what the home provides, but is limited as to what she can purchase herself each week due to her limited income.

Pamela said she likes her little flat as she knows where everything is; this has become even more important recently as her sight has deteriorated and she now doesn't have any light perception at all. She said the only thing she asked for in the past was to have her flat redecorated, as it had never been redecorated in the whole time she has lived there, but they always refused. Then just recently they said they would do it – but Pamela feels it's too late

now as she can't see at all and would worry about them moving all her things; at the moment she knows where everything is, and nobody else, not even her daughters, would know where to put everything back. Pamela says that at this time in her life she just couldn't face the upheaval of moving herself and all of her things out of the room for it to be redecorated.

- *Entertainment and activities*

Pamela explained how she spent Christmas day at the home; she listened to programmes on the radio which she enjoyed, rather than go to the party that took place for the residents (which included a game of 'pass the parcel') as she struggles to hear what's being said in the dining room now. She also said that she doesn't need a lot of company even though she likes people to talk to.

Pamela described some of the entertainment provided by the home, some of which she goes to; for example, on Wednesday mornings they have a discussion group, but she just sits and listens rather than joining in. She said they discuss anything that crops up, for example something someone read in the evening paper and can be quite interesting for an hour. They also sometimes have a senior citizens orchestra, which Pamela has gone to visit a few times; unfortunately the room in which they play hasn't got good acoustics so it sometimes gives her a headache, but because they are senior citizens and have bothered to come and play to the residents, she feels she should go and watch them.

In terms of leaving the home for outside activities, she said she doesn't go anywhere very often; in the previous summer she went for a drive to the local park in a mini-bus hired by the home, but said "*they don't do trips to the seaside like they used to.*" She said she hasn't been on another trip as they can only take 12 or 13 people in wheelchairs (which she has to have) in the mini-bus, and so the residents have to take turns. She said she probably gets a chance to go every 3 or 4 trips. She added that the residents don't decide where to go; rather, the staff members decide where it's best to go. She said she has had a lot of fun on the trips she has been on, even though they led each other around "*like little lost sheep*"; so she felt "*it hasn't all been doom and gloom!*"

She said the current manager (who had left by the time of the follow-up interview) runs the home differently to the former manager who ran the home when Pamela first moved in; whilst she tailored activities to the way that older people liked them to be, the current manager tries to run things in a more modern way that many of the residents don't like. For example, the current manager has once again hired 3 people from London to put on a pantomime for Christmas, the same people who came the year before; Pamela described how they kept playing different parts and changing their costumes "*but it were no good to me, I couldn't tell which were which or what they were on about, or anything! With not being able to see. So this year I'm not going down.*" Pamela felt the money that the residents raised for the activities in the home

could have been better spent on other things.

Pamela was looking forward to some activities at Christmas however; the following Friday, she described: *“I’ll be right busy, as it’s the Christmas fayre on Saturday – we buy boxes of ginger biscuits and brandy snaps, and we buy bags and count so many in each bag and sell them on a stall you see, and that makes a profit. It’s for the Christmas party, the funds they raise on Saturday.”* She explained that her daughter comes to help voluntarily for that, as do others. She does the counting in her room out of the way, as she has to count 8 in each bag and gets interrupted too much if she does them elsewhere, by people who come and ask what she’s up to! She said she’ll just carry on and will be *“as happy as anything, and then will have to have a good clean up after as it gets all sticky. I’m really looking forward to it.”* Then on Saturday, as she is unable to see and there aren’t any available staff members to take her around, she’ll sit at a table and fold all the counter foils for the raffle tickets: *“to save them a job. That’s my way of doing my bit for what they do for me like. Even though you can’t see there is some things isn’t there? [that you can do].”*

- *Support provided in the home*

Pamela felt the quality of care that she receives compared to when she first came to the home is now much poorer, and felt that the younger carers were often not as caring as the more ‘mature’ ones. She described a number of occasions where, despite the fact she has told them a number of times what she needs, the staff either forget or do not pass the message on to other staff; for example:

The lack of communication between staff was demonstrated during the first interview; although Pamela had explained to one of the staff that she was expecting a visitor [the researcher] and that she would have her lunch later on, four different members of staff came in during the morning to ask her about the arrangements she wanted for lunch. *“The office lot don’t seem to communicate with each other, things would get done better if they did because they would know what they were doing. I mean take today for instance, there’s no [communication] whatsoever.”*

Pamela has been very disappointed with her level of care at the residential home. She said you would think they would know to fetch her at lunchtime, but she has to buzz them every time or struggle down on her own. She has explained to them in the review what she wants, but 2 days later they’ve forgotten – she describes it as a waste of time. She said you can ask the carers to write comments in a little book that is kept in her room, for ‘resident feedback’, but feels it is pointless as nothing is ever done about it.

She felt that part of the problem is that the home employs a lot of temporary staff and that they are not given appropriate training to know how best to deal with people with hearing and sight loss:

The temporary staff members aren't aware of Pamela's routines or how she organises her flat, so they sometimes put things where she is not expecting them and she then falls over them: *"they don't think in the office to tell them when they come. To me, I think there should be some recognition on the doors to say you have hearing and sight loss. They have them when they have wheelchairs so I don't understand why they don't for me. Would be a help to them who are coming in to look after me."* She added: *"It's strange that they do training for how to cope with residents who have heart conditions, but not for those with visual impairment, and yet so many of the residents in the home are visually impaired."*

She later explained that some of the permanent staff were unhappy over their work conditions compared to those of the temporary staff: *"our girls won't work the same when there's agency staff on as they're paid more than they do, and yet they have to show them what to do, and it grieves them, as it will do. So it's a vicious circle really."*

Pamela explained that she had a really good key worker who is employed by the home, but not full time. Pamela felt that one of the reasons the other staff did not do their job very well is that they worked for too many hours:

"a lot of them are working full time without much of a break – they work 9 days followed by a 2 day break which isn't enough – they seem to come back as tired as when they left... it's worse at the weekends, as there are fewer staff on. They only have 2 staff on overnight instead of 4."

Pamela says she has brought up her concerns about the short-staffing at the residential meetings but the management at the home claims that they're not breaking the law. However, Pamela worries that in the event of a fire, they wouldn't get all of the residents out in time. She gave another example of the effects she felt that short-staffing has on her care:

As she is quite independent and doesn't ask for a lot of help, she said she tends to get forgotten and sometimes goes from early evening till 11am the next morning without any member of staff checking in on her. If she had a fall she would possibly lie there for hours undetected. She said that the other night her alarm was sounding for half an hour before a member of staff came to check whether she was ok; she said sometimes they don't come at all. When she asked them why, they said they just don't have the time!

Pamela felt she would be much happier living in the home if she had more company, but felt that the staff didn't have any time to spend with her:

"I would like a little more company because I've found I feel much better after, and I think it's because I go for days and days and days and [they pop in briefly] then I don't see them again for ages and ages. They're supposed to give you so much quality time each day but they haven't got the time, there's so many people that need caring for and that, they haven't got the time, and I'm sorry to say it, they're not carers like they used to be when I first came in. There's a lot of young ones here for the money and I mean, there are two that let us down on Saturday, the weekend was shocking, let us down on Saturday, said they were sick and they were both seen in [local town] watching 'em put Christmas lights on. It's wrong in't it? I don't call 'em carers, if you come into a job like that you've got to be dedicated don't you?"

When asked if the management in the home ever ask for the residents' opinions, Pamela replied *"Yes, but like other managements they says they're seeing to that, [but] don't get round to doing it. [We] have resident meetings where it's brought up but nothing happens."*

When Pamela was first visited (for the initial interview), the lady in the room next to her had Alzheimer's, and used to constantly shout and ring her neighbours' doorbells, disturbing Pamela and the other residents in her corridor at all hours of the day and night. She was told that they were building an extension to accommodate all of the residents with Alzheimer's together:

Pamela explained "it will be a bit quieter, and I'll be able to get some sleep. Like everything, they're short of staff and as fast as they put her in bed and they've gone, she's back out and ringing your [door] bell and your letter box".

However, the manager promised that this would happen over 12 months ago. Pamela wanted to stress that she has nothing against people with Alzheimer's but feels that they are not being given the care and attention they need; she worries that the staff forget the lady with Alzheimer's next door like they forget her and don't ensure she is fed or her needs cared for. It was clear that Pamela was very distressed about the situation but didn't want to appear that she was complaining all the time.

By the time of the follow-up interview, they had just opened the new wing and all of the residents with Alzheimer's had been moved there. Pamela is not so disturbed now with her constant shouting and banging on her door at all hours of the day and night, and said it has been better for the lady who was next door.

When visited for the first interview, Pamela said that the previous manager had left to work in another home that was apparently in 'dire straits' and needed to be sorted out. Yet Pamela felt that the home she lived in needed improving too. She described the home as being *"one of the best in [the city] even though the shell inside is deteriorating."* Whilst the previous manager did sort things out like the appearance of the entrance, by refurbishing it with new carpet and pictures, Pamela felt other things were more pressing. She

gave examples of a leaking bath, a new shower which was too small to enable help to be given.

At the time of the first interview, Pamela felt that the new manager would be more thorough, though she hadn't personally met her at that stage. She was hoping that she would *"pull it back to the way it used to be"*, as it was run so much better when Pamela first moved in. However, by the time of the follow-up interview some 6 months later, the new manager had still not introduced herself to the residents and Pamela felt the problems within the home and with her care in particular were still occurring.

Despite the problems she faces living in the home, Pamela said she has never thought of moving as she has been at the home for so long and likes her little flat: *"I'm not going anywhere else; when I go out of here they'll be carrying me out! I'm happy here after all this time"*. She said she feels safe as someone can only come in if they have a key and she knows where everything is. This is despite her daughters encouraging her to move because of the recent problems.

Other participants' views about residential accommodation

A number of participants talked about the future, and what would happen if they were no longer able to cope with living in their own home; this seemed to be a particular concern for those who lived alone. Most had negative views of residential homes and felt very fervently that they did not want to end up having to go into one; here are some of their explanations as to why they felt that way:

Colin (92), who lived at home with the daily support of a care agency and his two daughters, described a good residential home that he knew about that was run by the council, where you had your own room; he used to visit a friend there and go round the lounges and talk to people. But in the other places where he has visited, they were never moved: *"[The residents] were just all sat there in a semi-circle and it wasn't nice at all. So I don't want that, not ever. I daren't say it, I keep telling daughters its time that I popped my clogs but they do get cross, they tell me 'don't be so daft Dad'."*

Emily (87): *"I tell myself at least it's still my own home and I can do what I want – because that would be dreadful, if I had to end up in a home – there's no way I could cope, I'm sure I couldn't cope with it. Because I've never been that sort of person, always been brought up to be independent."*

Demonstrating how strongly Emily felt about remaining in her own home, when asked near the end of the interview what the most important thing in her life was, she reiterated that it was to remain living independently in her home:

Emily (87) *“To keep my independence... that is one big thing I would really.., that would finish me off if I had to give up and go in a home, I couldn't see myself cope, could you?” [Question directed at DB worker].* When asked what put her off about going into a home, she replied: *“The thought of having to be dependent on people, doing things and taking you here and taking you to the toilet, oh no. [pause] Lose my independence and I don't think I would last very long to be honest, I think I would just fade away.”*

Jackie (88): When asked whether she has any particular worries, she said *“I pray that my sight will just last me out so that I'm not totally blind; otherwise it would mean the [name of local residential home for people with sight loss] or something.”*

Molly (88) talked about nursing homes and reports on the news about how people living in them are mistreated – she said she can't understand it as that's when people need someone to be kind to them.

One of the participants was more open to the idea, though she still saw it as something negative that she would have to 'cope with':

Betty (86) *“Nobody can see into the future and we have tried to make the best provisions that we can for ourselves. Will probably end up in a home, [but] will cope with whatever it is.”*

Views of the participants' families

As described in the 'Methods' section, all of the participants were asked whether they could recommend a family member, friend or professional that works with them that the research team could usefully interview in relation to their hearing and sight loss. Most of the participants did not suggest anyone; however, some participants did, and we eventually interviewed a spouse of one of the participants separately over the telephone and collected the views of five other spouses and a son and daughter-in-law by interviewing them concurrently with the main participant. All of those who took part in an interview were the main carer of the participant. Some of their views about the participant and their lives together are weaved into the preceding sections, whilst their more personal views are presented where appropriate below.

Thoughts about the participant's hearing and sight loss

Two spouses talked about how they reacted when their husband or wife's sight loss first became apparent; understandably, they described it as something of a shock and difficult at first to come to terms with it:

Fiona's husband explained: *"[losing her sight as a result of the syndrome] wasn't supposed to 'kick in' until her late 60's/70's. So at that stage it was long away in the future so I was like an ostrich with head in sand – didn't think we needed to worry about it yet. But then the op' in 1991 started it off early – and in 1994 she was retired from her job. First thing was 'why us?' the second was wondering whether we'd be able to manage. It was a case of getting used to it – it was a gradual process to come to terms with it, plus the sight loss was gradual. I didn't know at the time it would be hearing loss as well – when we found that out, it was again a case of 'why us?' – A question not really worth asking but you can't help but ponder it."*

Jack's wife agreed with Jack it was a shock when his sight loss was diagnosed - *"the first month was pretty devastating"*.

Clearly, they have managed to come to terms with the participant's sight and hearing loss as they were all continuing to lead their lives as well as possible under the circumstances. Some of the spouses, however, did struggle at times to allow the participant to do things independently, or felt they were over-protective:

Jack's wife described how he used to walk along the canal twice a day, but when he lost his sight she wouldn't dare let him go on his own. However, being independent Jack said he could do it by himself. So she let him go but followed him staying well behind just to make sure he was okay; she then realised he could manage, so let him go alone on subsequent occasions.

Fiona's husband: *"I sometimes think I'm over-protective... I sometimes get aggressive with people when they don't see or ignore that she has problems, and perhaps walk away or bump into her."*

One of the spouses said that she felt guilty that her partner couldn't see and enjoy things as she does:

Jack's wife said there are certain things you miss doing, like going away on holiday; she said she always felt guilty when they went abroad that she could see places and Jack couldn't – places like Lake Garda – felt so sorry that Jack couldn't see them. However, Jack said he can feel things, feel the atmosphere of a place.

Similarly, another spouse described how she felt guilty when she asked her husband's opinion about something when shopping together, momentarily forgetting that he is unable to see it:

Jeremy's wife: *"the only thing is I don't do shopping like now, I don't look round at things because he can't properly see, and I have to be careful because sometimes I've still got a nasty habit of picking something up and saying 'Do you think you'd like that [Jeremy]?' and he says 'Well, why ask me [name of wife], I can't see it', and I get annoyed then and then I say things like 'This is no life is it really'."*

Another participant worried about what other people thought about her husband's sight loss, particularly after some people had been unkind:

Jeremy's wife described how she worries about what people think and say about her husband's sight loss; *"It's the things they say, and [Jeremy] says 'I don't care what they say, [name of wife], just take no notice'"*.

Impact of caring for the participant

Some of the carers talked about the impact that caring for the participants had had on their life; for example:

Fiona's husband: *"Yes, a big impact – when you go out, you have to think not only about yourself – have to make sure [Fiona] is alright – I sometimes think I'm over-protective. Need to plan a lot. At night it's particularly awkward as she can't see at all at night."* He also has to take on all of the responsibility when they go away on holiday now - he has to take charge, and *"do all the 'right, we'll go this way", and "we should stand there", and "it will be so long before the flight leaves"*. It used to be a shared job – now the planning is solely his.

Jeremy's wife described how she has been told that she needs a knee replacement; however, she refuses to have it done as she knows she won't be able to walk for some time afterwards, and she is aware that Jeremy needs her support which would be difficult if she was incapacitated.

One participant had become so weak from his leukemia that his daughter-in-law had to give up working to care for him full-time at home:

Daughter-in-law of Kulvir (80): *"Most of the time he just spends up here, he goes downstairs to have his lunch, but when he's feeling really weak then I bring his food up here; that's why I had to stop work for a while because his condition was getting quite worse. Because he does, like, need assistance around the home."*

Support for the carer

Understandably, some of the carers required support themselves in order to continue to care for the participant; here are some descriptions of the support that has helped them to cope:

Fiona's husband said their situation sometimes gets to him, and he thinks "Why me?" – he often talks about it to Fiona, but only after she has prised it out of him. He said like most men he doesn't easily talk about things, but they do talk about things together. He is on good terms with her doctors so he can talk about it to them – but he felt other people don't really understand what they are going through: *"while friends sympathise, they don't really know what it's like."*

Fiona's husband talked about the importance of having some respite from caring for Fiona:

Fiona's husband still works part time, 2 or 3 days a week. He said he didn't go part-time due to caring for Fiona, though he guesses that is partly the reason now. He said it is nice to get a break from being a carer, though you can sometimes feel selfish for thinking that or needing a break. The job gives him a bit of extra money and gets him away from the caring role and environment, though he added hastily that he doesn't want to get away often.

Another spouse described how respite had been provided after the participant came out of hospital, but the care offered did not meet *her* needs as a carer:

Lionel's wife: *"he could do nothing for himself and he was really very disorientated and they send in, they said 'Oh we're sending carers', never mind about what I needed or what I wanted, I mean it became very clear from just after he came home, I realised that instead of having carers during the day I wanted one overnight just to really sit with him and be there so I could get some sleep, because I need my sleep because I've got epilepsy and I need to sleep. I can sleep during the day but I do need sleep at night because we can't be both 'drunk' [from lack of sleep]."*

A couple of the spouses mentioned that they also attended the courses that their partner was invited to that were hosted by voluntary organisations for people with sight loss, covering many different aspects of living with sight loss, and the support services that were available to help them:

Jack's wife described how she went with Jack to the series of lectures he attended which she described as being very helpful to both of them.

Fiona's husband said the course was really useful, as it gave him an idea how other blind and partially sighted people live. He described how partners are taken aside and are asked to try different glasses that attempt to give an indication of different eye conditions; you then had to walk round the house and see how it affects them. He said it also made partners think about the well-meaning things that they sometimes do that don't help the visually impaired person, like grabbing and leading them rather than asking them if they want help across the road. The course also provided lots of practical information on things like state benefits, and even things for Fiona like how to put make-up on, which she hadn't done for years. He said it is nice to know you're not alone; it was good to meet other visually impaired people and partners of visually impaired people, so that you could get your heads together over a beer and ask how they coped with things. He said when Fiona first told him about the course he thought it would just be for her, but it was intended for him as well. At first he wasn't keen, but he agreed to go as he wanted both of them to learn something from it.

One of the carers said that, whilst she could care for her husband, the difficulty she experienced was managing to keep on top of other household tasks at the same time; she described how a voluntary organisation for people with sensory loss were trying to help her sort out all of their paperwork:

Lionel's wife: "Well, it was through Social Services because I needed some extra help, still trying to sort out paperwork because it's like painting the Forth Bridge, you know, it's never ending... it keeps coming and coming and I never know quite where, and I'm not the tidiest of people, so we've sort of set up a filing system that will work and I can get it sorted, get it all in place, and I won't have everything all over the floor, which is what I don't want anyway. I don't think, I can't seem to find any way of doing it any different but we are trying, honest. We are very trying, but there we are, so that's how we got to know [community workers from VO for people with sensory loss], they work together and they come and they've been pretty good, very supportive and that's what we do find. When you want things, you want somebody that comes in; see I'd rather look after him and get someone to clean the house, because I'd rather look after him because that's what I can do."

One of the spouses had made contact with a local support group for carers; whilst he had not yet felt the need to call upon their services, he said it was good to know they were there just in case. He also described other sources of support to both him and the participant:

Fiona's husband explained that there is a local support group for carers, from which he gets a newsletter; he said it's nice to know it's there, but he doesn't need their assistance yet. He also said that the social services deafblind service had been really helpful, as have other organisations who have offered assistance if they ever need it – like the Army Benevolent fund and the Royal Military Police Association (mostly in terms of financial assistance).

Carers' views of their current life with the participant

A number of the spouses reflected on their life together with the participant; for example:

Jeremy's wife: *"I think sometimes it's a cruel world but, well, there are a lot of people worse off than you."*

Jacks' wife did not feel any resentment about caring for Jack as she felt he had looked after her throughout the 55 years of their married life together, stating *"it's my turn to look after [Jack], though he doesn't need that much looking after!"*.

When asked what the most important thing in their lives was at the moment, one spouse replied:

Fiona's husband: *"being together and doing as much as we can before [Fiona's] sight gets any worse - it's very much a 'live for today' situation in a lot of respects".* He said they do whatever they can do. He agreed it has affected his philosophy on life, saying *"you never know what's round the corner. We don't have the life we had 30 years ago, but you just have to get on with it and enjoy what you can – not what either of us would have chosen, but there it is."*

Carers' views of the future

Some of the spouses talked about their future together with the participant; some focused upon practical concerns, others were more philosophical; for example:

Norris' wife was concerned that her sight was also deteriorating and that soon she would be unable to drive their car; when talking about the future, she had more immediate practical concerns, about how they would get around if she was no longer able to drive.

Fiona's husband: When asked what he thinks about the future, he replied *"one day at a time is how I see it; these conditions she's got, could wake up one morning and be totally blind. You can't really plan for that. It won't be greatly different, she will just see a bit less than what she does now. It's a gradual process of deterioration – we're getting an introduction to it. It's a case of 'we will do what we have to do'. That's all you can do about it... [Fiona's] conditions are a unique situation, not many others with them. It's not like heart disease where it's well documented and well known and a raft of things you can do about it. Nothing you can do about it but follow the medical advice they give you. Very much a one-day-at-a-time situation. You know it's gonna get worse, and there won't ever be a miracle or cure."*

Professional views of services

A range of professionals who were in contact with the research team to support participant recruitment were asked about the services that they worked for. Seven individuals filled in an online questionnaire, while two (for various reasons) answered similar questions via telephone or face to face. Not all of the questions were answered by all the respondents; the word 'all' is used where five or more people responded in this way, and the others did not respond. The data collected therefore represents information provided by nine professionals, who worked in different parts of the country and held a number of different roles.

Six of these professionals were working primarily in services for people with dual sensory impairments, either for a local authority or for a voluntary organisation. One other was working as a deafblind worker in a voluntary organisation which provided services for visually impaired people, while two worked for voluntary organisations concerned with older people. Three were working in contracted-in services to a local authority.

The services were organised in different ways. Four were working in teams devoted to older people, with sensory needs/dual sensory impairment being the specialist service within this for two of them. Five others worked in teams primarily related to people with sensory/physical needs, three of these being specific to dual sensory impairment (for people of any age).

Eligibility criteria for receiving the services

Some services were set up specifically for people over 50 or 60 years of age, while others were for people with combined sensory loss whatever their age. Four of the services clearly did not require their clients to be registered as dual sensory impaired, despite their 'specialist' status, but instead used the criteria of having difficulty with communication, information and mobility in relation to their dual sensory impairment. One of the professionals explained this by saying it was a useful definition as it related to function.

Eight of the nine professionals said that their team recognised combined sight and hearing loss as a distinct disability (for one voluntary organisation this was a difficult question to answer, although the individual had some skills particular to the needs of people with both sight and hearing loss).

All said that the participants who were referred to the project were broadly typical of the clients they worked with, although obviously there were some individual differences. One of the professionals said that the clients she worked with were very ethnically diverse.

Registers of people with sight and hearing loss

Of the nine respondents, three services said they were not responsible for keeping a register of clients with both sight and hearing loss. All of these worked for voluntary organisations, two working primarily with older people. Four others said they kept an informal register, or a simple list which was updated by contacts. One had a formal register in relation to the county council. This respondent said that the register was very useful in providing statistical information for performance indicators, and that it also contained information which would be useful to the generic workers who came into contact with them, for example, about communication methods. However, she was not sure that they used it. One other used a register which was regularly updated and this was used throughout her organisation. Another said that she was responsible for keeping records up to date, and that she did think her more informal list was useful. Most of her clients were registered as having sight or hearing loss as single sensory impairments. One other who kept an informal list did think this information was useful, at least about those clients who were on it, but she considered that most people with combined sight and hearing loss were not identified, and so not included on the list. One who kept a structured list, regularly audited, said that this made it effective, and that it was used to shape the services offered and as a basis for applying for funding.

Description of caseload and referral routes to services

The respondents were currently working with 73 people they identified as dual sensory impaired. Two of the deafblind specialists said that about 90% of the clients on their lists were over 50 years of age, while one other said all her 5 clients were over 50. Another described 22 clients in a service for older people who were blind, of whom 10 also had hearing loss. One other person, who had 62 older clients, described only one as having both sight and hearing loss. The clients were described as being referred by a range of routes, including by themselves or a family member or carer, by social services departments (or by other teams in their own department), by hospitals, occupational therapists, or GPs, or when being registered as visually impaired or seen in audiology clinics, or by voluntary agencies. There was no shared agreement between the professionals as to what is the most common referral route; the participants who took part in the project were referred to the professionals by one of the aforementioned routes. Some services had a waiting list for particular services (such as communicator guides) and referrals were prioritised in some areas, for example, allocating priority to people with dementia, cases linked to demonstrable risk, or urgent need. Others said that responses to referrals were delayed primarily by the logistics of heavy caseloads and having sole responsibility in the team for the clients.

Description of services offered

The teams the respondents worked for provided a range of services (in relation to older people), and liaised with other teams, in both their own and other organisations, who also provided services. A range of objectives for the services were described, and amongst these, 'promoting independence' was mentioned by all. Other objectives mentioned by more than one person included maximising health (physical and mental well being), enabling their access to the wider community, ensuring safety in and out of their homes (including mobility), and supporting communication. Supporting their own choices, helping them to recognise their disability, referring to other appropriate services and reducing social isolation were also mentioned. One person talked about the role of documenting and sharing good practice.

The services which were provided by these teams are outlined in the table below, divided into sections.

Table: Range of services provided by the organisations that respondents worked in

<u>Rehabilitation and daily living</u>	<ul style="list-style-type: none"> • care services at home • provision of equipment • shopping service • bathing • accompanying to medical appointments • food services (meals on wheels) • arranging the services of communicator guides (specialist workers with training in combined sight and hearing loss, who visit individuals to help with the tasks of daily life) • arranging for home care • arranging transport • supporting independence • providing support for the use of technical aids • maintaining homes
<u>Emotional support</u>	<ul style="list-style-type: none"> • short breaks • respite care • weekend care • emotional support • befriending • advocacy • helpline
<u>Community access and activities</u>	<ul style="list-style-type: none"> • day centres or clubs • communication support • deafblind forums • social groups for deafblind people
<u>Assessment</u>	<ul style="list-style-type: none"> • Occupational therapy assessments • identifying and assessing the needs of people with both sight and hearing loss • bathing assessment
<u>Benefits and money advice</u>	<ul style="list-style-type: none"> • advice on benefits

All of these services were described as being provided directly by one or more teams, though some respondents indicated that similar services were provided 'indirectly' – for instance, by referring to other agencies.

In addition, they liaised with other professionals and agencies, including providing training both in their own organisations and outside of them. The services offered by each person depended on their job role and the organisation they worked for. Training in dual sensory impairment was provided by five people, two of whom considered they did not do this often enough, because of the demands of their caseload. One other offered training in relation to sight loss. Awareness raising of the issues related to combined hearing and sight loss was considered to be very much needed.

Some services were provided at no cost to the user, and transport (for day centre attendance, for example) might also be provided free. Equipment and communicator guide services were provided free by one team, while for other services in the same team, financial assessment indicated an individual's ability to pay. Some services were provided by paid staff (such as communicator guides, or meals on wheels), whilst others were provided by volunteers, co-ordinated by the team (for tasks such as help with shopping, or reading someone's mail).

In addition, the respondents provided information about many other services and agencies to which they referred their clients. These included local societies for visually impaired or deaf people, advocacy, fire safety advice, equipment, local clubs, churches and paramedical services (audiology, podiatry and so on).

One of the professionals felt that 'activity groups' were not always seen as welcoming and that people with hearing and sight loss did not always want to go because they had trouble communicating with others in the group.

Respondents mentioned the need for additional awareness and training, for staff in several allied fields, to help older people to adjust, access opportunities and receive good services. This included staff in residential homes, day centres and groups, and hospital services.

Regarding staff in residential homes, respondents felt there was little attempt to identify people with sensory impairment or to adapt for them. Support was also identified as a need for staff in day centres and groups, since by their very nature they made difficult demands on people with sight and hearing loss; for example, one respondent described how younger people (i.e. in their 50's and 60's) liked to get involved but the more elderly might have got out of the habit of 'joining in' and isolation was seen as a very real threat to their welfare; transport to these services was also needed to encourage people to go. Finally respondents felt staff in hospital services required training, as they were aware of very negative experiences of hospital services, where sensory impairments were not taken seriously by other professionals. Consultants may also tell people that 'nothing' can be done for them, which leads to low

expectations amongst those who could actually benefit from environmental changes or special equipment, for example.

Description of services that are not currently offered

The respondents suggested a number of other services that were not currently provided which would benefit their older clients with combined sight and hearing loss. These included:

- Home care (cleaning etc); although difficult for people with sight loss, this is not always addressed by services such as direct payments;
- Improved access to education such as computer skills; this was considered a resourcing issue – there was not enough to meet individual need;
- More specialist respite facilities;
- Accessible social activities; this would likely be small groups with communication support and appropriate activities. Forums of older people were also mentioned;
- More one to one ‘human’ support;
- Communicator guide services (in particular, a bank of people who could be available for one-off situations);
- More training of professionals to ensure people with combined sight and hearing loss are identified; this would promote the development of appropriate services;
- Advocacy; in one case, an increased need for advocacy had been seen following an occasion when a family had had very low expectations for an individual, and in the end the provision of services had ceased. In another case, a person wanted help in drawing up a will, leaving money to charity;
- Identification of people in minority ethnic communities; one professional said they had not been able to identify any people in these communities, despite deliberate attempts to support them with services;
- One to one support with equipment; it was considered that equipment was often given out without training or review, or troubleshooting;
- Provision for mental health care in older people;
- Preventative care.

Discussion

This section summarises the findings described in the previous section and also draws out some implications. It also suggests how some of the difficulties and challenges faced by the participants could potentially be overcome. In particular, data collected during the round table discussion meeting (RTD) held near the end of the project is used here; these include actual and potential solutions suggested by the professionals who attended the meeting.

Vision, hearing and other disabilities and health problems

The participants had a variety of levels of hearing and sight, though, partly because of how the sample was constructed, no participants were profoundly deaf. With some exceptions, it was common for participants to have limited knowledge of the medical conditions which caused their sensory loss (e.g. they rarely knew the medical name of their condition). This seemed to particularly be the case in relation to their hearing loss.

The vast majority of participants reported additional health problems or other disabilities (e.g. arthritis, heart problems, mobility problems, problems linked to bowels and stomach), some of which were clearly very debilitating.

In most cases the participant's hearing and sight had deteriorated over the previous year (indeed often their general health was deteriorating also). This change in circumstances would mean that many would likely have benefited from assessments in relation to low vision aids, lighting and hearing aids, but attendance at appropriate clinics may have been problematic given common mobility and travel difficulties.

Generally there were positive views of both hearing aids and low vision aids which enabled the participants to do things which were otherwise impossible, like reading their own mail or participating in conversations. Nevertheless, there was some discussion about some of the inadequacies of the technology, and clearly some of the participants did not know how to correctly operate the aids that they had been given or required further hearing or low vision assessments to ensure they had the appropriate aid for their current level of sight or hearing (which was reported as changing by many).

The data revealed a variety of different interpretations of the participants' disabilities when asked. Often the participants described their disability in medical terms (e.g. associated with an illness), while others reflected upon a loss of part of themselves and the skills they once had. Many also linked their disabilities with old age. Nevertheless, many participants appeared to rationalise their disabilities with pragmatism ('nothing can be done', 'you've got to get on with it'), reference to their faith, and that they were in a relatively fortunate situation compared with others who were worse off. Exceptions to

this may be those participants who had a hearing or sight loss from a younger age.

Linked with general health were that many participants were very vulnerable to suffering falls within their homes; only a few had a safety system in place (e.g. personal alarm services) or modifications to the home (e.g. handrails). In fact, in some cases the presence of a personal alarm service caused participants anxiety as they did not know how it worked and they sometimes did not want to disturb their family, who would be called should an emergency arise.

RTD Feedback. *“A local initiative in falls prevention was to introduce a falls risk screening tool for use by all health and social care mainstream staff (including District Nurses, Therapists, Social Workers, etc). One of the risk factors for falls is sensory impairment. Feedback from staff using the tool said that though they were happy that this identified risk factors, it didn't help as they then didn't know what to do to address the problem. This resulted in a resource pack being developed providing staff with guidance on what to advise, where to refer, useful leaflets and website contact details, etc.”*

RTD Feedback. *“Rehabilitation interventions such as introducing effective lighting, magnification, colour contrast, etc, in order to maximise the individual's mobility and to minimise risk of falls.”*

Identification as sight and hearing impaired

In terms of identification as sight and hearing impaired, it is interesting to note participants' relatively low awareness of their registration status as deafblind (in contrast to a clearer understanding of their registration as blind or partially sighted). This may be partly explained by the fact that the statutory requirement for deafblind registers is relatively recent, and also the process of registration may feel less formal or important (and therefore less memorable) to people because it does not involve medical staff.

Reasons for low registration as a deaf or hard of hearing person (or certainly lower awareness of it) are even more speculative. We are confident that many of the sample were *not* registered perhaps reflecting that our sample contained people with relatively less impaired hearing (compared with sight) – for example there were no people with profound hearing loss in the sample. Also fewer people in the population as a whole are registered as deaf or hard of hearing compared with blind or partially sighted.

In terms of being identified by services as having hearing and sight loss, most participants had been identified by a voluntary organisation at the very least, though in some cases this was through an informal referral by a friend or family member. Professionals at the RTD talked at length about the best ways of ensuring that people who are assessed by non-deafblind specialists in generic services are identified as having hearing and sight loss and referred

on to appropriate services where necessary, but also to ensure that the professionals can then seek advice on how best to communicate with them:

RTD Feedback. *“Front line staff (e.g. GPs) should ask about any difficulties with sight and hearing. Need to ask in a sensitive way and to be aware that people don't necessarily see themselves as disabled.”*

RTD Feedback. *“Within Health and Social Care statutory services all professionals should ask about sensory impairment as part of their assessments. There is still a requirement (from the NSF OP 2001 DH) to introduce the “Single Assessment Process” and part of this is an overview assessment which includes sensory impairment. This information should then be shared with appropriate other services and professionals to ensure needs are met.”*

One of the RTD attendees gave an example of an initiative which was trialled, but ultimately failed; the professional, who was a nurse consultant for older people, explained:

RTD Feedback. *“it is a challenge in generic services to be aware of the many specific specialist services that are available. In terms of sight and hearing loss services in my area, I am aware that there are both voluntary and statutory services, some very small and local, others large and national but it is hard for mainstream doctors, nurses, therapists and social workers to know how to access every service and what it would offer. Resource Directories have been tried, but things such as contact numbers, etc, change as fast as it is updated.”*

Clearly, there are benefits to initiatives such as these; what is needed is a solution that overcomes the constant maintenance issue.

Communication and social interaction

An extremely strong theme to emerge from the research was the communication challenges faced by many. Communication in groups was very difficult, but also difficulties with mobility and travel beyond the home for those who lived alone meant that opportunities for communication were also limited. The telephone was problematic for some but these problems of access were overcome for many (e.g. by adding amplifiers).

This difficulty with communication meant that some felt very isolated, e.g. *“I go for days and days and days [without company].”* (Pamela, 86); *“After you've gone it will be just like a morgue again”* (Colin, 92).

Leaving the home and getting out and about

In terms of leaving the home, participants often described difficulties they face. Often they talked about personal / health barriers (e.g. energy, difficulty walking, and fear of falling). Nevertheless, many described strategies that they have when travelling (ringing ahead, asking people, using public transport, taxis). It was common for people to go out with others, in particular partners they were living with. Some described a fear of crime which prevented them from going outside.

RTD Feedback. In order to make using public transport easier, one professional described the benefits of trains, buses and trams that announce the next stop. Also bus stops that announce the number of the approaching bus as well as having more visible signs.

RTD Feedback. A participant highlighted the importance of mobility lessons to increase confidence and effectiveness in getting around safely.

Activities within and beyond the home

Many participants described leisure activities relating to the spoken word (e.g. talking books, radio, and television). People often talked about the importance of people (friends, family) visiting their homes. Contact with religious groups was highlighted by many as very important and in particular its role in connecting them with a community of people. Many re-iterated difficulties they had leaving their home and how that reduced opportunities to do things outside. Some, not surprisingly given the lack of variety in their life and reduced opportunities to go out, talked positively and at length about holidays and breaks that they had experienced. Others did not see the need or thought it too difficult / too much trouble.

RTD Feedback. For those unable or willing to leave their home, suggest activities they can participate in at home; e.g. Teleconferencing choir that "meets" weekly.

Day centres were discussed in a largely negative way by participants. Participants were negative about the inability of staff to cater for a range of people and their different needs. They felt that many had an institutionalised feeling. Data from the RTD suggested that this is a common problem: for example:

RTD Feedback. *"One deafblind man I met (in his early 80s) expressed profound boredom in an afternoon tea group for blind and partially sighted people. He was plied with tea and cakes but otherwise left alone until it was time to go home".*

RTD Feedback. In order to support attendance at older people's forums, one professional said they provided assistance with transport to the venue; once at the venue, communication between participants with hearing loss was supported through a loop system.

RTD Feedback. A RTD participant outlined a number of good practice initiatives they have undertaken to include people with hearing and sight loss in their groups, in both decision making and the activities themselves: *"We have started an art project on site, which will concentrate on tactile art and pottery. Service users will receive 1:1 support."*; *"We discuss what sort of events and activities the service user would like to get involved in, and how we could adapt existing services to achieve this."*; *"Should an individual require 1:1 support this is provided via volunteers or care and support staff."*

RTD Feedback. A RTD participant remarked that if someone has never been a "joiner" they won't want to join a group now, later in life. This reflects the comments of some of the participants who said that going to groups 'wasn't really their thing'. Therefore, there is a need to offer alternative one-to-one social opportunities, like linking up with a volunteer or befriending scheme.

Daily living and sources of support

While people had or required different levels of support, a key source of support for many participants was family (whether family who lived with participants or family who lived locally). Discussions about support revealed many different views about independence and dependence. Certainly for some participants avoiding 'feeling a burden' to family or friends was a great concern.

Having support to carry out shopping was highlighted by many. The RTD professionals talked about the importance of offering support to enable participants to go shopping with a helper, rather than having someone doing the shopping for them as this can lead to a reduction in the food choices the participant's can make, thereby increasing their feelings of dependence and lack of power/choice further:

RTD Feedback. *"Waitrose provide wheelchairs and a supporter to take you around the shop. Also, there are some very good local transport (voluntary) systems that give a great deal of help with shopping trips (including cups of tea/lunch in the café and carrying the shopping back into the kitchen)"*

RTD Feedback. *"Effective local transport initiatives; guide shopper schemes."*

Nevertheless, there may have been some evidence that while participants were keen to maintain their independence (including financial independence), this can lead to unusual decisions (and potential vulnerability to people who might exploit them) – for example two participants who did not want to rely on

others described spending a lot of money on technical equipment which they could have had on free loan.

Whilst many participants were in contact with a support service for people with sight loss and/or sensory loss, the referral routes were not always clear, and in some cases participants still required support for particular needs that were not being met. This demonstrates that participants who have difficulty with communication and accessing information often need support in accessing support services. RTD feedback also suggested that such support is often necessary:

RTD Feedback. *“Sometimes requested by the deafblind person to make contact with a service on their behalf on an individual basis.”*

RTD Feedback. *“By raising issues with services when we find them explaining communication methods and barriers met by deafblind people when accessing services “*

It is clear that there was very little awareness of rights or involvement in processes with which the participants could influence services. Those who did discuss their ‘rights’ in this manner (e.g. awareness of DDA, participation in access forums/groups) were younger participants (with only one exception).

The importance of including people with acquired hearing and sight loss in service decision making was highlighted by many professionals who attended the RTD as being of key importance. This may be difficult for many of the older people who participated in the research who appear to align themselves with a culture which emphasises personal responsibility and a reluctance to ask others for help. Nevertheless, professionals who attended the RTD described many examples of where this had successfully worked:

RTD Feedback. *“Older people's forums, run by older people themselves, that have close links with the Older People's Partnership Board which has high level membership from all Statutory Services”*

RTD Feedback. *“We have two Deafblind Service User Reference Groups, so they can have input to how they would like services to look.”*

RTD Feedback. *“DB Service Users being involved in recruitment of new workers “*

RTD Feedback. *“Oldham and Dudley LVSCs actively use service users on LVSCs to assist driving services forward.” However, in some forums several users have left LVSCs as they haven't been able to communicate; must avoid just paying ‘lip service’”*

RTD Feedback. *“Having safe and confidential systems in place to encourage evaluation and honest feedback”*

Daily living and independent living skills

It was clear that the participants faced many challenges, both large and small, on a daily basis; being able to complete what might seem to outsiders as small, simple tasks, can mean a lot to older people who have lived their lives independently. Clearly, the participants' sight and hearing loss (but particularly the sight loss) made many of the tasks difficult, though this was often exacerbated by additional health problems and disabilities affecting the participant's strength, dexterity and mobility.

Of central importance to the participants was the need to retain independence, therefore solutions aimed at overcoming any difficulties should attempt to enable the participant to carry out the task independently where possible, taking additional disabilities and health problems into account (e.g. provide ILS training and specialist equipment like a liquid level indicator to enable them to make themselves a cup of tea, or suggest other strategies where the hearing loss prevents audible specialist equipment being used).

Some of the participants were concerned that they were a burden upon their family, therefore input from services, in particular communicator-guides and volunteers to help around the home, are of key importance for enabling participants to live independently without them having to rely solely upon the support of family members who often live far away. Professionals may also have to play a role in ensuring the participants understand that using services does not constitute failure in terms of living independently.

Professionals at the RTD described a number of services offered around the UK aimed at helping people retain their independence whilst living in their own homes:

RTD Feedback. *"The aim of 'Fresh Start' is to provide services to older people to enable them to live as independently as possible for as long as they choose to do so. The menu of services falls into four categories: services in the home, information and sign posting, health and social care, active lifestyles / getting together"*

RTD Feedback. *"The Bridges Project in Sandwell is not solely for those with sight and hearing loss but provides support (volunteer sitting / help with household chores / transport / access to grants / information) to (usually older) people with cancer. It has user involvement."*

RTD Feedback. *"In one service there is a priority system in operation called 'Complex Rehab', where people are prioritised for support and training for a number of reasons – sight loss being one of them."*

Accessing information

The participants who had attended courses for those who were newly registered or diagnosed appeared to have obtained a lot of value from them. Whilst some participants could not recall details of the support or information they had received at the time of diagnosis, the participants who attended courses running over a number of weeks appeared to have much better recall about the information they received. This suggests that attendance on courses, rather than just giving out leaflets and verbal advice, could be a better source of information for participants. Additionally, the courses enable socialising and communication with other people with hearing and sight loss which many participants viewed as important.

The support provided to partners and carers on such courses was also appreciated by both the person with hearing and sight loss and the carer. A greater understanding of how the sight and hearing loss affects their relative (both practically and emotionally) may improve communication between them; it may also reduce the participant's feeling of being a burden upon their family, since the carer will have a better understanding of how they can facilitate their independence, rather than dependence.

Some of the participants in this study appeared to have attended courses that focused upon sight loss. In light of the little knowledge the participants appeared to have about their hearing loss and available services, it would seem prudent to offer courses that covered hearing loss also. One of the professionals at the RTD described a service that offered such a course:

RTD Feedback. *“Specialist deafblind rehab groups meet one morning every week for 12 weeks. Skills such as money recognition, kitchen tasks, and getting around are covered, as well as offering people the opportunity to share their experiences with others with the same circumstances.”*

Whilst only four participants were using computers, it was clear that it offered them many opportunities, and that they were using them very effectively. The participants who were using them had received support from family members on how to use and set up the computer, or had experienced using them in their previous occupation pre-retirement. There is a need for provision of one-to-one support for older people with sight and hearing loss to enable them to be included in the opportunities that technology affords.

Access to and participation in medical services

In terms of medical services and their sight loss, many participants reflected upon their medical experiences. Inevitably these were often told as harrowing and emotionally painful personal journeys. In some cases the stories perhaps reflected the participant's own confusion about the treatment they were receiving (it has already be highlighted that participants had relatively limited knowledge of their medical conditions). There were also both negative (e.g.

insensitive staff, lack of continuity, poor communication) and positive (e.g. “wonderful” staff) recollections of the services received. On the face of the data there was nothing obvious in the findings which differed from patient experiences reported elsewhere in relation to sight loss (for example, the Network 1000 study). However, it may be that some dissatisfaction and confusion experienced by participants was linked to poor communication and hearing loss. In a recent study by Wallace et al (2008), patients in an eye clinic who had additional hearing loss were less likely to comply with their medication. This may reflect that patients in eye clinics with hearing loss may be finding it more difficult to understand the information being given to them by staff.

Experiences regarding audiology offered more novel findings. For some participants, it was clear that visits to hearing specialists were difficult due to their sight loss, and that maintenance of hearing aids can also be difficult. There was a general feeling amongst some of the participants that prioritising those with sight loss for hearing aids is important. However, many seemed vague about the services on offer relating to hearing loss. In the case of hearing aids in particular, there was a lot of confusion in terms of referral routes, the boundaries between NHS and private services, and cost.

In terms of receiving general medical services, many of the participants were unclear (and passive) regarding referral routes and there were a number of examples where they had encountered difficulty in getting these services (e.g. Colin who finally received a flu jab in his home after his communicator-guide intervened). The experiences were mixed however, since other participants appeared to receive regular visits to ensure they were up to date with required vaccinations and general health check-ups.

There were also mixed experiences regarding hospital admissions; most were negative and often linked to staff not identifying the communication needs of patients. Whilst it is difficult to speculate the detail of what led to the breakdown in communication in the particular cases documented in this study, it is clear from discussion at the RTD that there is shared agreement that adaptations to wards and improved training regarding the implications of hearing and sight loss for hospital staff is needed; some potential solutions were discussed at the RTD:

RTD Feedback. One professional mentioned ‘Red tray’ schemes on hospital wards to alert staff that the patient needs assistance with eating.

RTD Feedback. More 'quiet rooms' in ward areas could be provided for private / quiet discussions with sensory impaired patients. Onsite optician service (e.g. for mending broken spectacles) for in-patients (especially frail, elderly/immobile patients who can't get to an outside optician).”

RTD Feedback. The elderly care wards at Guys Hospital in London has been redesigned to facilitate finding your way around, e.g. clear signage for toilets.

However, clearly the difficulties some of the participants faced were not related to staff failing to identify that they had hearing and sight loss, but rather a lack of understanding about the implications of their sensory loss, and additional support they would need in terms of communication and information whilst they were in the hospital.

Social and emotional needs

Many of the participants felt somewhat negative about their current life and prospects for the future. This seemed to be particularly true (though not exclusively) for those who lived alone. Unsurprisingly given the age of this group, bereavement was also common. Key coping strategies appeared to be drawing upon positive memories and their religion (the latter played a strong role in many of the participants' lives).

In terms of the future, many felt they lived day to day, and coped with their anxieties about the future by refusing to let themselves think about it. However, many expressed anxiety about their health and sight (in case either deteriorated further); about becoming a burden upon their families (particularly their children); and being able to stay in their own homes rather than having to go into residential care. Interestingly, the latter two anxieties are somewhat incompatible, in that for many, the only way they could remain living in their own homes is with the support of their families. It is likely that such tensions play on participant's minds causing further anxiety. Even participants with a high level of care put in place by social services required a lot of daily support from their family in order to stay in their own homes (e.g. Colin, who had daily support from his daughters in terms of cleaning the house and preparing his daily meals).

Residential care homes

The participants seemed overwhelmingly negative about the thought of moving into a residential home. This seems to be linked to feelings of losing independence, and was seen as the ultimate price when participants lost 'the fight' to remain living independently in their own homes. It is difficult to clearly decipher why the participants felt this way, but it is likely that negative experiences of visiting homes coupled with negative portrayals of such care in the media have heightened their anxiety regarding such a fate.

Pamela's experiences of living in a residential home for over 15 years suggest dissatisfaction with the care she receives, though interestingly she would still not want to move elsewhere if such an option was possible. This suggests the importance of the 'familiar' and 'routine' for older people who have lost their hearing and sight. However, it was clear that she was frustrated by her lack of power and 'voice' within the home compared to how she perceived things to have been when she first came. It is difficult to speculate about problems in the home and why they have emerged in recent years. However, Pamela's hearing and sight have deteriorated over that time and it might be that staff

have failed to recognise or respond to her changing needs, and this has resulted in her increasing isolation and loneliness. Certainly, professionals at the RTD felt that training issues for staff in residential homes was a problem for many; some solutions were suggested:

RTD Feedback. *“One service carries out in-house training at nursing/residential homes. In one instance they played a DVD to generic staff where deafblind people spoke of their experiences. Generic staff were apparently shocked and challenged by this.”*

RTD Feedback. An issue is that the staff are poorly paid, and so staff retention is poor. One solution would be to pay care staff more so that they stay and build a relationship with service users and therefore get to know individuals' communication needs.

Views of the participants' families

Though it was a small dataset, the data from interviews with the families gave an indication of how much support they give to the participants on a daily basis. There were various issues that would relate to carers generally, e.g. the need for respite care, and advice and support about the caring role, but an issue particularly relevant with this older group is that the spouses were themselves vulnerable to aging and complications of deteriorating health and disabilities. It was clear that the participants in the study who had spouses had more comprehensive care and companionship, and appeared happier than those who lived alone. However, there was a feeling that this support was delicately balanced because at any point it could be reduced or taken away. This anxiety was expressed by a number of participants but most clearly realised by participants who had recently suffered bereavement of loved ones.

Professionals' views of services

Although the sample of only nine professionals is small, the responses illustrated that they had a range of ways of managing caseloads and making use of registers of deafblind people.

The professional respondents provided the research team with a list of the different services they aim to provide. Positively, these services mirror many of the issues and needs raised in the interviews with the participants with hearing and sight loss. The difficulty may therefore be that time and resources are not sufficient for the professional to adequately assess the needs of, or provide the resources for, each person in the depth that is required. Some of the professionals felt frustrated because this was all they could manage.

Awareness training of staff in allied sectors was also seen as an important role (e.g. for generic staff in day centres, residential homes, and hospitals).

However, scarce resources and clients who need potentially high levels of support meant that professionals felt unable to carry out this work very often.

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