

Health and Social Care Committee

Inquiry into residential care for older people

RC42 – Sense Cymru



December 2011

Health and Social Care Committee

Inquiry into Residential Care for Older People

Submission of research into hearing and sight loss in care home residents

About Sense Cymru

Sense Cymru is the leading charity that supports and campaigns for children and adults who are deafblind in Wales. We provide expert advice and information as well as specialist services to deafblind people, their families, carers and the professionals who work with them. Sense Cymru provides community services, including communicator-guide services, in many areas of Wales, working closely with local authorities who commission these services. The majority of those using these services are over the age of 65.

Deafblindness is a combination of both sight *and* hearing difficulties. Most of what we learn about the world comes through our ears and eyes, so deafblind people face major problems with communication, access to information and mobility. People can be born deafblind, or become deafblind through illness, accident or in older age.

The research

We would like to submit to the committee a recently published report of research carried out by Sense and the University of Birmingham and funded by Bupa Charitable Giving. A full copy of the research report is attached. The project looked at the needs of older people who have combined hearing and sight loss and who live in residential homes, and the training needs of the care staff who work with them. Staff involved in the research and dissemination of the results in the care home sector would be happy to give oral evidence to the committee about the findings.

Phase I of the project developed the use of a screening tool in care homes to identify residents with combined hearing and sight loss. The key aims of Phase II were to explore the needs and circumstances of a sample of older residents identified as potentially having both sight and hearing loss, and to assess the training needs of the residential care home staff who work with them. In Phase III the information gathered will be used to develop training and development materials for staff and care workers in residential homes.

Key issues arising from the findings

- The large number of people who were not included because they were considered unfit to consent is of concern because of the possible interaction between perceived dementia and difficulty in communicating due to combined hearing and sight loss.
- The concept of combined hearing and sight loss was broadly unfamiliar to both staff and residents.
- Many residents with hearing loss had difficulty in communicating against background noise.
- Simple strategies to help people with combined hearing and sight loss to manage, such as a loop system, large print newspapers, and different coloured plates could help.
- Many residents were unaware of when they had last seen, or would next see, a clinician. Staff also need to follow up medical appointments to ensure residents understand what has been said.
- Few homes, and therefore residents, had any contact with voluntary organisations related to hearing or sight loss, or the services and support they could provide.
- It was difficult to include residents with combined hearing and sight loss in the community life of the home, although this was not always attributed by the individuals to their combined sensory loss.
- While residents were appreciative of the efforts of staff for their care, staff had little training in sensory loss (particularly combined sensory loss), and were often too busy to spend much time with residents.

Sense Cymru has also submitted wider ranging evidence jointly with RNIB Cymru and Action on Hearing Loss Cymru.

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**UNIVERSITY OF
BIRMINGHAM**



**The Identification and Assessment of the Needs of Older People with Combined
Hearing and Sight Loss in Residential Homes**

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4th November 2011

Funded by Bupa Charitable Giving

**Research report prepared for Bupa Charitable Giving on Phase I and II of the
project**

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Acknowledgements

We would like to thank all those who helped us to prepare this report, most particularly those older residents from residential homes who talked to us about their lives in the perspective of sensory loss. We would also like to thank all those care staff who facilitated the screening process, the consent process for residents, and arranged for interviews, as well as those who were kind enough to talk to us about their own views. We are grateful to the project Steering Group for their support and encouragement and to Bupa Charitable Giving for funding this project.

Note on terminology

The term *resident* is used here for those older people who lived in residential homes.

The word *carer* is used in most cases for staff who work in those residential homes, although more specific terms related to job roles are used where these are relevant.

Final Project Report: The Identification and Assessment of the Needs of Older People with Combined Hearing and Sight Loss in Residential Homes

EXECUTIVE SUMMARY

Aim and overview

This report presents the results and discussion from two phases of a project based on the needs of older people who have combined hearing and sight loss and who live in residential homes, and the training needs of the care staff who work with them. It was carried out by Sense and the University of Birmingham and funded by Bupa Charitable Giving.

Phase I of the project developed the use of a screening tool in care homes to identify those residents with combined hearing and sight loss. The key aims of Phase II were to explore the needs and circumstances of a sample of older residents identified as potentially having both sight and hearing loss, and to assess the training needs of the residential care home staff who work with them. In Phase III the information gathered will be used to develop training and development materials for staff and care workers in residential homes.

Phase I

Phase I (completed by Sense researchers) developed a screening tool based on one originally used in Scandinavia that aimed to identify awareness of hearing and sight loss in older people.

The screening tool contains three sections (A, B and C). Part A includes questions related to a carer's assessment of the resident's hearing and visual functioning. Part B and C are aimed at the resident and ask (B) two summative questions about their sight and hearing, and (C) questions related to everyday functioning that is possibly affected by hearing and sight loss.

Care homes within the Birmingham area were contacted to be part of the screening phase of the project. From 121 homes in this area, 13 homes agreed to take part (only eight were included in the end), and the total number of residents within these homes (according to the Care Quality Commission website) was 651. Visits were arranged to meet with the care home managers and care staff to explain the project in detail. All residents who wished to take part and whom staff considered competent, were included, with each resident also giving individual consent. 89 of the screening tools were returned, with 69 of these giving sufficient data in relation to sight and hearing loss. Of these 69 respondents, 25 were identified as having both hearing and sight difficulties.

Discussions with care staff in the homes suggested that the tool was easy to use. Analysis of the use of the tool however suggested several potential areas for further development. These included

- finding out why residents and carers do not identify difficulties consistently with one another (staff and residents frequently did not match in their perceptions of sensory loss)
- rewording sections to make answers potentially less ambiguous
- removing questions which did not discriminate between hearing and sight loss
- changing the instructions and scoring mechanism to be more straightforward

Phase II

Phase II involved face to face interviews with both residents and staff, in the residential homes in which the residents lived. This was to explore the needs and circumstances of the residents and the training needs of the care staff. Ethical approval was given by both the University of Birmingham's Research Ethics Committee and Birmingham City Council's Research Governance process.

The method chosen for collecting information was the life story interview. This was to enable residents to predominantly talk in the interview, rather than have to listen to and answer multiple, survey-like questions, and to

gather deep and rich information that was not shaped too much by the point of view of the researcher.

14 people identified by the screening phase and who were still willing and able to take part were recruited, and each also gave their individual consent. In addition, nine members of staff were interviewed either face to face or by telephone. Interviews were carefully arranged to take account of sensory loss, and wherever possible were carried out in a quiet room away from background noise. Nevertheless a number of participants required a significantly raised voice from the researcher in order to understand the questions.

Residents' self-perception of their hearing and sight loss

None of the residents said that they were registered as sight impaired. Half said that their lives were not really much affected by sight loss, and some thought that their sight was relatively good, although they had difficulty reading. Just over half reported that a hearing loss was affecting their lives, most often in relation to hearing conversation in crowded environments. Five of them had hearing aids which they used, two had hearing aids but did not use them and seven did not have them at all.

None of the participants talked about having a dual sensory loss or deafblindness – rather, they talked about their sight and hearing loss separately, and none of the participants talked about the compounding difficulties from having both sight and hearing loss.

Most residents were fairly pragmatic about their deteriorating hearing and sight, they considered that sensory loss is simply an unavoidable consequence of getting older and that they just had to adjust. However, some were very clear that their remaining vision was very important to them. Having difficulty hearing people when in group situations also appeared to affect many of the residents. This sometimes had particularly bad consequences since many of the activities provided in the homes were group activities, such as talks, quizzes, and social gatherings. Residents

who wore hearing aids had sometimes had difficulty in getting them appropriately prescribed, or in using them at all.

Accessing information, mental wellbeing and inclusion in the 'community' within the home

Most residents could still read to some degree, though many said that they could not read for long periods. Three had a low vision aid, though one described it as 'useless'. Good lighting was mentioned as essential to be able to read. In general residents kept up to date by watching television, or in some cases, listening to the radio.

About half of the residents described themselves as 'content' although this was sometimes tempered by saying they would rather live at home. Others felt that they had enjoyed busy lives and were not longer able to be active. Family and friends were mentioned by several as key to their enjoyment of present life. Deterioration of sight was a particular worry expressed. Most residents felt that they had some choices and control over decisions made about their life whilst living in the home, though in some cases they were happy to let trusted staff make decisions for them. Others felt however that they had no control, including over when they went in or out of the home.

Half of the participants said that they regularly socialised with other residents, and many had visits from friends and family. Two residents never went out of the home except for medical appointments. Most took part in some activities within the home, although several mentioned the difficulties of hearing in an environment with background noise. Others were not able to take part in activities which required good vision, in particular many missed being able to read.

Mobility, independent living skills, and support from staff within the home and external organisations

Most residents could still walk around although several of them had mobility difficulties related to physical issues and balance as well as possibly to poor

sight. Living in a residential home most were not required to do their own washing or make their own meals, but some did need help with eating and it was not clear whether this related to their sight loss.

Only two residents had seen any outside agencies (apart from clinicians) in relation to sensory loss, and in both cases this was someone from a voluntary organisation for people with sight loss. Neither of these residents had regular contact with the organisation concerned. Most of the residents could not recall their last involvement with clinicians about their hearing or sight difficulties.

Key issues identified from interviews with staff

Nine staff from seven homes were interviewed.

Facilities offered

All residents interviewed lived in single occupancy rooms and all homes where staff were interviewed had at least one communal area. Only one of the homes reported that they had a hearing loop system fitted. Otherwise, none of the homes had any adaptations specifically for people with sight and/or hearing loss (as far as those interviewed were aware). Some used large print notices and one ordered a large print newspaper.

Awareness and understanding of combined hearing and sight loss

Most staff thought they had not met many people with a combination of hearing and sight loss. While noting that hearing and sight loss would be part of an initial assessment process, this was not explored in detail. Some homes had sections in care plans that covered this, others did not. Most said that an optician visited regularly, and that the home referred residents with hearing difficulties to GPs. None of those interviewed were aware that the local authority has a duty to provide an assessment for people with combined hearing and sight loss under the Deafblind Guidance. Staff from

only two homes were aware of local services for people with hearing and sight loss.

Communication with residents with combined hearing and sight loss

All of the residents could still communicate by speech. When asked staff mentioned a range of other communication methods, but they also said that they used clear speech, and four of them mentioned helping residents to care for hearing aids.

Supporting residents in accessing information, their mental wellbeing and inclusion in the 'community' within the home

Most staff said their overall aims were to support residents in being as independent as they could, to include and involve them. This might include reading letters out loud, or adapting activities to include residents with sight and hearing loss. At one home one to one support would be offered for a trip outside the home for a person with sight loss.

Training for staff in hearing and sight loss

Five staff said they had had some training in sensory loss, though sometimes this was generic training. In three cases this was specific training using simulation to mimic eye conditions. Training in the maintenance of hearing aids was much rarer. All but one participant said they would welcome further training in the needs of people with hearing and sight loss and the specific areas they mentioned included; making care plans person centred; information about hearing aids; demonstration of aids to vision.

Issues arising from the study

The large number of people who were not included because they were considered unfit to consent is of concern because of the possible interaction

between perceived dementia and difficulty in communicating due to combined hearing and sight loss. In addition, this group is very under-researched and more information from their perspective, sought in an ethical way, is badly needed.

Secondly, the number identified as having sensory loss by the screening tool was perhaps lower than expected. Some improvements to the tool have been suggested. The concept of combined hearing and sight loss was broadly unfamiliar to both staff and residents.

Thirdly, many residents with hearing loss had difficulty in communicating against background noise. Staff working with audiology departments to try to improve the use of hearing aids could help.

Fourthly, simple strategies to help people with combined hearing and sight loss to manage, such as a loop system, large print newspapers, and different coloured plates could help. The importance of one to one contact was recognised by residents (and by the Deafblind Guidance DOH 2001).

Fifthly, medical and clinical appointments related to hearing and vision are very important in monitoring deterioration in sight or hearing. Many residents were unaware of when they had last seen, or would next see, a clinician. Staff also need to follow up medical appointments to ensure residents understand what has been said.

Sixthly, few homes, and therefore residents, had any contact with voluntary organisations related to hearing or sight loss, or the services and support they could provide.

Seventhly, it was difficult to include residents with combined hearing and sight loss in the community life of the home, although this was not always attributed by the individuals to their combined sensory loss.

Finally, while residents were appreciative of the efforts of staff for their care, staff had little training in sensory loss (particularly combined sensory loss) and were often too busy to spend much time with residents.

Final Project Report: The Identification and Assessment of the Needs of Older People with Combined Hearing and Sight Loss in Residential Homes

Background

This project was a co-operative study between the University of Birmingham and Sense (the voluntary organisation for deafblind people). It was funded by Bupa Charitable Giving in response to their own development in relation to older people in care homes. It was intended to explore the lives of older people with combined loss of hearing and sight who live in care homes. This group has not been widely present in previous research in this field. The first two phases of this project took 18 months, Sense was responsible for Phase I and III and the University of Birmingham for Phase II.

Literature and rationale

Dual sensory impairment – the impairment of both hearing and sight - is an area of relatively little research. Although the biggest cause of hearing and sight loss in the UK is related to ageing, there is less written on acquired hearing and sight loss than on congenital dual sensory impairment. The first conference (following some shorter symposia) of the Acquired Deafblindness Network was in 2009 but at this four day event, only five papers were specifically aimed at working with older people. Few of these were evidence based.

People who have combined hearing and sight loss are more likely to have difficulties with communication, with mobility and travel and with access to information (DoH 1997). These have a serious impact on an individual's ability to complete tasks in the community or their residences, such as shopping, cooking or answering mail, to socialise with community groups, to entertain visitors in their homes, or be entertained in others' homes, to talk to others by phone or letter as well as in person, to manage their own finance or benefits, or health and treatments, or to arrange for others to help them with these tasks. As such, people with this combined loss are at

risk of isolation, deprivation of independence and confinement in their homes or rooms.

Older people are more likely than younger people to have combined hearing and sight loss (Saunders and Echt 2007). Sense (2010), working on RNIB and RNID figures, suggested that nearly 9% of people over 60 have a sight loss, and 55% of people over 60 have a hearing loss. The Department of Health (1997) published '*Think Dual Sensory*' in response to growing concern about the needs of the increasing number of older people with combined hearing and sight loss. This was followed in 2001 by Social Care for Deafblind Children and Adults (DoH) which outlined the particular needs of people, including older people, who had both hearing and sight loss, and gave substantial guidance on the obligations of local authorities towards identifying and providing for them.

Previous research into older people with combined hearing and sight loss has shown that their lives are complex and that they are more at risk of additional problems than those with single sensory impairments. For example, they are more likely to suffer falls (Grue et al 2009) and more likely to have other physical and emotional health problems (Fischer et al 2009). The use of measures of ability to maintain daily life routines and everyday tasks has shown that people with sight loss are particularly more likely to have difficulty than people of similar ages without sight loss and that additional hearing loss increases this difference for some tasks (Brennan et al 2005). While sight loss affects physical abilities and the tasks dependent on these (such as cleaning or posting letters) hearing loss has a greater effect on involvement in social activities. The combination of these can therefore be expected to affect a wider band of life activity than a single sensory loss (Jang et al 2003).

Bodsworth et al (2011) reported that significant proportions of those dual sensory impaired people who responded to their survey (of whom almost two thirds were older than 66 and more than half were over 76 years old) showed high levels of psychological stress and depression. Depending on the criteria used in relation to the data, either half of them, or two thirds of them could be considered depressed. This is likely to be related to the degree of isolation and the lack of independence and control which follow

loss of hearing and sight. The measures of independence and emotional wellbeing as mentioned above are usually derived by psychological testing. While such evidence is valuable, it misses the personal perspective of people who have both hearing and sight loss.

Pavey et al (2008) investigated the impact of combined hearing and sight loss on older people from their own perspective. As these people (aged between 58 and 92 but averaging in their 80s) described their lives, the themes of problems with health, with communication, with accessing information and with leaving their home emerged, along with their limited inclusion in social activities, medical services and support. Only one of the 20 participants lived in a residential home. She felt that the staff did not understand the particular problems of people with combined sensory loss and reported that she was not able to join in with many activities because they were not adapted for those with sensory difficulties. Other participants, who lived at home, voiced their opinions strongly against moves into residential care.

In the residential care setting, Tester et al (2003) explored older people's perceptions of their own quality of life, including those of residents who had serious communication problems including dementia. They reported strongly that a 'sense of self' and some autonomy was important to residents, along with an ability to communicate whether in speech or not. Through their communication and control they could maintain relationships and participate in activities and exercise some independent control in their lives.

Resnick et al (1997) looked at the effect of sensory loss on the involvement of residents in nursing homes in activities and social occasions. Hearing loss meant that residents spent less time in activities, and difficulties in hearing, sight (or communication) showed strong associations with low levels of social engagement and the amount of time spent in activities. Combined hearing and sight loss increased the likelihood of such poor outcomes.

However, according to data from the Alzheimer's Society many people who live in residential homes have problems with dementia. In relation to

sensory impairment, dementia is seen as having an effect both on an increase of problems (e.g. Skove Udall et al 2009) and also on lower rates of identification of sensory loss.

The current project grew out of the recognition that the circumstances of older people with combined hearing and sight loss in residential care might be different and distinct from those living in the community. In 2007, Sense published 'Seeing me' which included advice for those working in care homes for older people, on matters such as service user plans, keeping social contact and providing specialist equipment. However, there was no evidence based research about the identification of the needs of this specific group. Identification had already been recognised as a difficulty for those in the community. In the USA (Horowitz 1994) showed that older people in care were not always tested for visual impairment, and sometimes confusion and difficulty in managing were attributed to dementia and there was no checking for sensory loss. The first stage of this project was designed to see if it was possible to identify combined sensory loss in older people relatively simply. The second stage was to explore the lives of those who were identified as having combined hearing and sight loss through their own perspective, and to examine the training needs of staff. The final phase will relate to responding to these staff training needs by devising training and development materials for care staff in residential homes.

Ethical issues

The ethical issues which were likely to be raised by the project included: the ability of vulnerable older people to give consent; the anonymity and confidentiality of participants and participant organisations; the issues raised by residents in relation to their combined hearing and sight loss.

Since the project would be based in care homes largely in the Birmingham area, consent was sought from the appropriate bodies to carry out the research. The individuals then identified were also asked for their specific consent. In this instance the appropriate bodies were the University of Birmingham Research Ethics office and the Birmingham City Council's Research Governance process. The project was therefore examined by two very informed and experienced bodies and additional material was supplied as requested. Both bodies accepted that their ethical conditions were met.

In seeking permission with individual residential homes, key criteria were put in place. This project was seeking to inquire of people themselves their perceptions of their lives; and in relation to both integrity of collected evidence and to appropriate participation, those who were not able to give fully informed consent were excluded from the evidence related to the identification questionnaire and from the detailed interviews. It was recognised from the beginning that this excluded the group who might indeed have the most acute and possibly unmet needs; those who had dementia in addition to hearing and sight loss, or those who were considered to have dementia when in fact their difficulties were related to sensory loss. This is a group which is very hard indeed to research. In this case individuals were asked to give their informed consent and consent arrangements were made by letter, which was sized appropriately or read to the potential participant. Staff who took part were similarly asked to give their consent to taking part in the discussions.

Any information that has been shared during the course of the project and any information that is subsequently used will fully protect the identity and

confidentiality of the participants involved, and to this end the research team have been following the Data Protection Act of 1998.

Phase I

Sense is a national charity that supports children and adults who have both hearing and sight loss. Sense provides expert advice and information as well as specialist services for people with hearing and sight loss, their families, carers and the professionals who work with them. Sense constantly strives to improve services and develop innovative approaches to meeting needs.

Bupa Charitable Giving awarded a grant to Sense to carry out a research project entitled 'The identification and assessment of the needs of older people with both hearing and sight loss in residential homes.' The project was developed and undertaken in conjunction with the University of Birmingham. The project was divided into three phases; Phases I and III were undertaken by Sense and Phase II by the University of Birmingham. The underlying aim of all three phases of the project is to develop an assessment tool which will help care homes to identify and assess the needs of their residents in relation to hearing and sight loss. Bupa and Sense are particularly engaged with this project because those who live in care homes may already be isolated and hearing and sight loss can have a further serious impact on communication and social interaction, that may make residents more socially and emotionally isolated and have a negative impact on their confidence, independence, and ability to carry out daily living activities.

Phase I of the project was intended to develop the use of a screening tool in care homes to identify those residents with hearing and sight loss. It was anticipated that this tool would be used with all the residents in a care home, except those with dementia. Staff would be provided with a series of questions which they had been shown how to use, and they would ask residents to respond. Care staff would also answer some questions themselves.

In Phase II the University of Birmingham explored the needs of those residents identified in Phase I as having combined hearing and sight loss through the use of one to one interviews with residents and through some discussion with care staff. This included some discussion of training needs.

Phase III of the project (yet to be undertaken) will involve Sense responding to these training needs by devising training materials for care staff in the participating homes.

Steering Group

A Steering Group was established at the outset of the project and was made up of members of the research team at Sense, the research team at the University of Birmingham and the Head of Research from the Thomas Pocklington Trust. During Phase I of the project the Steering Group met four times where the group provided expertise and guidance for the project and progress was reported. The project team also met separately in between the Steering Group meetings to deal with any queries emerging from each of the phases of the project.

Screening Tool

Svingen and Lyng (2006) developed a screening tool which was used to identify older adults with both hearing and sight loss. As the tool had already been piloted and used in Norway it was therefore selected for use in Phase I of the project, and other changes were made for this project. Even though the tool had already been translated into English some changes to the wording still had to be made to make grammatical sense in English.

The original screening tool (Svingen and Lyng 2006) was a questionnaire that consists of two parts. Part A of the tool was designed to be completed by a member of staff/carer who knows the individual and consisted of seven questions relating to hearing and seven questions about sight. In Part B, the older person/resident was asked about their hearing and sight but this was completed only if the carer's scoring suggested that the resident could potentially have both hearing and sight loss.

The tool was further developed for this project by researchers from Sense. Particular modifications in terms of language and grammar needed to be made to Svingen and Lyng's tool before it could be used in residential homes in the UK. For residential homes to take part in the study, the tool would need to be fairly quick and easy to use. This was achieved by dividing the adapted tool into three parts to provide additional data and a summative question about hearing and sight loss was added.

The Network 1000 project (Douglas et al, 2006) questions were used to form additional questions to the section related to sight loss and a similar approach was used to add questions for hearing loss. These questions were specifically focused on a residents day to day activities and if these were at all affected by any issues relating to a residents hearing and sight.

Written instructions for using the screening tool were provided at the beginning of the tool. The care staff who completed part of the assessment for each resident then added up the total number of positive responses and so ascertained whether combined hearing and sight loss could be present

so that they could then refer the resident for a further assessment to a health professional.

The original Svingen and Lyng tool was designed to be completed by a carer, and scored by the carer. If an older person was scored by the carer as having two difficulties as outlined, then the person was asked about their own perception of their difficulties. In the adapted tool, **all** eligible residents were asked all the questions, whether or not care staff considered they had difficulties related to hearing or sight loss. The judgements of both care staff and resident could then be compared. The differences between carer's judgements of a resident's hearing and sight loss and the resident's judgement of their own hearing and sight loss will be discussed later.

The adapted screening tool which was used in the project contains three parts (A, B and C) each of which contains a series of questions linked to the resident's hearing and visual functioning. Part A includes questions related to a carer's assessment of each resident's hearing and visual functioning (seven and eight questions respectively). In contrast, Part C includes questions for the resident related to everyday functioning as possibly affected by hearing and sight loss (seven questions each). Part B includes two summative questions about sight and hearing difficulties which are aimed at the resident ("How do you assess your vision compared to other people of your age?" and "How do you assess your hearing compared to other people of your age?").

The rationale for having a part C was primarily to separate questions on functional ability so that the tool was easy to use. The additional questions were added to provide a better understanding of what the resident could and could not do day to day. Part A was completed by the carer/nurse/member of staff who usually worked with the resident, and parts B and C were completed with the resident present and reflected the resident's own perception of their hearing and sight. In this study, all parts were used with all eligible residents.

No scoring table was included in the adapted tool because this could have influenced the validity of the tool by suggesting which answers would

receive positive responses if the resident did indeed have sensory loss. It was however scored by adding up positive responses suggesting sensory loss. A certain number of positive responses were considered to represent the likelihood of combined sensory loss. The criteria for inclusion in Phase II of the study are presented on page 27.

Before approaching the care staff in the homes the adapted tool was piloted with employees of Sense who had a range of communication styles. This was to explore whether the questions made sense, whether any further changes needed to be made to the wording of the questions, and also to establish how much time per resident would be needed to complete the tool. This would then enable the staff in the care homes to have a better idea of how long it could potentially take to complete the tool with their residents.

All participants in the pilot were Sense staff. One participant had no reported hearing or sight problems, the second had severe visual impairment and a mild to moderate hearing impairment in one ear and wore a hearing aid. The third had Congenital Rubella Syndrome and used British Sign Language (BSL) to communicate and the fourth also had Congenital Rubella Syndrome and used Tadoma (a communication method where the 'listener' touches the speaker's face to gain information from vibrations, motions of the jaw and facial expressions). For each participant the tool took between 5- 20 minutes to complete.

Recruitment

Care homes within the Birmingham area were contacted, because Phase II of the project would be conducted by the University of Birmingham. Birmingham, as a major city, presented with a range of different types of care home; run by the local authority, the voluntary sector, and private organisations. The interviews would then not involve great distances to travel, thus enabling as many interviews as possible to be carried out. The project could have expanded beyond Birmingham if there was an insufficient response in the Birmingham area.

An initial search on the Care Quality Commission directory on the web, using the search terms 'older people', 'care homes' and 'Birmingham and West Midlands' identified 121 care homes in the voluntary, local authority and private sectors. All of these homes were then contacted via letter highlighting the aims and rationale for the research and what their involvement would be if they decided to take part in the project. Only four homes responded. Following this, the remaining homes were then contacted individually by phone with the intention of recruiting homes from each of the three categories: local authority, private and voluntary, so that there was a balance in the type of homes that would be taking part in the research.

In a number of cases it was quite difficult to get hold of the care home managers and several messages were left with staff members who were unable to make such decisions, so a request to call back at a more suitable time was suggested. On a couple of occasions the care homes were in the process of closing due to funding constraints so were unable to give their consent to take part but expressed an interest that they would have liked to be involved had the circumstances been different.

Whilst those homes willing to take part frequently expressed keen interest, many also refused, for a number of reasons including that;

- they were currently focusing on other priorities
- they were very busy and could not commit the time needed
- they had participated in research before and had never received any feedback on what the outcome of their participation had been, so were very reluctant to participate in research again
- their residents would not cooperate
- the home did not have anyone who had both combined hearing and sight loss.

The most common reason that was given was the homes were unable to agree as all their residents had been identified or diagnosed as having dementia so would therefore be unable to give their informed consent to take part in the project.

Although the research team did anticipate that this would be an issue at the outset the number of homes in which this was reported to be the case was unexpected.

After making calls to the care home managers, 13 homes agreed to take part in Phase I. The total number of residential places across these homes was 651. These included one local authority home, nine private homes and three run by a voluntary organisation.

Visits were arranged to meet with the care home managers and care staff to explain in person and in further detail the purpose of the project, followed by an explanation on how to use the screening tool. Dates for the return of the completed questionnaires (the screening tool) to Sense were agreed. Staff were asked to look through the tools and raise any questions that they had with the research team. The homes were provided with a consent form, a questionnaire form for each resident and pre paid envelopes in which to return the questionnaires to the research officer at Sense.

It was emphasised to staff that for each resident that wished to take part, written consent was required and that no information could be used if the resident did not give their written consent. The written consent form needed to be returned, along with the completed tool. The staff and the residents were also given contact details of the researcher for any further queries or if questions emerged after the visit, and they were encouraged to call or email if they needed to ask anything about the tool, the research project, their participation, the process and anything else that they wished to discuss relating to the project.

Feedback from care home staff regarding the screening tool

Once all the screening tools had been returned the care home managers/staff were contacted to follow up on what their experiences of the tool had been. Of the homes that took part in Phase I, four homes responded (and the rest were not able to be contacted). They were asked to comment on the following questions in relation to the screening tool: Was the tool easy to use? Were the instructions clear? Was there anything you particularly liked/disliked regarding the content? Do you have any other comments?

Overall the responses that were given to the questions asked regarding the use of the tool were positive, identifying no problems in using the tool and reporting that residents found it easy as well.

A more detailed analysis of the tool itself is discussed later.

The interviewer for Phase II also discussed the tool briefly with some care home managers. Overall they felt that the tool was easy and simple to use, that it did not take long to complete and that the questions were easy to understand. Any development of the tool for screening in care homes needs to make sure these points are considered, and this report makes suggestions on how to do this.

Data

Of the 13 homes that gave their consent to take part, 89 tools were returned from eight homes. These represented one home run by a voluntary organisation, one by a local authority and six private homes. There would have been a potential of 313 residents had they all been able to take part. The remaining five homes who had agreed to participate were contacted and reminded to return any completed tools. One of the homes had since changed management so the care home manager who had originally agreed to take part had now moved on and no data was received from them. Another home had said that upon reflection none of their residents had actually wanted to take part and the remaining three homes simply did not return any of the tools. This meant that of the original potential 651 residents that could have taken part from 13 homes, only 8 actually took

part and returned the completed tools, thus drastically reducing the potential number of residents within these homes to 313. This did not take into account the number of residents who actually could not take part due to a lack of capacity. The table below highlights the actual number of residents within the homes and the number who could not take part due to a lack of capacity.

Table: Details of the homes that took part in Phase I.

Residential Home, home number signifies the order in which the tools were returned	Type of home (P=Private, V= Voluntary and LA= Local Authority)	Number of residents in residential home	Number of tools returned	Number who could not take part
Home 1	P	22	7	15
Home 2	P	30	14	16
Home 3	P	20	8	12
Home 4	P	50	9	41
Home 5	P	15	3	12
Home 6	V	65	17	48
Home 7	LA	64	28	36
Home 8	P	47	3	44
Total		313	89	224

Of the 89 screening tools that were returned 20 could not be used as the residents had not given their consent, although the carer had still completed and returned part A of the tool (the staff member's perception of the residents hearing and sight loss).

Of the data received 22 respondents were male, 66 were female and one resident did not report their gender. The age range of the residents spanned from 59 years to 103 years of age. Once received, all the data was

entered into a spreadsheet which was only accessible to the designated members of the research team within Sense and the University of Birmingham.

The scores from the data were then added up (see analysis following) to ascertain which residents were likely to have combined hearing and sight loss. These residents would then be interviewed for Phase II. Two possible threshold levels for the identification of combined sensory loss were used, a liberal and a conservative scoring threshold. In the conservative threshold, a resident was judged as presenting with a possible combined hearing and sight loss if they had three positive responses from either carer or resident in relation to both hearing *and* sight difficulties. In the liberal threshold, two positive responses in relation to both hearing and sight difficulties were required. More details are given below. Some residents were therefore identified as having possible combined hearing and sight loss by both themselves and a carer; some by only a carer, some only by themselves, and of course, some had no positive responses related to hearing or sight difficulties either by the residents themselves or by care staff.

On the conservative criteria 17 people were identified as having hearing and sight loss whilst by the liberal criteria there were 25 people. All of these 25 people were contacted in relation to Phase II; more details are given on page 27.

A detailed explanation of the scoring methods (conservative and liberal) is discussed in detail later.

Analysis and reflection upon Phase I data

This part of the report presents a summary of the scoring of the data collected in relation to 89 older people living in care homes.

Overview of the scoring of parts

Carer assessment (Vision)

Questions V1 to V7 (Part A) of the vision-related questions are in relation to visual functioning (e.g. “V2: S/he has trouble reading the newspaper”). The carer was required to answer ‘yes’ or ‘no’ to each question. A simple scoring system (yes = 1, and no = 0) led to an aggregate score from 0 to 7. Question V8 assessed the use of vision related aids (e.g. magnifiers, canes). While this is important information, it is not the same as visual functioning (rather, it is related to an intervention). For this reason question V8 was not included in the aggregated score. The tables below summarised the question responses, as well as the aggregate ‘Vision (Carer)’ score (out of seven).

Table: Responses to the individual vision (carer) questions (N=88)

Question	% Yes
V1. S/he will not recognise you when you come into the room unexpectedly	37%
V2. S/he has trouble reading the newspaper (e.g. holding the newspaper very close)	33%
V3. S/he has trouble watching the television (e.g. sitting very near the screen)	24%
V4. S/he needs help to find items that are relatively close	24%
V5. S/he has trouble telling the time because it is difficult to see the face of a standard sized clock/watch	34%
V6. S/he needs to be accompanied when moving around outdoors and in unfamiliar places	60%
V7. S/he has complained about difficulties relating to poor sight	25%
V8. S/he has been assigned one or more aids for impaired vision (e.g. glasses, screen magnifier, magnifying glasses, cane, extra lighting)	87%

Table: Breakdown of the frequencies for the aggregated vision (carer) score (N=88)

Score	N	%	Cumulative %
7 (100%)	4	5%	5%
6 (86%)	8	9%	14%
5 (71%)	8	9%	23%
4 (57%)	3	3%	26%
3 (43%)	9	10%	36%
2 (29%)	13	15%	51%
1 (14%)	27	31%	82%
0 (0%)	16	18%	100%

The tables highlight that V6 ('needs to be accompanied...') and V8 ('assigned one or more aids for impaired vision...') score relatively highly. In terms of V8 this is encouraging as it suggests that many people do (in theory at least) take actions to account for sight loss. In terms of V6, it is possible that 'yes' responses to this question may have been in general terms and not just related to sight loss. Therefore re-drafts to the screening tool might usefully look to modify this question (e.g. add some reference to difficulties with sight) or drop it all together.

Question V1 is phrased as a negative style ("S/he will not recognise you when you come into the room unexpectedly") and therefore the meaning of a 'yes/no' reply is uncertain. Replacement with "S/he has difficulty recognising you when you come into the room unexpectedly" (or similar) may be useful.

The cumulative percentage gave an indication of the proportions of residents judged by carers to have difficulties with different sight-related tasks. For example, approximately half (51%) of the residents sampled (N=88) were judged by carers to have difficulty with two or more of the vision-related tasks. Similarly, approximately a quarter (26%) of the residents sampled were judged by carers to have difficulty with four or more of the vision-related tasks.

Carer assessment (Hearing)

Questions H1 to H6 (Part A) of the hearing-related questions were in relation to hearing functioning (e.g. "H2: S/he cannot hear you knock on the door or ring the bell"). A 'yes/no' answer as before, gives an aggregate score range from 0 to 6. Question H7 assessed the use of hearing and related aids (e.g. hearing aids, induction loop), and this important information related to intervention, not hearing loss itself, so it is not included in the aggregated score. The tables below summarise the question responses, as well as the aggregate 'Hearing (Carer)' score (out of six).

Table: Responses to the individual hearing (carer) questions (N=88)

Question	% Yes
H1. S/he cannot hear you knock on the door or ring the bell	23%
H2. You need to speak particularly loud and/or slowly, or repeat yourself so that s/he will hear what is being said, although it is quiet around you	24%
H3. S/he finds it difficult to understand what you say when there is noise in the room (e.g. the radio is on, noise from the vacuum cleaner, traffic noise etc)	47%
H4. S/he has difficulty keeping up with the conversation, when there are several people talking	41%
H5. S/he has difficulty in understanding what is said on the radio or television unless the volume is turned up	31%
H6. S/he has complained of difficulties with poor hearing	22%
H7. S/he has been assigned one or more aids for hearing impairment (e.g. hearing aids, induction loop, voice amplifier, light signal or vibrator connected to the doorbell, telephone or alarm clock)	47%

Table: Breakdown of the frequencies for the aggregated hearing (carer) score (N=88)

Score	N	%	Cumulative %
6 (100%)	0	0%	0%
5 (71%)	11	13%	13%
4 (57%)	13	15%	28%
3 (43%)	10	11%	39%
2 (29%)	6	7%	46%
1 (14%)	12	14%	60%
0 (0%)	36	41%	100%

These tables highlight that H3 ('difficult to understand what you say when there is noise in the room...') and H4 (difficulty keeping up with the conversation, when there are several people talking') score relatively highly and perhaps discriminate people particularly well. Question H7 ('assigned one or more aids for hearing impairment...') also scored relatively highly. This is encouraging as it suggests that many people do (in theory at least) take actions to account for hearing loss.

The cumulative percentages give an indication of the proportions of residents (as reported by carers) that have difficulties with different hearing-related tasks. For example, approximately half (46%) of the residents sampled (N=88) were judged by carers to have difficulty with two or more of the hearing-related tasks. Similarly, approximately a quarter (28%) of the residents sampled were judged by carers to have difficulty with four or more of the hearing-related tasks. This distribution seems to be similar to that for the vision-related questions.

Question H1 is a negative phrased question which could lead to confusion with yes/no answers and a replacement such as 'S/he has difficulty hearing a knock on the door' could help.

Resident assessment (Vision)

Questions V1 to V7 (Part C) of the vision-related questions were all in relation to visual functioning (e.g. "V1: Can you read standard print in newspapers/books?"). There were three challenges when scoring these questions. Firstly, the resident was given a choice to answer each question in one of the following ways (taking question V1 as an example):

- 'Yes'
- 'Yes often'
- 'Yes sometimes'
- 'No, I cannot read newspapers/books'
- 'Don't know'

With the benefit of hindsight the scale is a little ambiguous, and 'Yes' was taken to mean 'Yes, always'.

A second challenge was that questions V4 to V7 ask 'negative' questions; such that an affirmative answer would imply poorer vision (the reverse is true for V1 to V3). Therefore, when aggregating these questions with V1 to V3 the scores needed to be reversed, for example, 'yes' or 'yes often' scores 1 for questions 4-6 but for questions 1-3 it scores 0. 'Yes sometimes', 'no', and 'don't know' score 1 for questions 1-3 but 0 for questions 3-6..

A third challenge is related to V7. The current draft of the questionnaire allowed the resident to answer either 'Yes' or 'No' (i.e. different to the response options for the other six questions). For all the above reasons a standard way was chosen of categorising residents as having sight-related difficulties for each question which is presented in the Table below:

Table: Scoring method for individual vision (resident) questions (V1 to V7)

Question	Not Vision difficulty	Vision difficulty
V1. Can you read standard print in newspapers/books?	'Yes' 'Yes often' 'Don't know'	'Yes sometimes' 'No'
V2. Do you see well enough to write a letter, complete a form?	'Yes' 'Yes often' 'Don't know'	'Yes sometimes' 'No'
V3. Can you read the subtitles on the television or films?	'Yes' 'Yes often' 'Don't know'	'Yes sometimes' 'No'
V4. Is it difficult to recognise people you see unexpectedly? [Reversed]	'Yes sometimes' 'No' 'Don't know'	'Yes' 'Yes often'
V5. Do you bump into objects, door frames, furniture etc? [Reversed]	'Yes sometimes' 'No' 'Don't know'	'Yes' 'Yes often'
V6. Do you find it difficult to see objects if they have been moved from their usual place? [Reversed]	'Yes sometimes' 'No' 'Don't know'	'Yes' 'Yes often'
V7. Is there anything you used to do that you no longer can do, or that you are prevented from doing as a result of your vision loss? If so what? [Reversed]	'No' 'Don't know'	'Yes'

Using this formula, the tables below summarise the question responses, as well as the aggregate 'Vision (resident)' score (out of seven).

Table: Responses to the individual vision (resident) questions (N=69)

Question	% Vision Difficulty
V1. Can you read standard print in newspapers/books?	41%
V2. Do you see well enough to write a letter, complete a form?	42%
V3. Can you read the subtitles on the television or films?	39%
V4. Is it difficult to recognise people you see unexpectedly? [Reversed]	23%
V5. Do you bump into objects, door frames, furniture etc? [Reversed]	4%
V6. Do you find it difficult to see objects if they have been moved from their usual place? [Reversed]	16%
V7. Is there anything you used to do that you no longer can do, or that you are prevented from doing as a result of your vision loss? If so what? [Reversed]	23%

Table: Breakdown of the frequencies for the aggregated vision (resident) score (N=69)

Score	N	%	Cumulative %
7 (100%)	0	0%	0%
6 (86%)	4	6%	6%
5 (71%)	6	9%	15%
4 (57%)	7	10%	25%
3 (43%)	8	12%	37%
2 (29%)	6	9%	46%
1 (14%)	12	17%	63%
0 (0%)	26	38%	100%

The table highlights that V4 to V7 (the reversed questions for scoring) score relatively low (compared with V1 to V3). Question V5 ('Do you bump into objects, door frames, furniture etc?') scored extremely low (only 4%). It therefore does not discriminate residents effectively and might be dropped or replaced in future drafts of the questionnaire.

The cumulative percentage gives an indication of the proportions of residents who judged themselves as having difficulties in different vision-related tasks. For example, approximately half (46%) of the residents sampled (N=69) judged themselves to have difficulty with two or more of the vision-related tasks. Similarly, approximately a quarter (25%) of the residents sampled judged themselves to have difficulty with four or more of the vision-related tasks.

Resident assessment (Hearing)

Questions H1 to H7 (Part C) of the hearing -related questions were all in relation to auditory functioning (e.g. "H1. Do you find it difficult to understand what people say to you?"). Unlike the equivalent vision-related questions, all the questions were in the same direction (i.e. positive responses for all seven questions implied the resident had difficulty hearing). Even so, as with the vision-related questions, the scale was a little ambiguous for H1 to H6, and 'Yes' was again taken to mean 'Yes, always'.

In addition, question H7 in the current draft of the questionnaire allowed the resident to answer either 'Yes' or 'No' (i.e. different to the response options for the other six questions). Again, following the approach taken for the equivalent vision related questions, a standard way of categorising residents as having hearing-related difficulties was used for each question as presented in the Table below:

Table: Scoring method for individual hearing (resident) questions (H1 to H7)

Question	Not hearing difficulty	Hearing difficulty
H1. Do you find it difficult to understand what people say to you?	'Yes sometimes' 'No' 'Don't know'	'Yes' 'Yes often'
H2. Do you find that people speak too quietly or too fast for you?	'Yes sometimes' 'No' 'Don't know'	'Yes' 'Yes often'
H3. Do you find it is difficult to understand what is being said during a telephone conversation?	'Yes sometimes' 'No' 'Don't know'	'Yes' 'Yes often'
H4. Do you find it is difficult to understand what is being said when you are in a group of people?	'Yes sometimes' 'No' 'Don't know'	'Yes' 'Yes often'
H5. Do your hearing difficulties prevent you meeting new people?	'Yes sometimes' 'No' 'Don't know'	'Yes' 'Yes often'
H6. Do you need to turn up the volume on the television/radio?	'Yes sometimes' 'No' 'Don't know'	'Yes' 'Yes often'
H7. Is there anything that you used to do, that you can no longer do or that you are prevented from doing as part of your hearing difficulties?	'No' 'Don't know'	'Yes'

Using this formula, the tables below summarise the question responses, as well as the aggregate 'Hearing (Resident)' score (out of seven).

Table: Responses to the individual hearing (resident) questions (N=69)

Question	% Hearing Difficulty
H1. Do you find it difficult to understand what people say to you?	16%
H2. Do you find that people speak too quietly or too fast for you?	14%
H3. Do you find it is difficult to understand what is being said during a telephone conversation?	23%
H4. Do you find it is difficult to understand what is being said when you are in a group of people?	32%
H5. Do your hearing difficulties prevent you meeting new people?	3%
H6. Do you need to turn up the volume on the television/radio?	14%
H7. Is there anything that you used to do, that you can no longer do or that you are prevented from doing as part of your hearing difficulties?	12%

Table: Breakdown of the frequencies for the aggregated hearing (resident) score (N=69)

Score	N	%	Cumulative %
7 (100%)	1	1%	1%
6 (86%)	0	0%	1%
5 (71%)	3	4%	5%
4 (57%)	4	6%	11%
3 (43%)	3	4%	15%
2 (29%)	10	14%	29%
1 (14%)	12	17%	46%
0 (0%)	36	52%	100%

The tables highlight that H1 to H7 scored relatively low (compared with the vision-related questions). Question H5 ('Do your hearing difficulties prevent you meeting new people?') scored extremely low (only 3%). It therefore does not discriminate residents effectively and might be dropped or replaced in future drafts of the questionnaire.

The cumulative percentage gives an indication of the proportions of residents who judged themselves as having difficulties in different hearing-related tasks. The questionnaire (using the scoring method described above) identified far fewer people with hearing difficulties than the equivalent vision-related questions. For example, approximately a third (29%) of the residents sampled (N=69) judged themselves to have difficulty with two or more of the hearing-related tasks (compared to a half for vision). Similarly, approximately a tenth (11%) of the residents sampled judged themselves to have difficulty with four or more of the hearing-related tasks (compared to a quarter for sight). Interestingly, the same pattern was not found for the carers' assessments (where approximately equivalent numbers of people with hearing and sight difficulties were identified, albeit with a slightly larger sample). This is perhaps surprising given the estimates that up to 55% of people over 60 have a hearing loss (as seen in literature review).

There are several possible explanations for this. Firstly residents may find it harder to assess deterioration in their own hearing function compared to their eyesight (or not judge it to be such a significant difficulty). Secondly, the hearing-related questions in the screening tool questionnaire may not have discriminated very well (i.e. the use of different questions may allow participants to identify difficulties more readily). Thirdly, the (spoken) questionnaire approach to the screening tool may have meant that residents with hearing difficulties were less likely to take part in the study (i.e. a selection bias). There is some evidence for the third explanation (although very speculative). Data was gathered in relation to 89 residents from their carers. However, data was gathered only from 69 of these residents about their own hearing and sight. Analysis of the carer's views of the twenty residents who were not interviewed directly suggest that they appear to have had (as a group) greater difficulties with their hearing than the sample as a whole. However, their exclusion appears to be related to

administrative difficulties at a single care home rather than a systematic bias against interviewing participants with hearing difficulties.

Part B offered another source of comparison data. Part B included two summative questions about vision and hearing difficulties (“How do you assess your vision compared to other people of your age?” and “How do you assess your hearing compared to other people of your age?”). In keeping with the Part C responses, a greater proportion of residents described themselves as having poor vision most of the time (22%) than having poor hearing most of the time (13%).

The relative low numbers in this study means that there is a limit to the analysis which could be carried out . Nevertheless, it seems that the current draft of the questionnaire is less sensitive at identifying people who judge themselves to have difficulty with hearing-related tasks. This might be explored in future drafts.

Criteria for deciding if someone has ‘hearing and sight loss’

The purpose of the screening tool was to give an indication as to whether residents have both hearing and sight loss. There are many alternative criteria that could have been applied using the data gathered in the screening tool, but of centrality is that the resident is judged to have difficulty with hearing *and* vision. Two possible methods were explored – one ‘conservative’ and the other ‘liberal’ – which are described in turn.

Conservative approach

The screening tool recorded two perspectives upon the resident's sight and hearing loss: the carer's and the resident's. Previous sections describe the data which was collected and below the ways in which this data can be combined to identify residents with possible combined hearing and sight loss is described.

- (a) Carer assessment: the resident is judged to have hearing and sight loss if hearing score (carer) *and* vision score (carer) both have greater than three marks. In the case of hearing, this is >3 of 6 (i.e. >50%) – in practice then, it is the score of 4 of 6 or greater (i.e. 67% or more). In the case of vision, this is >3 of 7 (i.e. > 43%) – in practice then, it is a score of 4 of 7 or greater (i.e. 57% or more).
- (b) Resident assessment: the resident is judged to have hearing and sight loss if hearing score (resident) *and* vision score (resident) both have greater than three marks. In the case of sight and hearing this is >3 of 7 (i.e. > 43%).
- (c) Clearly, the carer and the resident assessments provide different scores. Based upon the conservative criteria above, the table below presents the findings for the 69 residents for whom there is full data.

Table: Conservative numbers of residents identified as having hearing and sight loss by carer (Part A), by resident (Part C), or both. (N=69)

Assessments	N	%
Both Carer and Resident	2	3%
Carer Only	11	16%
Resident Only	5	7%
Neither	51	74%
TOTAL	69	100%

Liberal approach

The 'liberal' criteria are the same as the above 'conservative' criteria, except *two* marks on the scale is chosen rather than three (i.e. increasing the number of participants who fulfil the criteria). Based upon the liberal criteria above, the table below presents the findings for the 69 residents for whom there is full data.

Table: Liberal numbers of residents identified as having hearing and sight loss by carer (Part A), by resident (Part C), or both. (N=69)

Assessments	N	%
Both Carer and Resident	7	10%
Carer Only	9	13%
Resident Only	9	13%
Neither	44	64%
TOTAL	69	100%

Reflection upon the screening tool structure

Based upon the conservative criteria described above, approximately a quarter of residents were identified as having hearing and sight loss by their carers, themselves, or both. In fact, carers seem to have been more likely to identify residents as having hearing and sight loss than the residents did themselves, and this appears to be particularly true for aspects of hearing difficulties (residents seemed more reticent to describe themselves as having a hearing difficulty or less likely to recognise it compared to their carers). If the more liberal criteria were used then approximately a third of residents were identified as having hearing and sight loss by their carers, themselves, or by both.

Validity and reliability

One of the reasons for using the screening tool was to identify potential participants for Phase II of the project. Other sections of this report describe the findings of that phase of work and the implications for understanding of the validity of the screening tool.

Nevertheless, the findings presented above suggest that the residents and carers do not identify difficulties consistently with one another. For example, cases four and five are both residents who judged themselves to have both hearing and sight loss (by the criteria outlined here), yet in both cases the carer did not think they have *any* hearing loss (although marked sight loss is noted for both). The project was able to gain some (though limited) feedback from care homes who had piloted the screening tool with those who gave feedback being broadly positive (feeling it was straightforward to use). Nevertheless, by drawing upon the analysis above, the experiences of the project researcher who used the screening tool, as well as a critical review of the screening tool structure and wording, the following broad recommendations are offered for further development.

Screen tool redevelopment and usability

Redrafting of the screening tool might usefully consider:

- (a) The resident and carer sections (parts A and C) of the screening tool could be more closely aligned so that they cover similar questions and topics.
- (b) The different parts (hearing and sight) should ideally have the same numbers of questions.
- (c) The scales used in the screening tool might be usefully reconsidered, perhaps simplified (see below), and used consistently.
- (d) The use of negative questions has some methodological advantages (for example, some authors recommend the use of reversed questions to ensure the respondent is engaged in the questionnaire). However, this must be balanced against the potential for respondent confusion and the need for easy scoring. Given the intended use of this screening tool (with people who may have communication difficulties, and carers who

want to carry out rapid assessment), a simplification of the screening tool is recommended so that all the questions are in the same direction and use simple language.

- (e) Develop clear instructions of how to use (and score) the screening tool. It may be easier to use a simplified scale which enables easier scoring, e.g. “count the number of ‘Yes’ answers” as in some of the current subsection.

Phase II: Assessing the needs of residents identified as having combined hearing and sight loss and the related training needs of staff in residential homes

Rationale for Phase II

The key aims of Phase II were to explore the needs and circumstances of a sample of older residents who were identified in Phase I as potentially having both hearing and sight loss, and to assess the training needs of the residential care home staff who work with them.

Description of the research methods used to collect data

The research methods chosen to collect data were face to face interviews with both residents and staff, in the residential homes in which the residents lived. This method was chosen in order to enable the resident to take part easily with as little disruption as possible to their daily life. Once the residents had been identified from the data collected in Phase I, the managers of the homes were contacted and asked to confirm that the resident was well enough to be contacted. A letter and information sheet about the project and in large print was then sent to the resident. The managers of the homes agreed to help the resident to access and read the letter if they needed this assistance. If, after having read the information about Phase II, they decided they wanted to take part, they were asked to sign a consent form and return this to the researcher either in an enclosed SAE or by giving it to the researcher when she visited them. In four cases the residents gave their consent during the interview (which was recorded, with permission) rather than by completing a consent form. Members of staff who initially agreed to take part in an interview were also provided with an information sheet about Phase II and their involvement, and asked to sign and return a consent form.

The life story/history method was used with residents in order to enable them to predominantly *talk* in the interview, rather than have to listen to and

answer multiple, survey-like questions, and to gather deep and rich information that was not shaped too much by the point of view of the researcher. The life story interview has a wide range of applications and is a useful way of allowing the participant to have some 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. This method allowed this research to be distinctive by using the perspective of the older people, rather than having their views shaped and directed by a highly structured questionnaire. It is also a useful method with people who have difficulty in hearing as it does not rely on them having to listen and respond to multiple questions as in a survey-like interview.

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 a specific period of the participant’s life regarding their experiences of hearing and sight loss whilst living within the residential homes, though in practice this also touched upon their life before the onset of the hearing and sight loss and their move into the home.

This approach was also used within Thomas Pocklington Trust funded hearing and sight loss project (Pavey et al, 2008) that involved case studies of 20 older people with acquired hearing and sight loss; it has proven to be a very successful method in helping participants with communication difficulties due to hearing and sight loss to take part in the interviews and talk about aspects of their lives that were important to them.

Broad topic areas that were explored within the interviews with residents included the following:

- the identification of dual sensory impairments and the relevance of this identity to the individual;
- the effect of loss of hearing and sight on communication, mobility and information and

- how staff can support residents with these areas;
- the effect of difficulties in communication, mobility and information on the residents' lifestyle and opportunities within the homes;
- mental wellbeing and inclusion in the 'community' within the home;
- the material needs of their environment within the home, and equipment and how these needs are met;
- the awareness and understanding of those around them, including paid staff, and the residents' ability to adapt.

The residents were also asked a series of questions designed to capture demographic details (age, marital status, ethnicity, etc) as well as information about the nature of their sensory impairments and other health difficulties and disabilities.

A semi-structured interview framework was used to gather information from managers and other staff within the residential care homes about the training needs of staff, both in terms of identifying residents with dual sensory loss and assessing and supporting their needs; in particular, data were collected about:

- details of each home and its facilities;
- the daily support and care given to residents with dual sensory loss, including support for hearing aids and/or aids to vision, medication, and support for other health problems;
- staff training issues and their awareness and understanding of sensory loss.

Description of sampling and recruitment processes

The homes were approached about all of the residents who were identified as meeting either liberal or conservative criteria (n=25, see 'Phase I' pages 41-42 above) from the data that was received from the homes. Of these people, two were considered no longer able to consent, and take part (according to their key worker in one instance, and a close friend in the other); two had passed away; two were unwell or in hospital; and six had decided that they did not want to take part. In total 14 residents consented

to being interviewed. This included one resident who was identified by the manager of the home as having both hearing and sight loss but who had not taken part in Phase I – therefore the screening tool assessment was carried out by the researcher with him and one of the staff members before he took part in the Phase II interview.

In addition, the managers of all the homes that had sent back data (identifying residents with possible combined hearing and sight loss) were invited to take part in an interview, as were other staff members who worked on a one-to-one basis with the residents. In the end, nine members of staff across the seven homes were interviewed including six managers, one senior nurse, one key worker and one administrator (who was interviewed at the same time as the manager of the home).

One manager and one care worker, at two different homes agreed to be interviewed in principle but were not interviewed due to timescales.

Reporting qualitative data

The reporting of qualitative data is inevitably far more subjective than the reporting of quantitative data. This is partly because of the openness of the questions, but also to the subjectivity of the analysis. The approach used here is to identify excerpts from the interviews which make useful and helpful representations of what people said. An important reporting protocol used is that of *quantifiers*, such as ‘a resident’, *some* residents, and ‘many residents’. Although this approach is common in the reporting of qualitative data of this kind, the use of quantitative language such as ‘many’ requires defining. Quantifiers have been used throughout the report to give the reader an appreciation of whether one (‘a’), two or more (‘a few’), five or more (‘some’), or over half of all participants (‘many’ or ‘most’) made a similar point. Importantly however, the reason for identifying a theme raised in the interviews is because the authors of the report thought it important and useful in understanding the issue, irrespective of whether one or many of those interviewed raised the point.

Description of the final sample of residents N=14

The 14 residents included nine females and five males, and were aged between 78 and 94 years old. In terms of ethnic group, 13 of the 14 residents could be described as White British. The remaining resident was born in St Kitts, and could therefore be described as being of Black Caribbean origin. In terms of marital status, eight of the residents were widowed, two were divorced, and one had never been married, whilst three were still married. Of those, one still lived with his wife in a sheltered flat, whilst the other two residents' partners still lived in the family home (in one case nearby, in the other some distance away).

Whilst the aim was to recruit participants living in residential homes, two of the participants lived in sheltered accommodation that was located with and supported to some degree by one of the residential homes that was recruited to the project. This was due to the fact that the screening tool was piloted on residents living in the sheltered accommodation as well as in the residential home. A further resident (described earlier in section 'Description of sampling and recruitment processes' on page 48) who lived in the nursing home section of the same complex was also approached to take part, despite the fact that he had not taken part in the Phase I screening. In order to give depth to the project, all these were included in the final sample for Phase II.

One of the requirements for taking part in the project was that the resident should have the capacity to give informed consent to take part in an interview for Phase II. Of the 14 residents who took part, it was judged that all had this capacity (before they were contacted), this decision being made by the manager of each home. Based upon the interaction with the 14 participants, the researcher concurred with this view and felt that in all but one of the interviews the participant had understood the questions posed to them. In one particular interview the participant gave short, clipped answers and at times did not keep on track with the focus of the interview, and so it was not clear whether the participant understood the questions. However, this could have been partly due to the difficulty both the researcher and resident had in understanding each others' accents. In three other cases the participant appeared a little confused or forgetful at times, unable to recall the question when half way through answering, or unable to remember recent or long ago events. On the whole residents seemed to

understand and respond to most of the questions. In a few of the interviews there was, not surprisingly, some difficulty due to their hearing loss, which was largely overcome by the researcher adjusting her speech level or position. Whatever the underlying reasons, these examples demonstrate the difficulty that older people can face when communicating with others, even with optimal environmental conditions (i.e. face to face, one-to-one situations in a relatively quiet environment without any background noise).

Interviewing and sensory loss

Wherever possible interviews were carried out in a quiet room away from background noise. Nevertheless a number of participants required a significantly raised voice from the researcher in order to understand. The use of a font size chart with some of the participants to identify what size print they could comfortably read led into discussions about their sight and how any difficulties might affect their daily life.

Interestingly, none of the participants talked about having a dual sensory loss or deafblindness – rather, they talked about their hearing and sight loss separately, and none of the participants talked about the compounding difficulties from having both hearing and sight loss. The fact that it appeared that none of the participants had severe impairment of both hearing and sight could partly explain this.

Sight loss

When the participants were asked about their sight, only four participants were able to name their eye condition, with most of the others describing their difficulties with sight as simply being due to old age, or stating that they did not know what was wrong with their eyes. Four residents who were able to name their eye condition said that they either currently had cataracts, or had them removed in the past. In one case this had ‘transformed’ the participant’s sight for the better, but in another the participant said the surgeon had ‘botched’ the operation resulting in her sight deteriorating quite badly. Of these four participants, one also described having cysts at the back of her eyes, whilst another said she also had macular degeneration.

Half of the participants said that their daily life was not really affected by their sight loss, and in some cases they described their eyesight as being relatively good though in one case they also described having difficulty reading. A few participants said they could not really explain what was wrong with their vision, but that it was just blurry and they did not really know why.

None of the participants confirmed that they were registered as blind or partially sighted, with most stating that they were not registered or that they did not know. One resident who was severely sight impaired could not remember whether she had had her eyes checked recently, and was not sure if she had an upcoming appointment with an optician or other medical professional. This highlights the issue of the importance of a professional assessment of vision, to provide appropriate care and support, for example with mobility. Other participants could not recall when they last saw an optician, or whether they were due to see one.

Hearing loss

In terms of their hearing, eight of the participants described having a hearing impairment that affected their daily life in some way, particularly their ability to take part in a conversation with any background noise or when in a group setting. One of the participants said that it also affected his balance, which was one of the reasons he no longer felt confident going into town as he had done regularly until recently. Four participants described their hearing as not being 'too bad', though when prompted they said that it did affect them sometimes, for example when there was a lot of background noise or if someone had a particularly soft or quiet voice. The remaining two participants did not feel that they had any hearing loss at all. Interestingly, in terms of the screening tool one of these participants had reported having a significant level of difficulty with their hearing (defined as answering 'yes, always' or 'yes, often' in response to the questions) to two of the questions relating to their hearing (i.e. they met the liberal criteria for hearing loss— see Phase I description), whilst the other did not indicate any difficulty when answering the questions regarding hearing loss (though they answered 'yes, sometimes' to six of the questions, which in this project was

not scored as an indicator of hearing impairment). However, in this case the carer who completed the carer's part of the screening tool indicated that the resident had a significant level of difficulty in four of the seven questions; hence they were identified as possibly having a hearing loss.

Only one participant could name the cause of their hearing loss, which she described as "*tubercular mastoid*", a condition which she had had since childhood. Another said that the hearing loss was caused by the high level of noise involved in a previous employment, as a wood machinist. However, most said they did not know what had caused it, or considered that it was just due to old age.

Of the 14 participants, five said that they had hearing aids and used them regularly (one with some difficulty), two had hearing aids but did not use them, and seven participants either said that they did not have a hearing aid or did not mention them (and were not wearing them at the time of interview).

Other health problems and disabilities

Perhaps not surprisingly given their age and the fact they were residents in a care home, most of the participants described having other health problems and/or disabilities, in addition to any sight or hearing loss. The health problems mentioned included: prostate problems which affected the participant from sleeping uninterrupted through the night making him feel very tired much of the time; Parkinson's which affected almost every activity, but particularly the participant's mobility; a stroke around three years ago which affected the participant's leg and mobility; stomach and bowel problems, hiatus hernia and osteoporosis; kidney problems (needing regular dialysis) and breathlessness affecting the participant's mobility and opportunity to leave the home and go out; arthritis and polymyalgia in the wrists; and another participant had suffered what she described as a 'mental breakdown', although she could not remember when or for how long.

Six participants said that they did not have any other health problems or disabilities, although at least five of them had difficulty with their mobility

and had to use either a wheelchair or another mobility aid like a zimmer frame to get around. Two of the participants attributed their mobility problems simply to the fact that they were getting older.

None of the participants described their deteriorating hearing or sight as being the main reason that they moved into the home, though for one it was a combination of his sensory losses with other serious health problems. For most, it was because they (or others, such as family) felt that they were no longer able to cope living alone in their own homes, citing incidents such as frequent falls or other accidents and struggling to carry out everyday tasks as examples of the difficulties they had experienced before moving into the home. In one case a partner was no longer able to provide care due to physical disabilities. Another participant cited loneliness as the main reason she had moved into the home, which was nearer to her son who now visits her often.

Description of the data: key findings from interviews with residents

Residents' self-perception of their hearing and sight loss

One of the themes that the research team aimed to explore was the identification of combined hearing and sight losses and the relevance of this identity to the individual.

When the participants were asked how they felt about their deteriorating hearing and sight, most appeared to be fairly pragmatic about it, with the view that sensory loss was simply an unavoidable consequence of getting older that one has just to deal with.

One participant described it as “*not nice*”, whilst another said it “*makes me very depressed*”, a comment that referred mainly to her visual loss. Another participant focused more upon her hearing loss, revealing how telling others that she has a hearing loss gets her ‘down’:

“I always say to people if necessary that I’m hearing impaired, I don’t like to tell people but I think some people it’s necessary to tell them. [What about other residents, are they aware of your hearing...?] Not

all of them no, I mean I don't go around saying it to everybody. That way, I would go down like that if I did that. You wouldn't feel good, and you've got to feel good about yourself."

In relation to her sight loss, another participant said *"it has taken me a long time to come to terms with not being able to see properly. I know you are there but I cannot see your face"*; she was particularly worried about the future, regarding the possibility that the sight in her better eye would also deteriorate:

"I hope it does not go in this one, I do not know what I will do. I just hope, if I lose my sight, I lose my life as well. I would not want to live if I could not see at all. There will not be any pleasure in it. Sounds a bit dramatic, but..."

Communication

One of the areas the interviews explored was the effect of combined sensory loss on communication, and the effect that difficulties in communication had on the residents' lifestyle and opportunities within the homes.

Participants were asked whether they could hear and understand what staff members said when they talked to them; most of the residents said that they could. One participant, who sometimes found it difficult to talk to other residents due to her hearing loss, said that if she did struggle to hear the staff she would ask them *'what did you say?'*, and that the staff *"understand that"*. She appeared more able to share with staff that she has difficulty with her hearing than with other residents.

The effect of communication difficulties on the residents' lifestyle and opportunities within the homes

Having difficulty hearing people when in group situations appeared to affect many of the residents. This could have particularly bad consequences since many of the activities provided in the homes were group activities, such as talks, quizzes, and social gatherings.

When asked whether she struggled to hear when there is background noise, one participant replied:

“yes, that’s fatal, background noise, or if you’re in a room with a lot of people. Because you can’t say to people ‘I can’t hear you’, that’s embarrassing. Stupid to say that but it is, I’m that type of person.”

Other participants simply avoided group activities altogether, because they found it so difficult to hear what a person was saying to them when others were talking in the background; for example, one participant said he found group situations very frustrating – he would like to go to coffee mornings, but as soon as they all start talking he explained that he can’t hear a thing. Therefore he prefers one-to-one activities but in the home there are far more group-based activities on offer.

One resident remarked during the interview how much she was enjoying talking to the researcher since she had few opportunities to talk to other people in the home. She explained that *“the trouble is you sit here all day and don’t talk much”*, and so when she did get the opportunity to talk she felt a bit breathless. She also explained that she had never slept so much in all her life, partly as she is more frail and tires easily now, but also because she does not have much else to do. She agreed that talking to someone was particularly difficult when in a group of people: *“yes, you don’t realise how bad it is when you can’t hear. Because you miss half the conversation”*.

One participant who at first said she did not feel that she had a hearing loss, agreed (when prompted) that she did have problems hearing if there was background noise. She also found group conversation difficult:

“It does affect us when you can’t hear and see, I mean, when they chatter away sometimes I can’t hear what they say [so it’s more difficult if there’s group conversation?] yes, and if there’s noise its difficult more”.

Another participant managed when there was background noise by wearing her hearing aid:

“The hearing isn’t too bad because I have got a hearing aid I can use, and if I think I’m going to be in company where there’s a lot of background noise... otherwise I can hear you and anybody else just talking one to one. It’s when I’m in a crowd that I need a hearing aid. I got myself a new one last year.”

Some other participants chose not to wear their hearing aids despite having difficulty with their hearing; for example, one participant said it irritated her, making her ears itchy. Another said that he could not tolerate the loud ringing sound whenever he put them in (a ringing sound suggests they were not properly fitting or perhaps not properly maintained). Another participant said that her aids caused her too much pain:

“I did have one but then when I put it in, I left it in too long, it would start my ear up again, it would start discharging – not necessarily a lot but I knew it was about to discharge. And then it did discharge once or twice, and then the pain you see, it was painful”.

However, she said she had decided that she would return for another check-up soon and enquire about another hearing aid.

Another participant, who found it very difficult to socialise with people in a group, described how he was not getting on very well with his hearing aids, which had been prescribed by the NHS fairly recently; he wondered whether this was because he had not had much time to get used to them. He said that they showed him how to use them at the time of the appointment, *“but there’s a limit to how much you can do when you’re handing them over”.*

One participant said that he had never had a hearing aid or been offered one despite having had difficulty with his hearing for many years:

“No, I don’t (have a hearing aid). I’d have thought they’d have perhaps done something about it, you know? [Do you have regular checks for your hearing?] The only checks we had was some firm came round trying to sell you some hearing aid, and you know you didn’t know that till they’d finished and they said. [That you had to pay for them?] Yes”.

Similarly, another participant had purchased a hearing aid from a private company for her right ear which, it turned out, was not the ear she had most difficulty with:

“[Are they NHS hearing aids?] These are, but first I had just one because the man said that was all I needed but that was private, nearly £2000. [A lot of money!] Cor! I was not happy at all! I did not know then that I needed one in the left ear more than the right but he said the right was worse so I just bought the one. [So that did not really help?] Then somebody here said you shouldn’t have to pay for them, you should just get them on the National Health. I waited for about nine months for an appointment.”

Accessing information, mental wellbeing and inclusion in the ‘community’ within the home

People with combined hearing and sight loss can often have difficulty in accessing information; the residents’ ability to access information was explored in the interviews, including the effect that such difficulties had on the residents’ lifestyle and opportunities.

In terms of reading, most residents could still read to some degree, though even those who could read the 18 point font on the ‘test’ font sheet (that the researcher took to the interviews) said that they could not read for long periods as they would either get too tired/eye strain, or their eyes would get blurry or water constantly, rendering any further reading impossible. One participant could barely read at all, and struggled even to read a very large newspaper headline. She used to have a magnifying glass but said her eyesight *“had gone past that now”*.

Only three people said that they used a low vision aid such as a magnifier, but one of these described it as “*pointless*”, to the extent that he had no idea why they had given it to him; he told them as much at the hospital but they apparently told him to take it anyway. The only thing he used it for was the in-built light. Indeed, several of the participants mentioned that they needed good lighting in order to be able to read anything.

Most of the residents said that they kept up to date with what was happening in the outside world by watching television, or in some cases, listening to the radio. Others read a newspaper. Only one participant had difficulty answering the question, and seemed unsure as to whether they were up to date with what was happening beyond the home.

The interviews also explored the residents’ mental wellbeing and the extent to which they felt they were included in the ‘community’ within the home. When asked how they would describe themselves at this point in their life, there were mixed responses, perhaps unsurprisingly to such an open question: six participants described themselves as content or fairly happy, though this was often tempered with an added comment such as “*I’d like to be home but it’s the next best thing to that*”, and “*fairly happy, not so happy as I used to be*”. Other participants were less positive: one reminisced about how busy her life had once been compared to now:

“A bit sad when I look back, but there again I say to myself ‘well, you’ve done all these things, and I have to sit back and see other people do it’ so I guess that’s what it is”.

Another wished she could be more active, and sometimes felt discontented with her current life, whilst another participant replied “*hopeless, the way I feel... I’d be better off being dead the way I am*”.

One participant described how she coped with feeling down by having a laugh with others, and giving herself a ‘pep’ talk, whilst another participant said he brushed off any worries and tried to take it in his stride. A few participants talked about their religious beliefs, and how this gave them the strength to face any difficulties. When asked about what was the most important thing in their life now, several participants said it was family and friends. Two participants cited good health and their eyesight respectively, both of whom were concerned that their health/eye condition was

deteriorating further. Another participant responded that “*trying to get from day to day*” was the most important thing in her life now. Similar responses were given when asked for their thoughts about the future; one participant reiterated that she worried about her sight deteriorating further and that she would not want to carry on living if she could no longer see at all, whilst another repeated that she wished she could be more active and just hoped she would get through it “*the best that I can*”. Another participant somewhat pragmatically replied “*well I’m 91 so I don’t expect to be all that long; so long as I have had an active life I can’t (complain)*”. Another participant agreed that she did not feel very positive about the future: “*Not very good, no*”.

The two participants who were currently living in sheltered accommodation were asked whether they would ever consider moving into the residential home part of the complex, and if so, under what circumstances. Whilst both said that their preference would be to remain living in their sheltered accommodation, they both would consider a move if they could no longer manage living more independently due to their health or a deterioration of their eyesight respectively. One was concerned about how they would manage to pay the fees for the residential home, should they need to move. Both agreed that having priority on the waiting list to move into the residential care was a particular benefit of living on the complex, particularly as they already felt part of the overall community and knew many of the residents. Indeed these residents were two of only four participants who said that they felt included in the community life in the home complex in which they lived, though other participants indicated as much via more indirect comments.

The residents were asked whether they felt that they had choices and control over decisions made about their life, whilst living in the home. The majority felt that they did, though in some cases they were happy to let staff make decisions for them as they trusted that such decisions were made in their best interests. One commented that they were allowed to have visitors any time of the day whilst other homes did not allow this, whilst another said that “*generally speaking you get what you want*”. Four participants did not feel that they had enough choice or control: one commented “*no, no control, not really*” though the participant would not elaborate on this statement,

whilst another participant from the same home said “*no, not a great deal because of the rules of the home – like when we go out and what we do*”. Another participant in a different home said that she did not feel she had enough choice and control, but commented that she had not been in the home for very long so felt she could not really judge it very well yet. She explained that “*for the moment they’re quite alright, they’re not bossing me around... good meals and a good bed, and that’s all I look for today to be honest*”.

In terms of being included in the community life within the home, half of the participants said that they regularly socialised with other residents. Three participants said that they only interacted with one or two other residents, because they felt they did not have anything in common with other residents. For example, one participant gave the reason that nobody else was having the same medical treatment as him, whilst another said the medication she was on made her too drowsy to converse with other residents. One participant, who had moved into the home because she had been lonely living in her own home, felt there was too much of an age gap between her and other residents, and had difficulty getting to know them because she did not know anything about their past and they did not know anything of hers. Similarly, another participant who wished she had more company, said “*You don’t make friendships overnight*”. This perhaps hints at some of the difficulties that people with sensory losses can face in establishing friendships.

Many of the participants had friends and family who visited them, and a few occasionally went out of the home for social activities such as going for a meal or visiting relatives. One of the participants who had previously lived in the vicinity of the home still attended her local church – when asked whether she thought it was important to keep in touch with old friends she replied “*in a situation like this I think it’s vital*”. Another expressed a desire to attend her local church service but said that she had no way of getting there. Two participants said that they never went outside of the home for social purposes; the only time they left the home was to attend a medical appointment.

Several participants said that they still kept in contact with old friends, but too often this was via infrequent phone calls or letters. Only one of the residents mentioned that they had access to a private telephone (in this case a mobile so that his daughter could ring him), although some were able to contact friends using a family member's phone when they visited them.

In terms of taking part in activities offered within the homes, most of the residents were included in this way for at least some activities. A range of activities were mentioned, including coffee mornings, moving with music physical activity sessions, quizzes, bingo, sing-along sessions, talks with outside speakers, discussion sessions, arts and crafts, and bible readings. A few participants expressed a dislike for group or "community-type" activities, preferring their own company or one-to-one activities. In some cases this preference was due to the difficulty they experienced in holding a conversation with people in environments with a lot of background noise (as discussed earlier in the section on 'communication'). In other cases it was simply a personal preference.

One participant described how she used to love doing arts and crafts sessions but could not anymore due to her deteriorating eyesight. Similarly another participant missed sewing and making clothes. Other activities that were mentioned which participants could no longer do included gardening, fishing, shopping and walking (all due to mobility problems, mainly related to shortness of breath and general frailty rather than their sight loss), as well as cooking, baking and voluntary work.

The activity that most residents missed however was reading books for pleasure, an activity they no longer carried out due to failing eyesight. A few residents mentioned that they listened to talking books and those that did said that they obtained them from their local library, though the choice of books on offer was reportedly limited. Only one of the participants had ever heard of organisations like the RNIB talking books service and Calibre, two of the largest lending collections of audio books in the UK. One participant used to listen to talking books regularly and enjoyed them greatly, but stopped her subscription when she moved into the home. She had anticipated that she would not need them as she would be kept busy

participating in the activities provided in the home and socialising with other residents, though this reportedly did not transpire. (Where appropriate, the researcher gave advice about talking books organisations both to individuals and to the home staff).

Mobility, independent living skills, and support from staff within the home and external organisations

All but two of the participants, who both used wheelchairs, could still walk around the home in which they lived. Several of the participants used a zimmer frame or walking stick to aid their mobility. None of the participants had a long cane (sometimes called a 'white stick') to give visual guidance, though one participant mentioned that she had been given a symbol cane - a white cane which can indicate the person is visually impaired - for when she went out and about.

Two participants said that they often felt unbalanced when moving around; one attributed this to his hearing loss whilst the other participant thought it was related to her sight loss. Two other participants said that they enjoyed going into the gardens at the homes in which they lived, but were afraid of falling and so only ventured out if there was a member of staff available to take them.

In terms of mobility beyond the home, most of the participants said that they went out on a fairly regular basis, but only one ever went out unaccompanied. Most only went out if their family came to collect them for an outing, and in many cases they had to use a wheelchair as they would not be able to walk far. One of the residents used to go out on his own regularly into town but deterioration in his health meant that he could not walk to and from the bus stop, as he got very breathless. He said that the staff in the home would not let him go on his own now; he had been told about the local 'ring and ride' service by a social worker who came to see him, which he thought would be ideal, but he was then told there was a waiting list and he has not heard anything about it since.

The participants were asked about different independent living skills, such as washing and dressing in the morning, use of the toilet, and eating meals (it was assumed that most would have their meals prepared for them, and their laundry washed and dried, etc although some had tea making facilities in their own room which they were able to use). Three of the participants said that they needed help to get washed and dressed in the morning, but most of the others seemed able to do this by themselves though some said it depended on how they felt on a particular day. Most of the participants had their meals in the communal dining rooms, though some ate breakfast in their own rooms, and in one home this was encouraged so that breakfast time was not regimented but could be taken at leisure. A few participants needed help when eating – it was not clear in most cases whether this was due to dexterity problems or their eyesight, though one participant said that she had been recommended (by a macular clinic) to use a black plate so that she could see her food contrasted against it, though as her sight deteriorated further this only helped when she ate white foods like rice.

The participants described various levels and types of support that staff gave to them on a daily basis. In most cases they said that the majority of staff were very kind and took good care of them, though they were always busy and rarely had time to simply chat with them. For example, one participant explained:

“they look after us here, and (name), one of the managers, is lovely, they all are, cannot fault them. The carers are nice too, you cannot get better than that. [Do you feel they spend enough time with you?] Oh no, the carers, they are always rushing about, always busy.”

The majority of participants said that they took medication and in every case they said that the staff in the home administered it to them. Some of them were not sure what the medication was for, but relied on the staff knowing what they were doing.

In terms of contact with outside agencies that might offer them support for hearing and sight loss, only two participants could recall having seen someone – in both cases, it was a specialist who worked for a visual impairment organisation. One of the participants said that a man from a locally-based visual impairment voluntary organisation had come to visit her

twice, but that he had not been that helpful beyond providing her with a talking clock. He had encouraged her to join others with similar sight problems on day trips but she had not been very keen on the idea. The other participant had had contact with a specialist worker for visual impairment (she was not sure from which agency) indirectly when she had come to assess her now-deceased husband about his visual impairment; she had commented that her eyesight was so bad that she needed support herself, though she had since never received any support and wondered whether it was because she had never been registered as visually impaired.

With regard to contact with medical staff about their hearing and sight impairments, few residents could recall when they had last seen a specialist about their hearing or sight, or whether they were due to see a specialist in the near future.

Some of the residents said that family members accompanied them to medical appointments, but for those without family members living nearby, staff would accompany them. In one case, the participant said that she struggled to understand what the eye specialist was saying to her as she did not understand her accent and she spoke very fast. Although a member of staff from the home accompanied her to the hospital, she did not go in to the actual appointment with her. A participant from another home also experienced this difficulty when going to an eye appointment, struggling to understand the specialist due to their accent. This suggests that there is a need to have someone present who can listen and then discuss the appointment with the resident to ensure they understand what the specialist had told them.

Key issues identified from interviews with staff

Eight interviews were carried out with nine members of staff in seven different homes. Six of the staff members who were interviewed described themselves as managers of the homes, undertaking a variety of tasks from responsibility for the day-to-day running of the homes, ensuring adherence to the National Care Standards, carrying out staff training, supervision and disciplinary proceedings, auditing care plans and overseeing budgets. One

of the participants was an administrator, carrying out various aspects of administration including liaison with staff, district nurses and GPs, but also overseeing the manager's role in their absence. Another participant was a key worker/carer who described her role as providing personal assistance for residents, attending to their needs, including escorting them to GP and hospital appointments. A senior nurse was also interviewed who described herself as a registered nurse at level one, whose role included supervising staff and looking after residents as necessary.

Of the seven homes that took part in Phase II (i.e. residents, staff or both took part in interviews for Phase II), two of the homes were run by voluntary organisations and the remaining five were privately owned (in one home where staff gave an interview no residents were interviewed). They varied from being purpose built residential homes to homes that were converted from former family housing, and in terms of capacity they ranged from registration for 15 residents up to 65, with a mean average of 36.

The homes also varied in terms of the facilities they offered, with some having single occupancy en suite rooms, whilst others had single rooms with shared bathroom facilities. At least two residential homes had shared rooms, but one manager said they were decommissioning these as they were not very popular with residents. Some of the homes had lift access, whilst others used stair lifts. All had at least one communal lounge area and dining room, and some had separate rooms for arts and crafts, and video and CD libraries. One had its own hairdressing salon, others arranged for hairdressers (and other services, such as chiropody) to visit on a regular basis.

Only one of the homes reported that they had a hearing loop system fitted (as well as portable communicators), although one had been promised a hearing loop system (presumably arranged by social services, though the manager could not remember), but for some unknown reason no-one had ever arrived to fit it. Otherwise, none of the homes had any adaptations made specifically for people with sight and/or hearing loss (as far as those interviewed were aware). However, some of the more generic adaptations made for all of the residents, such as having handrails fitted, reportedly benefited residents with sight loss in particular.

When asked to describe the residents in the home, most were described as catering for elderly people without dementia or other specialist needs, though three homes said that they also took patients with dementia (in two cases only 'mild' dementia, in the other they were registered for dementia residential care but they also catered for residents without dementia). However, in several of the homes the residents were described as having a wide range of health problems.

The participants were asked "*what would you say are the main issues that the home is concerned with regarding all residents care?*" In response, none of the participants talked specifically about hearing and sight loss, although one participant did mention falls prevention and how that can be linked to sight loss. Other participants mentioned care for residents with dementia, the general health and well-being of residents, and the need to ensure that residents had nourishing diets.

Awareness and understanding of combined hearing and sight loss

One of the topics which the interview schedule for staff members explored was the awareness and understanding of staff who worked with residents with combined hearing and sight loss.

Participants were asked how many people with combined hearing and sight loss they had encountered during their careers; most thought that they had not met many who had had both hearing and sight loss, as residents tended to have one or the other, if any. A couple commented that they had not met anyone with either total blindness or profound deafness (or indeed both).

In terms of identifying residents with combined hearing and sight loss when they entered the homes, most said that hearing and sight would form part of the initial assessment process, but in many cases this might consist of just a couple of questions and so would not explore the resident's level of hearing and sight in much detail. None of those interviewed said that the identification of any sensory loss would make the residents more or less likely to come into the home; rather, it would not make any difference as the home would cater for whatever needs residents had anyway.

Whilst some of the staff described sections in their care plans that would cover hearing and sight loss (sometimes as part of a section exploring other potential health problems or disabilities), quite a few did not cover it specifically at all. In these cases, the care plan was described as being tailored to the individual resident and their needs. Whilst this enables flexibility, it relies on the writer's ability to recognise that the resident might have problems with their hearing and their sight (in the event that hearing and sight loss had not already been formally identified).

One of the managers said that if a resident was falling over it could be due to a sight problem, and if they seemed unbalanced when moving about it could be related to their hearing – so they always referred them to the resident's GP or optician, as appropriate. Another manager felt that her staff were good at picking up when residents were having problems with their hearing and sight, and although there was always room for improvement, she felt they already did a good job and had good insight into their residents' needs.

Most of the homes said that an optician regularly visited to check residents' sight, and they referred to GPs whenever they felt there was a problem that needed to be explored. In particular, if residents appeared to be struggling to hear they would refer to the GP in case a resident simply needed their ears syringed due to a build-up of wax. Some homes had a district nurse who visited regularly to check residents' general health and well-being. Visits to the homes from audiologists were less common (mentioned by only one home), with most residents having to visit a clinic.

There was a mixed awareness of social care support services available for people with hearing and/or sight loss. Interestingly, none of the participants were aware that the local authority has a duty to provide an assessment for people with combined hearing and sight loss under the Deafblind Guidance (DOH 2001); this generated some interest amongst the participants, and the researcher provided them with a Sense publication that explained it. One remarked: *“No, I didn't know that. They keep that quiet! Well it's obviously because of funding isn't it? [Offered her Sense publication about it] Any publications, yes, would be great.”*

Of the seven homes, participants from only two said that they were aware of local services for people with hearing and sight loss; in one case it was a voluntary organisation for sight loss, in the other they mentioned a voluntary organisation for people with dual sensory loss. A participant from another home said that they have had people come in the past but could not remember from what organisation. A further participant said that one or two residents used the talking book service (but was unsure of which one) but that they had not been aware of voluntary organisations in the area that could offer support to residents. Another participant said they were not aware of any support, and felt that people in residential homes were not seen as a priority for support (interestingly she talked more about medical support than social care support):

“No, it doesn’t seem to happen – once they’re out of hospital that contact doesn’t seem to keep (up). Obviously if they’re a patient in the hospital they’ve got access to a lot more professional people like physio and OT, but once they’re out in the community or in nursing homes it seems as if that level of care stops, that support is gone. [Do you think having some specialist support that you could draw upon would be useful?] Oh gosh yes, definitely.”

Another participant felt that people in residential homes were excluded from community activities and specialist support, because they were not seen as a priority for specialist services such as day centres for people with hearing and/or sight loss; one of the residents still attended an external community group (for the elderly, rather than specialist provision for sensory loss) but only because she had joined the group before moving into the home.

Communication with residents with combined hearing and sight loss

None of the homes had residents who could no longer communicate via speech due to a hearing impairment, and few participants could recall having residents with such profound hearing loss in the past that they could no longer hear what people said to them. When asked whether they were aware of alternative communication methods, only a couple of participants described methods used specifically with people with dual sensory loss

(e.g. BSL, finger spelling, Block, larger print, Braille) though other communication methods were mentioned such as alphabet boards, picture cards/boards, light writers, and lip reading for profoundly deaf people without any sight loss. A couple of the participants said that they communicated successfully with residents with combined hearing and sight loss by standing close to their 'good' ear, talking slowly and clearly, and ensuring other staff were aware that they had to do this when communicating with them. One participant said that the home provided activity items (books, etc) in Braille and large print, and talking books.

Four participants from four of the homes said that they helped residents to maintain and use their hearing aids, including cleaning them and changing the batteries when necessary. Two participants said that sometimes a resident refused to wear their hearing aid but that was their choice and they could not be forced.

Supporting residents in accessing information, their mental wellbeing and inclusion in the 'community' within the home

When asked about the overall aims of the care that they give to residents, many of the participants said that it was to support residents in reaching their potential, to be as independent as they could be, and to include and involve them in the life of the home so that they felt part of the community; for example:

"Keep them involved, keep them in the loop. Make them know how important they are so they can take part. I hate it when the ladies say they cannot see or hear, but I think it is a bit of apathy as well because of their age. So involve them really so they do not feel left out".

And:

"It's about outcomes, quality outcomes and it's about supporting people to be individuals and reaching their best potentials really – and that's all we can do to the best of our abilities. We want people to do what they want to do, and I think we do that by regularly reviewing

their care plans and getting together with families and professionals to make sure we are maximising the potential of individuals”.

In terms of helping residents access information in print, the participants said that staff members would read letters to a resident if they would struggle themselves to read it, and some made sure that any notices around the home had large lettering. Another mentioned that they regularly buy a large print newspaper for residents to read so that they can keep up to date with what is happening in the outside world.

In terms of activities that are offered to the residents, a number of group activities were described (e.g. movement to music exercise classes, bingo, talks and lectures, singing groups, quizzes, etc) as well as some one-to-one and solo activities (arts and crafts, computer classes, reading to residents, etc). Several of the homes employed an activities coordinator who in some cases would tailor activities to a resident's needs (e.g. if they could not see or hear very well), or would work on a one-to-one basis with them. In one home the member of staff said that most of the activities on offer were one-to-one as there were not many residents who wanted to join in with group activities. Another participant said that they try to encourage residents to do activities that they used to do but have not done for some time for whatever reason; she gave an example of a resident who used to love painting and calligraphy but was not able to do that at a previous home. No examples were given relating to any residents with sensory loss.

Two homes said that volunteers (from a local school) and students on placement (from a local college) came in on a regular basis to carry out activities with residents, though it was not clear how they would work with residents with sensory loss if at all.

One of the participants said that they did not have any activities in the home that catered specifically for people with sight loss though residents, in her opinion, were able to take part in the activities that were on offer despite having sight loss. Another participant described how they had carried out food tasting sessions which were particularly appropriate for residents with sight loss. A manager of another home said that for residents who could not

see, 'big' print crosswords and 'big' numbers were provided for bingo sessions.

Few activities outside of the home were offered by the homes. In one case, a participant said that day trips were arranged but it often came down to how the residents felt on the day, and many would decide they did not want to go at the last minute. Other homes did offer day trips, sometimes to local places (pub meals, shopping centres, public gardens, etc) and one said that they provided one-to-one care for residents so that people with sight loss or other difficulties could still come along.

When asked whether there were any additional forms of support that they felt could or should be offered to residents with both hearing and sight loss, whether by the home or external organisations, three participants mentioned better access to activities like specialist day care centres (discussed earlier) reading, and watching television (talking books and larger subtitles on television pictures, respectively). Another participant mentioned improved signage with photos and pictures rather than wording around the home, whilst other participants said they could not think of anything.

Mobility, independent living skills, and support from staff

Some of the participants were asked how they supported the residents with DSL with their mobility in and around the home. In many cases they said that the residents did not need any support with their mobility as they could still see enough to get around by themselves, with the aid of a zimmer frame or walking stick. In many cases, their general frailty and other problems like arthritis were more of a problem in terms of mobility than their hearing and sight loss. One of the participants said that as the building was purpose-built as a residential home for elderly people, many of the features of the building like handrails and colour coding for different sections (to help identify where they were, and what floor their room was on) were also helpful to people with sight loss.

With regard to residents' daily needs such as taking medication, most of the participants said that staff administered medicine to the residents. One home said that residents could self-administer if they wanted to but the majority chose not to. Participants said that they helped monitor health issues for people with sensory loss where necessary, such as monitoring weight, blood sugar levels, and so on, and none had any concerns about this aspect of residents' care.

As would be expected, staff members also provided support to participants with daily living tasks and activities such as washing, dressing, eating and using the toilet, to whatever degree was necessary in each individual case. No issues related specifically to the residents' hearing and sight loss were mentioned, with regard to this aspect of their care.

Training for staff in hearing and sight loss

Participants were asked whether they, or other members of staff within the home, had ever been offered any formal or informal training in the needs of people with hearing and/or sight loss. Participants from five of the homes said that they had, although in two cases it was part of generic training that staff undertook rather than any specialist training about sensory loss. In the other three cases, training was provided by a visitor from a voluntary organisation who got them to wear simulation spectacles in order to have an idea of what different visual impairments were like. They reportedly found this very helpful. However, in one case, the participant said the trainer was not very good, confusing wet and dry macular degeneration when describing them, and she felt that it had been an absolute waste of an afternoon.

In terms of training about aids, few of the staff reported having any formal training in the use and maintenance of hearing aids, though informally staff members shared what they knew and trained each other. In one of the homes staff had been offered such training, one of whom had also been trained to carry out ear syringing with the home's own equipment. One of the homes felt they did not need training in hearing aids as they were

‘straightforward’. Nobody mentioned that they had undertaken training in the use of other aids, such as low vision aids.

Regardless of whether they had already received any training, participants were asked whether they (or the other staff in the home) would appreciate any (further) training in the needs of people with hearing and sight loss. All but one participant said that they would. The other participant felt that it was perhaps too much to ask staff to come in on their days off for such training.

When asked what particular aspects they would appreciate training in, general awareness of issues around hearing and sight loss and how people can be supported was mentioned by several participants. One participant said that information on how to help people more specifically, that was more focused on hearing and sight loss would be useful because:

“our care plans, we are trying to get them person-centred as much as possible but in a lot of ways it’s not, it’s only done in their best interests – but how can we know what’s in their best interests if we are limited ourselves?”

One participant said that short, sharp training sessions that used visual things to demonstrate different aids and adaptations were the most effective, as they did not overload people with information.

Another participant said that information about how hearing aids work and how they should be maintained would be useful along with what to look for when people are having difficulty with their hearing aids.

Participants were asked whether they felt that the experience of taking part in the screening process (in Phase I) had changed their perception of hearing and sight loss, and whether they would change anything in relation to how they supported residents with combined hearing and sight loss. Three participants answered ‘No’, because they already felt that they were doing a good job in supporting their residents. Three other participants said that the experience had changed their perception, in as much as it had raised their awareness of some of the issues relating to hearing and sight loss and thus placed it on the ‘agenda’. One of the participants said that they had already incorporated some of the questions into their care plans in

the section about communication. Another asked whether the tool would eventually be available for them to use at some point, as it *“is more than what we have at the present time”*.

Phase III

Following the completion of Phases I and II, the project will enter its final phase, to be delivered by Sense. The information that was gathered in Phases I and II will be used to develop training and development materials for staff and care workers in residential homes, so that they are able to take the necessary steps to ensure that people with hearing and sight loss within the homes have the support that they require and need.

The data from Phase II about the needs of older people and the training needs of the staff who work with them will now inform the development of Phase III. This phase is about the design and delivery of training to staff working in the residential settings about the needs identified in Phase II.

The training

Each of the residential homes that took part in the project will be provided the training free of charge for their care managers and staff as an acknowledgement for having taken part in Phase I and Phase II of the project. This training will be delivered in Birmingham with notification of the actual training dates and venue being given well in advance to ensure that the date will best suit the needs of those attending. The training will take place over the course of one day. Some aspects of the training may also be delivered online. Whilst the training is not compulsory, what it will provide is an opportunity for care managers and staff within residential homes to understand and be more aware of what they need to look out for with residents who may have early signs of hearing and sight loss so that their needs can be supported within the residential home.

The awareness training will include what deafblindness (combined hearing and sight loss) is, what needs to be considered when working with people who may have combined hearing and sight loss in a residential home, and

how staff can identify early signs of possible hearing and sight loss in residents. It will also look at some practical, simple ways of supporting the needs of people who have combined hearing and sight loss in residential homes. Additionally staff within the care homes have identified that they would also benefit from learning about the maintenance of hearing aids which will also be further explored as a topic for the training.

Discussion

The study in Phase I and II has provided some interesting and useful data about the identification and perceptions of older people with sensory loss in residential homes.

In addition, there are some points about the research study itself which may be of value to other researchers.

Research related issues

The issues around capacity and consent (discussed further below) meant that recruitment of homes took longer than was expected, as further homes and residents had to be included in order to reach the number of participants hoped for. In addition, ethical approval took much longer than anticipated. These factors will need to be considered by any future researchers designing projects in this field.

The nature of the participants in this group (older people) means that events relating to illness, bereavement, and diminished capacity, and sometimes death, will emerge during the process from recruitment to completion of data collection and this potential participant attrition must be taken into consideration.

In some cases while recruiting the homes, 'gatekeepers' limited access to homes and responded that although the homes had previously participated in research, combined hearing and sight loss was not a current priority issue for their home but that their focus was now on mental health.

The lack of feedback from previous research projects which managers reported made some unwilling to take part in this research. Researchers should be clear about what the outcomes and feedback will be what participants would like, when setting out to recruit. For this project, staff and residents from the homes were provided with information about the project at the outset and were contacted during each of the phases of the project. Managers received a copy of the executive summary and an invitation to phone for a copy of the complete report, and participants received a large print letter with the key points from the report (and an invitation to request further information).

Dementia and sensory loss

The issue of dementia underlies all the work undertaken in finding the sample and testing the screening tool in this group of older people. In addition, it is important to understand the significance of the results which *were* obtained and were *not* in relation to the participants.

The very large number (approximately five out of seven residents) of those in the homes who were identified by staff as not competent to take part in the research or to give consent indicates that by far the **majority** of those living in the homes were not considered capable. This raises several issues of concern.

Firstly, this group remains very under-researched. There are clear ethical issues about under taking research with people who have dementia, but the lack of knowledge about this group is a serious problem. It seems obvious that such people are extremely vulnerable and that an understanding of their needs, however this is achieved, is vital if these needs are to be met. New research methods which are suitable for exploring these issues, and which are ethically acceptable, need to be developed.

Secondly, the researchers in this team did not approach anyone who was believed to be unable to take part or unable to consent. However, it is possible that more specific direction from the team as to what constitutes capability would need to be would have helped with recruitment. The Mental

Capacity Act, 2005 is based on the idea that it is only necessary to be able to consent to what is being asked; that could be that participants only need to be able to say that they are prepared to talk to someone about their life. This is not necessarily the level of consent that either homes or ethics committees actually considered. Tester et al (2003) were able to use various methods to communicate with people in residential homes including those who had dementia. The methods they used might not be suitable (as they involved *Talking Mats* which is visually based) but other strategies could be developed.

Thirdly and perhaps most crucially, there is no clear evidence from this research as to the degree to which dementia is masked by, exacerbated by, or confused with, combined loss of hearing and sight. It is quite possible that some people who are considered to be confused, struggling with reality, or similar, are in fact having difficulty with communication, or with accessing information, both of which are *outcomes* of dual sensory loss. Of course it is also likely that some people who have dementia are further confused and disorientated by the effects of single, or dual, sensory loss. In the current situation, where this is a difficult population to reach by research, it is very difficult to ascertain the numbers involved in either of these settings, but they could be very significant, given the projected levels of sensory loss in older populations (Robertson & Emerson, 2010).

Identification

The use of a screening tool was intended to assist in identifying people who had hearing loss and sight loss, and in particular both, though a combination of self report and carer assessment. The tool itself was examined, piloted and developed in Phase I. The resulting data showed perhaps fewer people with combined sensory impairment than might have been expected. The exclusion of people presumed to have dementia may have had some effect on this. Some suggestions for improvements to the screening tool have been made, including rephrasing questions so that they are not negatively phrased, the simplification of the questions, and leaving out questions which did not lead to many positive answers (see discussion on pages 36 and 39)

Whether or not it is important that older people understand their hearing and sight loss as something different from 'getting older' which might make them feel more 'impaired' is a question which this study did not explore.

There was a marked difference in carers' and residents' own perception of each resident's hearing and sight loss; in some instances staff were identifying hearing and sight loss in the residents but when the residents were asked they did not identify themselves as having hearing or sight loss. This has an effect both on recruitment and on perception and further research could help to identify what older people *consider* to be sight loss and relate that to clinical criteria.

The concept of combined hearing and sight loss, or the effect of one on the other, was not one which appeared to be widely considered by either staff or residents. Most staff believed they had only met a few people who had a combined loss, and this may at least partly have been a misunderstanding of the impact of moderate to mild sensory impairments. No resident linked difficulty in using sight to increased difficulty in using hearing, for example, an inability to lip read. However, at least some of residents were having difficulty with both their hearing and their sight which was affecting their daily lives.

The particular difficulties caused by the combination of hearing and sight loss were not discussed and it seemed that both staff and residents had not thought about this. The identification of sensory difficulties was only a small part of the initial assessments that were carried out in the care home and combined sensory loss was not considered separately. Staff training in relation to the effects of combined hearing and sight loss could focus on very practical areas such as knowing who has spoken in a group, difficulty with accessing instructions/advice/help given visually and by speech at the same time and the importance of proper monitoring of hearing and sight, particularly in someone who already has a recognised and diagnosed loss in one sense.

The effect of combined hearing and sight loss on lifestyle

Communication

The residents found that having difficulty in hearing against background noise kept them out of group conversation and group activities. For one resident the use of hearing aids compensated for this but others found they did not. The development of hearing aid technology could mean that hearing aids could be programmed to create a considerable improvement in this for some. This would require appointments with audiology departments and the understanding of staff as to how the aids work (different programmes could be set for one to one conversation, group settings, and so on). Some staff had been trained in the maintenance of hearing aids, but increased training in this area could ensure that staff were able to check that the aids were working properly, and so achieving their intended purpose. In addition, training for staff could mean they could help older people to get used to amplification by suggesting certain activities and giving improved advice.

Mobility and daily living

Most of the participants were able to get around homes by themselves, though two were using wheelchairs. Difficulties with mobility were often based in physical symptoms, a stroke, Parkinson's Disease, Arthritis and a range of other difficulties. It is likely that any difficulty related to sight loss has been subsumed in the mobility difficulties caused by a physical condition. Two residents who sometimes felt unbalanced thought this might have been related to sensory loss, in one case to poor vision, and in the other, to poor hearing. Most residents were however able to leave the home on a regular basis for activities or outings.

Access to information (and support)

A number of participants reported difficulty in accessing print, although in general they were able to keep up with the world through television news.

One home reported using large print notices so that those with sight loss would be more likely to be able to read them. Only one home had a hearing loop installed for the benefit of hearing aid users (and others benefit because this means that the television or radio does not need to be turned up for the person with hearing loss to hear). One home had a large print newspaper delivered.

The use of simple strategies such as a loop system, large print notices and newspaper and subtitles on the television can have a significant effect on the social inclusion of a person with single or combined sensory loss, and none of these are very expensive options. In terms of staff training, understanding how important such strategies can be could promote their use. However, it is also important to note that the participants clearly welcomed the one to one contact they had (for example with the researcher) and the personal contact involved in having a regular time to read letters, or a newspaper with a care-worker, or to discuss local events could be an even more important approach. Obviously this can be difficult for busy staff; Butler (2004) describes one worker at a day centre being given a 'social integration role' and being explicitly forbidden from taking on other tasks, so that she focused on engaging residents. Where this is not possible, even a short time allocated every day to assist someone with combined sensory loss could be a helpful approach.

Hearing and sight support; clinical

In most cases staff said that opticians visited the home as required and that they would refer any problems with sensory loss to the GP. Most homes said that residents would have to go to a clinic for tests of hearing.

Residents' perceptions showed them struggling with the use of hearing aids (which perhaps neither they nor the staff understood well). They were not usually aware of when they had last seen a medical specialist in relation to hearing or sight.

It seems that medical support and the understanding of the importance of this could be enhanced for both residents and staff.

Care managers reported that whilst it was relatively easy to receive an assessment from an optometrist in the home, domiciliary assessments from an audiologist were much rarer. This is probably related to the nature of the equipment used and the requirement for sound proof rooms for accurate assessment. The current use of digital hearing aids which require computer assisted programming may also be a factor. However, in at least one instance an audiologist did visit the home, providing an example of good practice, which may compromise absolute accuracy but is also likely to lead to better results from more frequent testing. Monitoring for hearing and sight deterioration could thus become a part of regular care-staff assessment, supported by clinicians as necessary.

When residents had to attend out-patient appointments, this often meant that both a member of staff and the resident would be out of the home for a large part of the day. This resulted in lower staff ratios in the home, the resident missing meal/s due to being out at the appointment, issues of transport and having to wait to be collected, all of which could sometimes take the whole day, thus cause disruption to the older person's usual routine.

A greater understanding of what hearing aids, and low vision aids (amplification and magnification) can do would help staff know when to refer to specialist services. Greater awareness of the services that assess for and supply such aids would help both staff and residents.

Once again, the importance of one to one contact is highlighted by the difficulty that residents had in understanding what they had been told by medical staff. Assigning one member of staff to follow up a medical appointment by answering questions (or finding out the answers) and describing again what was said could be a helpful approach and could improve participants' use of their sensory systems and the support of aids.

Hearing and sight support; community

Few of the homes (two out of seven) and only two residents had had any support from specialist services for people with sensory loss. Homes were rarely aware of what services they could access. Benefits which could come

from links with such services potentially include; advice about simple equipment such as loop systems, inclusion in outings to events for hearing impaired or visually impaired people, advice on activities and staff training. However, it is clear that not all the people who had hearing or sight loss considered themselves visually or hearing impaired, and they might not want to be involved in activities designed for people who had these impairments.

The fact that none of the homes were aware of the obligations of the local authority in relation to assessment of the needs of residents with combined hearing and sight loss suggests that further training in this area is needed.

Inclusion in the community; mental wellbeing

Most of the residents appeared to be pragmatic about their age, their difficulties and the effect these had on their life, although some of them did express fears about the future. There was a noticeable difficulty in making friendships which none of the residents put down to sensory loss but could in fact be related to difficulty in hearing conversation. Staff reported trying to include all residents in activities, but many of these were communal and could have been difficult to access for residents with combined sensory loss.

Reading was a particular difficulty for many; the involvement of a voluntary organisation to organise talking books has the potential to help with this.

Training in strategies to help include people who had combined hearing and sight loss could raise the level of participation in activities. Some examples of these might be the use of magnifying aids (for craft activities); or volunteers to provide one to one support for bingo, computer classes; the use of microphones and loop systems for bingo, talks and lectures. Encouraging residents to use smaller, quieter spaces (including perhaps their rooms) and arranging for other quiet spaces could also be a helpful strategy for improving relationships with other residents and possibly forming friendships.

Environmental adaptations for sight loss were not talked about by staff, and examination of lighting, particularly in circulation areas, and for reading/crafts could lead to improvements for residents. Likewise, the use of minor technology for hearing loss (such as loop systems) could improve inclusion in activities.

Staffing and training

Residents were generally appreciative of the efforts of staff and their care. They did say that staff were usually very busy, and were not able to spend much individual time with them. Staff were aware that they had had little training in the area of sensory loss. Almost all of them said they would appreciate more training, and various areas were mentioned such as general awareness, use of aids and adaptations, care plans.

In addition, it appears that training in the significance of the combination of hearing and sight loss could be a very important theme. Information about the role and activities of voluntary organisations, the assessment for, prescription of, use and maintenance of low vision aids and amplification aids was also indicated by the responses of staff and residents.

Summary

Phase II of this project explored the lives of people with combined hearing and sight loss who lived in residential homes, through their own description of their lives and discussion with the staff who worked with them.

Through this process a number of key themes emerged which would lead to possible aims for the training activities which are the focus of Phase III. It appears that hearing and sight loss are *not easy to recognise* in older people in residential homes. There are many other factors which also keep them from involvement in the daily life of the homes, such as physical frailty, personality and family circumstances and these can mask the impact of sensory loss. The assessment and remediation of such sensory loss (with aids or other adaptations such as lighting) could have benefited from

increased understanding by both residents and staff.

The effects of combined hearing and sight loss were apparent in the lives of the residents, in relation to their involvement in activities, and in particular in friendships. Staff training in these areas would in most cases be welcomed and could improve the lives of residents and would equally ensure that staff are able to provide a high quality of care to the residents that they care for. This will be the focus of Phase III.

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