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FINAL REPORT
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Short study on hearing and sight loss

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1 Executive Summary

This report describes the outcome of a literature review and workshop which sought to:
- Overview the key recent published literature in the UK and identify ongoing relevant work in the area of combined hearing and sight loss;
- Make recommendations for future work – which might include development work and/or further research.

The research focussed upon the following groups of people:
- Those whose dual sensory loss developed in older age;
- Older people who have adapted to blindness or partial sight during their life, and are now losing their hearing;
- Older deaf, deafened or hard of hearing people whose usual means of communication is speech, and who are now losing their sight.

The evidence gathered led us to identify four of themes which will be described in turn.

1. Population definition and prevalence

Unusually in the broader field of sensory impairment, deafblindness is defined in 'social-functional' terms (the DoH define deafblindness as sight and hearing loss which results in problems with access to information, mobility, and communication). However, the *use* of this definition appears to prove difficult and the fact that there is not accepted common practice in research and service contexts makes evidence based research difficult to interpret and difficult to carry out. No clear prevalence data exists for the group. In addition, older people are particularly unlikely to recognise themselves in the term 'deafblind' although they may have problems with both vision and hearing.

We recommend that useful work could be carried out which operationalises the current DoH definition of deafblindness so that it could be used more easily and consistently. Such work might have the following features:
- Make use of the World Health Organisation Classification of Impairment, Disability and Health (WHO, 2001) as a framework;
- Use language that would prove useful to a broad range of professionals (e.g. academics, policy makers, health and social care professionals), as well as incorporate lay-language to support communication with people who might not recognise themselves as deafblind;
- Trial and recommend screening tools to be used to identify deafblind people and go some way to identifying their needs

2. Needs and circumstances of older people who have hearing and sight loss

Some literature exists which describes in detail the needs and circumstances of the group. The identified needs are:

- Information – including public information
- Communication
- Mobility and transport
- Stimulation/relief from isolation
- Social work/counselling
- Housing/equipment
- Needs of minority communities

In the main (though not exclusively) this literature draws upon case studies, biographies, and expert views. However, we found that no substantial research has taken place which seeks to quantify the impact of combined hearing and sight loss upon various aspects of quality of life (both in terms of the size of the impact for the individual and the numbers of people this might affect).

We recommend that more substantial work should be carried out which seeks to quantify the impact of hearing and sight loss upon various aspects of needs, circumstances and quality of life of older people with hearing and sight loss. In the first instance, this might involve seeking secondary data sources for analysis and linking with existing research projects. Such survey data would usefully be combined with existing case study information. A longer term approach (which would be ultimately more robust and complete) would be to carry out a survey which focuses upon this specific group. The design and methods of such a study would require careful thought, and would be informed by the first part of this recommendation. Two areas of particular consideration in such a study might be considering the needs of ethnic minorities and the preferred methods of learning for this population.

3. Service development and evaluation

While there are clear common themes in the literature and the workshop in relation to provision, there is no empirical work to draw upon for the evaluation of services. We make the general recommendation that more evaluation of services should be undertaken, and this is in line with a general concern with measuring the impact of services. This covers a broad range of services including those services *for* deafblind people, and access to mainstream services *by* deafblind people.

We recommend an audit and evaluation of current specialist services provided directly to older people with vision and hearing loss. This will include Communicator-guide (guide-help) services. This will include identifying the range of services provided, and developing a method of assessing the effectiveness of the service, perhaps in relation to increased participation in community and daily life activities. This evidence will include the views of service users, gathered with appropriate communication support.

Such evaluation and audit work could be very large scale. Strategies which might be more manageable might include:
- Continuing and building upon the existing survey work of social services departments currently carried out by Sense;

- Evaluating relevant local authority inspection reports;
- The generation of case studies of service development and audit.

The evaluation of access to 'mainstream' services may also prove a useful insight into the circumstances of people with hearing and sight loss. Particular examples might be gathering deafblind people's views regarding access to heath services and inclusion in residential home and day care provision. Case studies based around people's experiences and examples of good practice might be a useful approach.

4. Staff and training

Professional groups can be usefully divided into specialist, direct care, and general workers. While there are specialists in the field, their learning has tended to be experiential as there are very few training programmes which are relevant to them. Specialists in social work departments are likely to have developed from a specialism in deafness or visual impairment. Recent training programme proposals and developments may go some way to address this problem, but care will need to be taken to ensure that the particular needs of older people with acquired hearing and sight loss are addressed.

For more general and direct care staff (for example working with working with older people) awareness of the likely needs of this group is necessary. Relevant training programmes appear to exist. However, while such training is relevant, it may not be accessible to all staff providing direct care who are working, for example, in care homes. Training opportunities may be rare, staff turnover is rapid and staff may not invest time in their own training for what is often a low paid and low status job.

We recommend an investigation into current qualifications held by specialist staff and direct care staff, to discover what training has influenced the delivery of effective services. Further work could include a cross section of general services staff. The value of meetings of groups with special interest, such as LADWIG (Local Authority Deafblind Workers Interest Group) could be included to see how this group could be a part of such development in training.

2 Acknowledgements

3 Summary and purpose

3.1 Background

In spring 2005, Thomas Pocklington Trust commissioned a team from the University of Birmingham to undertake a scoping study to investigate the recent literature in the area of acquired hearing and sight loss in older people. More specifically, the study brief had two broad objectives:
- To overview the key recent published literature in the UK and identify ongoing relevant work in the area of combined hearing and sight loss.
- To make recommendations for future work – which might include development work and/or further research.

The study has two stages. Stage 1 involved carrying out a short literature review (approximately 10 days work). A preliminary report prepared in July 2005 was the forerunner to the first half of this final report (sections 4 to 7).

Stage 2 involved carrying out a workshop. The purpose of that workshop was to validate the Stage 1 preliminary report and to generate ideas about future development and research needs. This workshop took place on July 19th 2005. This forms section 8 of the report.

3.2 Overview of the report

The following four sections form the short literature review:
- **Definitions** – this explores defining the population of concern, the scope of the review, and the implications of this definition.
- **The needs of older people with vision and hearing loss** – this explores the literature (generally case study) related to needs.
- **Policy and general literature** – this outlines the identified literature which directly deals with older adults with hearing and sight loss. The literature used (in particular the policy documents) is generally UK based, to be of practical value to workers in this country.
- **Supporting literature from other fields of study** – this explores other sources of literature, specifically in the fields of visual impairment, hearing impairment, and older people. Limited material was found.

This literature review was originally presented as a preliminary report, but substantially modified following comments made at the workshop, as well as written comments made by individuals (approximately 4000 words were added). The section entitled **Workshop** presents the process and broad outcomes of the workshop.

A final section, **Discussion and conclusions** is our analysis of the information generated in the project and identifies a potential development work and/or further research which we believe would contribute to this area.

4 Definitions

The issue of definition and terminology continues to raise controversy even within the field of dual sensory impairment. In the following sections we attempt to unpick some of these issues in relation to older people in order to draw boundaries around the scope of this review.

- The scope and inclusivity of the term
- Working definition for this review
- Prevalence
- The concern as to whether those people with dual sensory impairment recognise themselves as such.
- The categories of dual sensory impairment within the population of older people

4.1 The scope and inclusivity of the term

The terms 'dual sensory impairment' 'vision and hearing loss' and 'deafblind' are used in literature in relation to the older population with acquired hearing and sight loss, and may have similar meaning. But there is no common or accepted definition of the term, although one is perhaps beginning to evolve, since the use of a definition (as below) in key Government documents in 1997 and 2001 (Think Dual Sensory, DOH 1997 and Social Care for deafblind children and adults DOH 2001a). The definition is more usually now expressed in social than in medical terms – that is there is no definition of visual acuity or auditory thresholds, but the terms used express the difficulties caused by problems with vision and hearing

> Persons are defined as deafblind if their combined sight and hearing impairment cause difficulties with **communication**, **access to** **information**, and **mobility** (DOH 1997, our emphasis).

There is more consensus about definitions of visual impairment (for the register of visually impaired people) and of deafness/partial hearing (for the register of hearing impaired people DOH 2001b). Since 2001 (LAC Guidance) (DOH 2001a) local authorities have been asked to identify and keep a record of all deafblind people. One way of doing this has been to compare records of deaf/hard of hearing people and of visually impaired people, but this is not a complete solution. Research in Bury shows that identifying people from a combination of both registers is not easy, and that in fact people were missed altogether (Partington, undated). Keeping a record of all older people with loss of vision and hearing may identify large numbers as having dual sensory loss, but many of them will not require much additional help. Think Dual Sensory (DOH 1997) suggests inclusion, rather than exclusion, for the definition, in terms of services, since some people apparently meeting the definition may not require many services, but early identification may assist in ensuring that needs do not become overwhelming. However, the 22 people interviewed by Partington (undated) from his survey in Bury, all identified significant problems with communication, information and mobility.

Although the terms 'dual sensory impaired' and 'deafblind' are also used for younger, and congenitally deafblind people, the needs of these groups are not the same;

> Adventitious elderly deafblind people need distinctive help, as people with acquired sensory loss have a very different set of needs from the congenitally sensory handicapped. (Sense 1991 pg. 14)

The complex needs of this group, distinct from those of congenitally deafblind people, and from people with single sensory losses (DOH 1997) mean that a different kind of professional and a different kind of identification may be appropriate for them. Indeed, the use of the words 'vision and hearing loss' may be particularly appropriate for this group, because they remind the reader that the person probably previously had these faculties and their loss may truly be associated with feelings of loss.

Within the definition of dual sensory impairment, a combination of difficulties leading to difficulties in communication, information and mobility, in older people, a number of subgroups have been defined. The most significant difference is between people with congenital or early life dual sensory impairments, and those who acquire difficulties with either vision, or hearing, or both in later life.

4.2 Working definition for this review

In 'Think Dual Sensory' (DOH 1997) five groups are outlined,

- Those whose dual sensory loss has developed in old age
- Older people who have adapted to blindness or partial sight during their life, and are now losing their hearing
- Older deaf, deafened or hard of hearing people whose usual means of communication is speech, and who are now losing their sight
- Older deaf people whose usual means of communication is sign language or signed English systems, and who are now losing their sight
- Older people who have had dual sensory loss throughout all or most of their lives (pg 8)

Of course, congenitally deafblind people also become old. However, their needs, in terms of learning, adaptation, services and management, are likely to be different from those of older people who have acquired sensory impairment. Duncan and Bagley (1998) refer to five groups, thus discriminating between those who have profound pre-existing impairments and those whose impairments were less severe:

- Late life acquired deaf-blind
- Blind later life acquired hearing loss
- Visually impaired late life acquired hearing loss
- Deaf late life acquired vision loss
- Hard of hearing/late deafened late life acquired vision loss. (pg. 63-4)

The significant difference outlined by Think Dual Sensory (DOH 1997) is the use of sign language as a primary communication medium. Those who use

BSL (British Sign Language) may consider themselves to be a part of the Deaf community, and therefore their communication and rehabilitation needs are different from those of the other four groups, who are more likely to use speech as their means of communication, and to be a part of a hearing culture. (The distinction in relation to Deaf culture is not usually made in terms of people with visual impairments).

The needs of the other remaining three groups, while not identical, focus around the maintenance of communication through speech and reading – and share more features. This review henceforward focuses largely on the needs of people whose communication system is based on speech, and who have acquired vision and/or hearing loss later in life (this excludes, for example, people with Usher syndrome). Some profoundly deaf people may identify themselves most strongly with aural/oral language – these people would be included in the discussion below.

The needs of these groups are not of course identical. Those who have single sensory impairments of longstanding may have developed adaptive strategies which are affected by the loss of the other distance sense, for example, lip reading to support understanding of speech, or the use of auditory information for safe travel in the environment (Bagley 1998).They may thus be suddenly (or gradually) incapacitated by increased difficulty with the other sense which may, falsely, be linked to incapacity of age or comprehension, when in fact it is related to further, perhaps unrecognised, sensory loss. In addition to this, older people may be acquiring additional sensory losses to already impaired senses – cataract in addition to a visual field loss, or presbyacusis (the loss of hearing sensitivity which occurs in older people) in addition to a more specific low frequency hearing difficulty (Butler 2004b).

In summary then, we are concerned with:
* Those whose dual sensory loss developed in older age;
* Older people who have adapted to blindness or partial sight during their life, and are now losing their hearing;
* Older deaf, deafened or hard of hearing people whose usual means of communication is speech, and who are now losing their sight.

4.3 Prevalence

Policy and published literature based on research presents a confused picture in terms of prevalence of combined sensory loss in the older population. In terms of policy documents, the DoH National Framework for Older People describes 22% of people over 60 as having "both visual and hearing impairment" (DoH, 2001, p4). Based upon a population of approximately 9.6 million people over the age of 65 years alone (2001 Census, National Statistics Online), this would be 2.1 million people with a visual and hearing impairment over 65 years in the UK.

Compare this to the estimate of 40 per 100,000 for the whole population described in the 2001 Local Authority Circular (DOH 2001b) – which would

give approximately 24,000 across the entire population of Great Britain (although most would be in the older age group).

A different figure again can be gleaned from prevalence figures (and related surveys) associated with (for example) visual impairment. Bruce et al (1991) claimed a figure of approximately one million people with a severe visual impairment in Great Britain. While this figure is now thought to be an over estimate (see, for example, Evans et al, 2002) it offers a useful contrast because the survey associated with their work found that 35% of their sample reported that they would have difficulty hearing a normal voice in a quiet room. Therefore, this would give approximately 350,000 across the adult population of Great Britain who were blind or partially sighted and had a hearing loss (again, most would be in the older age group).

These are all simplified calculations but demonstrate the differences in the available figures (2.1 million, cf. 350,000, cf. 24,000). The clear cause of these differences is differences in criteria. Most likely, the lower prevalence figures are calculated on an assumption of 'severe' visual and hearing impairment (most likely 'registrable' in both cases). In contrast higher estimates assume some degree of non-correctable visual and hearing impairment. In terms of the 'social' definition of deafblindness as described above – 'causing difficulties with communication, access to information and mobility' (DoH, 1997) – then potentially all the figures have some validity and use. Nevertheless, it makes generalising research findings across a population far more challenging. If no figures or thresholds are universally agreed, then there can be no accurate, consistent prevalence studies. The current definitions are not presented in this way.

4.4 The concern as to whether those people with dual sensory impairment recognise themselves as such

While the definition adopted may be useful, many people with impaired vision and hearing may not recognise themselves as having a dual sensory impairment/loss or, more particularly, as being deafblind (e.g. Cox 1999, Matthews 1998). They may consider that sensory impairment is just one more effect of old age (Goodwin 1998, Butler 2004b). Impaired vision and hearing may have crept up on them slowly, so that they are not aware of their new needs, or they may be unwilling to accept the possibility that they have them (an example from the Netherlands is given in Wijnhoven 1998). While many older people with dual sensory loss may have other problems associated with ageing, the majority of older people consider themselves to be in good health and not to be limited by disabling conditions. For others though, sensory impairment may be compounded by the additional difficulties, some associated with ageing, for example, decreased mobility, difficulty with memory, other disease and for some, depression. These people may not recognise their sensory problems as 'deafblindness' Older people may also fight to maintain their self identity despite various types of loss. Matthews (1998) at the 'Expert Meeting' in Copenhagen suggested that it was important

to continue to insist on the title 'deafblind' because it alone described the effect of the combination of vision and hearing loss and indicated

> that different strategies and skills are required that include use of other senses – for example tactile approaches – and other techniques.   (pg. 37)

This does raise the question of whether it is, to some extent, for the benefit of the specialist interest groups in the field of sensory impairment, that the term 'deafblind' is applied to this group. This term is used by the major charities involved in working with this population (Deafblind UK, Sense, RNIB) and by Government departments (DOH, DfES). There remains a tension here between the value of the term to ensure that services appropriate to the individual are provided, and the difficulty in using it with people who do not understand it, non-specialist professionals and older people themselves. There are negative implications of the use of the term. Cox (1999), for example, comments regarding the provision of information to people called deafblind;

> this labelling proved highly damaging, allowing people to develop a false opinion of the information needs of the individual… information (was) refused because other agencies had labelled the person deaf blind and a culture of fear and misunderstanding had grown up around the ability to communicate with the individual (pg. 23.)

While the term 'deafblindness' provides visibility for this group and therefore the requirement for the provision of services, there is a need for a balance between these specialist needs, and those needs which could be met in generic services without significant additional change or adaptation .
There are clearly benefits in the use of this terminology. Since the 2001 Local Authority Circular (DOH 2001b), local government services are required to provide deafblind people with specialist and particular help which may not be available to this group otherwise. There are means of helping people who have vision and hearing loss which are not obvious to people who only have experience of one or the other sensory difficulty. The Northern Ireland study (2004) outlines a variety of means for communication, including hearing aids, audiotapes, large and extra large print. A professional with experience only in hearing loss might not recognise the benefit of a talking newspaper for someone who is visually impaired. Kaye (1998) talks about the use of resource rooms where older people with vision and hearing loss can try equipment to find what may be most suitable for them, balancing their difficulties with vision and hearing. A variety of equipment may help, including magnifying glasses, CCTV, hearing aids, magnetic loop systems (which work with hearing aids) (Technical aids, 1998).

Staff working with this group frequently do not use terms such as deafblindness, or would not identify with the use of this term, thus reducing the effectiveness of information (Prain 2000 from Australia). This is also discussed further on. However, perhaps a different focus on the needs of older people as older people with a range of difficulties, rather than particularly as dual sensory impaired, would in fact increase their access to these services.

5 The needs of older people with vision and hearing loss

Much of what is written about older people with vision and hearing loss is based in case study and biographical information and in this there is found a wealth of detail about the lives of people who live with vision and hearing loss. However, such material is likely to focus chiefly on those who have the greatest difficulty, and on those who have been identified as having dual sensory impairments. Those who may be missing from this literature include those who are not identified as having dual sensory impairment and those who have fewer difficulties.

There is also less detail about the extreme difficulties of gathering information from people with whom communication could not be established (Partington, undated).

The needs of this group are of course centred on the difficulties mentioned above with communication, information and orientation and mobility. Terry (2000) describes a 91 year old lady called Mrs Bacon with macular degeneration which has left her with almost no effective central vision and a hearing loss which prevents her from accessing speech almost entirely. Consequently, it was very difficult to communicate with her as she was not able to understand what others said. Teaching of fingerspelling alphabets (the deafblind manual which uses similar letter representations to those in British Sign language and is spelt directly onto the hand of the deafblind person and the Spartan/Block alphabet, where capital letters are spelt on palm in a structured consistent way) was introduced when they were not so essential to her communication and at this early stage she did not have sufficient reason to learn them. A variety of other strategies for communication have been used since with different degrees of success. These have included amplification through a speechmaster device (which has given her some hearing for speech), the use of a magnifier which was difficult because of her shaky hands, and the use of large black letters on white paper (Terry 2000).

Partington (undated) describes SB who is 87 and keen to continue to be involved in life. However public transport has become very difficult to use, because of problems in seeing bus numbers and with the layout and information at the bus station. Low floor entry buses help SB. Overhanging foliage and cracked pavements, cars parked on pavements and high kerbs cause difficulty if SB walks. Sometimes SB uses a four wheeled shopping trolley for stability but if it is raining SB cannot hold an umbrella and push the trolley. Lack of public awareness caused SB to have to leave shopping behind when a long queue meant that otherwise the bus would have been missed, but an explanation to a member of staff met with a negative response. There is less written concerning information needs, but this perhaps does not reflect the importance of the issue. Matthews (1998) describes the link between information and human culture and the deep need to connect with this in his short description of Nancy who watched the cup final on television

although all she could tell from the TV was that one team were playing in blue and one in yellow:

> It struck me that it was remarkable to persevere with watching the match with access to so little information. However, perhaps the important thing was watching the match as billions of other people were doing – of connecting with human culture (pg. 36).

Sensory impairments also significantly limit people's ability to maintain their independence and their involvement in daily routine. Matthews points out that in a study of people aged 90 years or more, only sensory impairments caused 'total incapacity' for completing activities of daily living (Bury and Holmes 1991, cited in Matthews, 1998). There is evidence that single sensory impairments can cause lack of independence in the older population (Prain 2000, cites the study by Carabellese, Appollonio and Rozzini et. al. 1993 in Italy). If single sensory impairments restrict the ability of people to take part in every day life activities, then dual sensory impairments can only add to the restriction. Daily routines and simple daily tasks are very important in people's perception of themselves and others as normal, able and members of the community, and in giving them things to do, a reason for getting up. Without these, people can become not only dependent but also completely isolated and bored.

These difficulties may be exacerbated by professionals' perception that they are to be expected;
> there's an almost institutional reluctance to address the needs of this group,...... based on the view that loss of sight and hearing are a normal acceptable part of ageing pg. 11 (Duncan, quoted in Wolf 1999)

6 Policy and general literature

There has been a growing awareness of the special and specific nature of dual sensory impairment over the last 20 years, perhaps partly because of the increased interest in congenital deafblindness and deafblindness in children, as reflected in the DES policy statement in 1989 where deafblindness was recognised as a disability distinct from either visual impairment or hearing impairment (Kaye 1998).

Reports such as 'Breaking through' (1988) began to present the issues of a wider population than children, and this was followed by 'Think Dual Sensory' (DOH 1997) which specifically recognised the needs of older people who are deafblind. This document recognised the needs of deafblind people for particular services, such as Guide Help schemes and appropriately trained and qualified workers concerned with dual sensory impairment. 'Think Dual Sensory' (DOH 1997) also provided examples of good practice from around the UK, which were presented as possible models for other authorities. These included the development of a Guide Support service in Bradford, the use of optometrists in low vision services to identify possible hearing difficulties after additional training (in Camden and Islington), the setting up of a social club for deafblind people in Bristol, and the creation of "good quality" guidelines for deafblind people living in residential homes, in Suffolk.

Following this, the DOH issued guidance in a Local Authority Circular on social care for deafblind children and adults (DOH 2001b – 'Social care for deafblind children and adults'). This placed key duties on Local Authorities in regard to deafblind people to identify, provide suitable assessments and appropriate services for deafblind people, to produce material in accessible formats for them and to provide strategic direction and management of services.

These points are used as the basis of the following discussion. (Examples from other European countries as reported are also used where relevant):

- Identification
- Assessment
- Services and provision

6.1 Identification

Identification of deafblind people is not simple, as has been shown above. Many older people with dual sensory loss do not recognise themselves as deafblind and may not be recognised as deafblind by those who work with them. As described above, they may recognise themselves as having a sensory loss, or they may see themselves as dealing with problems of old age. Where they are identified, central registers may not exist. (Since 2001 social service departments have been obliged to develop registers of people who are deafblind. In 2005 these are still emerging – see below.) In some cases, systems used for identifying deafblind people may not be comprehensive and people may be missed. While different definitions are used for dual sensory loss, it is difficult for prevalence figures to be equivalent. The use of different methodologies and entry criteria have meant that although a number of authorities have carried out studies to ascertain the numbers of deafblind people and to identify them, the same groups may not always be reached, and these reveal very different prevalence figures (e.g. Corrin 1991, Northern Ireland 2004 – although this survey was not concerned only with older people – Goodwin 1998, and also Mortensen, 1998). As Terry (2000) points out older people with vision and hearing loss are unlikely to protest and demand services. Early identification of vision and hearing loss, possibly through improved screening of people aged 75+, (Kaye 1998 and DOH 1997) could mean intervention as soon as possible for the preservation of communication systems or if necessary, the ability to develop new ones. This is more likely to be successful, it is argued, if undertaken before ongoing worsening impairments make communication difficult, and therefore learning new methods harder still. However, this may not always be useful (see the example of Mrs Bacon above, who was not motivated to learn a manual alphabet when she still had sufficient hearing). And further, without general professional awareness of the possibility of dual sensory impairment in older people, this diagnosis may not be made. All professionals in this field need to have access to information about the effect of combined vision and hearing loss.

Importantly, the DoH guidance (DoH, 2001b) has led Sense to carry out annual surveys of social service department provision (e.g. Sense, 2005). While these appear to be unpublished at this stage, they have been circulated

at ADSS sensory sub-committee meetings. The initial results show that identification has dramatically improved as a result of the guidance, with approximately 10,000 people who are deafblind being identified by the responding authorities (an increase of 67% in two years). The reports do not provide details of the ages of these people, but most are likely to be elderly, that is, over 65. Social services registers and associated surveys (and similar follow-up surveys) are likely to be an important source of evidence of identification of people who are deafblind as well as potentially providing evidence of service provision.

6.2 Assessment

The Local Authority Circular (DOH 2001b) identified the need for specialist assessment of people with dual sensory impairments. There are a number of issues related to this and arising from it. Assessments of people with dual sensory impairments take a great deal of time to complete properly (Partington undated, Kaye 1998), longer than those for people with single sensory impairments, or than might have been expected. As well as requiring increased time, appropriate, probably specialist, training is needed.   Without such training, professionals may not be able to make a true assessment of the effects of dual sensory impairment, as against the effects of other disabling conditions or ageing;

> Non-specialist assessors may put problems down to age or vulnerability, not deafblindness itself…. what may be missed… is the opportunity to help people make best use of their residual vision and hearing (DOH 1997 pg. 23).

Duncan (2002) describes how a specialist in dual sensory impairment may put together the 'jigsaw' of differing needs, and Schipper (1998) gives further examples of the success of specialist assessment (in the Netherlands). It is unlikely that a standard or simple answer will assist the person with a dual sensory loss. For example, they may need an adapted telephone to ensure that it is loud enough to hear. But such an adapted phone does not have tactual markings, and so is less accessible for the visually impaired person. The specialist may be able to find the best possible answer, for instance, marking the phone with raised symbols, combining her understanding of all the issues affecting the individual.   The Local Authority Circular (DOH 2001) explains that the commissioning of specialist services may be necessary.

In the absence of a specialist worker, someone with experience in visual impairment may be sent out with someone with experience in hearing impairment and deafness, to carry out an assessment together (Partington undated). This is both wasteful of time and possibly of opportunity, because it does not recognise that deafblindness is more than a combination of visual and hearing impairment, but a separate disability with its own particular conditions. The specialist worker for hearing impairment may suggest a solution which relies on visual ability, and not be able to provide an alternative. The alternative for a person with combined vision and hearing loss may be something else – for example, a microwave with a dial, rather than one with either a visual display or which speaks.   This approach may even lead to the situation where someone is asked to identify the 'major difficulty' in order to appoint a key worker (Partington undated). Particularly in the case of older

people, this is probably not an appropriate way to move forward. A totally blind person who has been blind all their lives, with a mild-moderate hearing loss might be assigned to a worker with a specialism in visual impairment, but they already cope well as a visually impaired person – it is hearing impairment, although mild, which is causing them renewed difficulty. This indicates again the need for awareness level training at least for all workers in the area of sensory impairment and with older people. In Northern Ireland (2004) 10% of people were visited by a specialist social worker from a team for dual sensory impairment, but 49% by a specialist social worker in visual impairment or hearing impairment. (This survey in Northern Ireland was not conducted solely with older people, but 75% were over 60).

Cox (1999) comments that increased use of generic, rather than specialist sensory, social work teams may mean that even less emphasis is placed on the significance of vision and hearing difficulty. For some, this may present a picture which a person with a vision and hearing loss recognises – as having a range of needs but these not specifically relating to sight or hearing loss. In other cases, a worker for older people may have awareness of the issues through experience and training.   Willets and Peaker (1998) suggest that there are insufficient links between professionals with roles with older people and those specialists working with people with sensory impairments. This is a major obstacle for effective assessment and provision of services. But in view of the needs which may be presented, such as the need to learn to communicate effectively in a different, or enhanced, way, specialist services may be needed (Duncan 1998). Research could help to indicate whether generic or specialist services best meet the requirements of users and to what extent these services are effective.

Clinical assessment (and treatment) are also essential for people with problems related to age, including vision and hearing loss. However, health services may be reluctant to treat people as dual sensory impaired (Cox 1999) but deal separately with impairments of hearing and vision, and information and communication maybe so poor that the person with sensory loss does not know what is happening. There is evidence for such difficulties in case studies given by several authors, e.g. Partington (undated). It may be difficult to obtain appropriate help, such as hearing aids, for this group (Matthews 1998, Butler 2004b). ‘Think Dual Sensory’ (DOH 1997) suggests that the ‘boundary’ between health and social services must be crossed, for effective assessment and management.   Such joint, combined assessments from medical/clinical and social perspectives would obviously be of great benefit to the individual, but case study and biography shows little evidence of this (Partington undated, Terry 2000).

‘Think Dual Sensory’ (DOH 1997) gives an example of what might be used in such an assessment, and this includes the need for assessment of:
> potential for learning new skills and the appropriate time to introduce them (pg. 21)

This potential for learning is a complex matter and no guidelines are given as to how this might be done. Terry (2000) gives some examples of what individuals needed to learn, and how this might be assessed, for example, the

use of deafblind manual or Brailtalk. Trickett (1999) suggests some further ways in which this applies to learning to communicate. Case studies, again, reflect the need for people with complex vision and hearing loss to learn new methods of communication, and for sensitive professionals with time to introduce them (Wijnhoven 1998, Duncan and Bagley 1998). Such new methods may include the use of amplification equipment, of enlargement (for notes and script), the use of tactile 'written' formats such as the Moon code, the use of fingerspelt alphabets (the deafblind manual) or even the use of objects as cues to what is happening next, where no more formal communication can be established.   Interestingly, the topic on how older people learn, although proposed at the expert meeting on older people with vision and hearing loss in Copenhagen in 1998 was not voted to be discussed by the participants. It appears that very little is known about this at present, and that research might help professionals to know how to present and motivate learning experience for older people, in particular for those with sensory impairments.

Such assessment should also include the needs of carers
separately... from those of the deafblind person (DOH 2001b pg. 21).

Carers themselves need to be a part of the package of support (Kaye 1998, Butler 2004a). They may need training, for example in communication methods (Terry 2000). Small scale studies show that older people with vision and hearing loss are frequently very reliant on one person with whom they can communicate, usually a close family member who is a carer (Partington undated, DOH 1997, Terry 2000, Northern Ireland 2004). These carers may be a partner, or a sister or brother, therefore may have sensory difficulties themselves – even a son or daughter of someone in their 90s may be 70+. These carers may be frustrated at their inability to communicate effectively, while the person with vision and hearing loss may be dependent on them for information and communication.   This may lead to problems and tensions in the family in addition to those with sensory impairment.

6.3 Services and provision

'Think Dual Sensory' outlines the following areas which 'will need particular attention' (DOH 1997)
- Public information
- Communication
- Mobility
- Stimulation/relief from isolation
- Social work/Counselling

As well as these matters, we would argue there are housing/equipment, and the needs of minority communities.

Information – including public information

Problems with information restrict both the life and the interests of older people with vision and hearing loss. Some examples of these problems, to illustrate scope and range, are given below;

- difficulty in reading food produce labels in the supermarket (Partington undated) and, additionally, difficulty in asking someone else what they say
- not knowing if they have dialled a correct number on the phone while leaving a spoken message (Terry 2000)
- not knowing what the sermon is about in church (Partington undated)
- difficulty in filling in forms or reading information leaflets, for example, for services (Cox 1999)
- not being able to read the newspaper or hear radio/television news (Terry 2000, Wolf 1999)

The Local Authority Circular (DOH 2001) says that authorities should provide information in accessible formats, including for example, large print and personal assistance through the use of deafblind manual. The deafblind manual is a means of communicating with a person who has severe vision and hearing loss by spelling out each word on their hand, letter by letter. It depends on the ability to read English (because it uses a 'code' for English letters), and requires close proximity and touching, which some people may find difficult. Cox (1999) and Partington (undated) both refer to the great difficulty deafblind people have in accessing public information, in particular that about services which they might use. 'Think Dual Sensory' (DOH 1997) outlines two types of information – that relating to all local citizens, and that relating specifically to deafblind people. In addition to this, there is of course, information relating to world events and issues, local issues, and family issues (to mention just three areas). Being isolated from the talking points of the rest of their community cuts people with sensory loss off from others (see below). Cox (1999) acknowledges that most of this group prefer to gain information through other people, using others presumably as 'communicators'. Cox comments that where information is relayed by someone else (who may be a relative), it may be limited or censored, rather than complete. However, considering that communication may be difficult and take a great deal of time, pared down information may be all that is possible or realistic. Cox shows that local authority services were not effective in passing on information about services, (which may be the case for older people in general), and that older people with dual sensory loss did not know, for example, which groups might be able to provide them with advice about sensory loss, information which might have been easier to get if fully sighted and hearing.

Information is a key tool for deafblind people in finding the most appropriate support and services. Lack of information denies deafblind people mobility/transport and other support and further disables and excludes them (Partington undated, Bashton 1998). The standards for care for people with dual sensory impairments produced by Lewin-Leigh (2001) emphasise the need for deafblind people themselves to know about the services they use and the way in which these are monitored. Only 22% of Cox's sample of fifty people (Cox 1999) wanted direct information themselves. Most wanted it through others, presumably through human communication intervention, either from professionals or from family members. The use of family members as communication support means that carers and family need to understand the importance of information and the best ways to present information, which can be complicated (for example, about benefits,

adaptations, and medical issues), in ways which are not too lengthy and do not require too much concentration. Cox's conclusions were that older people with vision and hearing loss had great difficulty in finding information, that accessible formats of written information were not used, or not available and that other means, such as human support, were not always used. The use of one to one help may alleviate this situation (examples are given in Partington undated), but most sighted hearing people constantly filter the vast amount of information available to identify those matters about which they wish to know more. It is hard to know how such power and choice can be given to people who are not able to access information so readily. Telephone communication may be possible by use of an induction loop in the phone to utilise the amplification of hearing aids, or a fax machine for those with sufficient residual vision (Terry 2000). Text messaging may be possible for others with sufficient vision but is less commonly used by older people. There are other devices to assist phone information, but these may be highly adapted (such as textphone system) or not very commonly used (such as the type talk system available through the operator) and both of these may seem unusual and atypical as well as unnecessarily complicated for the older person.

Communication

Communication is often seen as the key difficulty for people with dual sensory impairments. Many authors write of the problems and solutions for establishing and maintaining communication with older people with sensory losses.

Some examples of difficulties and solutions are given to show how this may affect individuals;

➢ loss of friends because of inability to speak to them on the phone, go out alone, or read or write letters to them (Terry 2000)

➢ difficulty in communicating with a group of people, even family, as a one to one communication environment is needed (Partington undated)

➢ the use of objects to signify key events – such as a knife and fork for a meal, a tactile domino for a game, because the person with sensory loss is unable or unwilling to establish more conventional communication (Duncan 1998)

➢ changes of communication method over time as senses deteriorate, for instance from lip reading to reading notes, then to using letters traced on the palm (DOH 1997)

➢ the difficulty in using assistive listening devices or hearing aids because no instructions or guidelines are available in large print (Bagley 1998)

Communication for some people with profound visual and hearing loss can be extremely difficult (DOH 1997, Terry 2000, Partington undated, Goodwin 1998, Duncan 1998, Bagley 1998, Duncan and Bagley 1998). However, as Bagley (1998) explains, it is not usually expressive communication that is difficult, but receptive communication, allowing the person with dual sensory loss to understand what others are saying.

> People who have lost vision and hearing in late life really want to cling to oral communication and visual functioning for as long as possible   (pg. 24)

Most use their voice (Northern Ireland 2004), or previous forms of communication (Chapman 2002).   However, case studies and biographies make clear that many people rely on others to interpret or relay information to them, and that communication may be difficult or even impossible. The partners with whom they communicate may also be old themselves (Partington's case studies illustrate this). Difficulty in communication can affect all other areas. Wolf (1999) gives an example of a man with a prosthetic leg which did not fit – but he could not communicate this effectively to anyone else, so it was not changed, and he became immobile. Case studies show that there is frequently difficulty in communicating with doctors and medical professionals, who do not take sufficient time or notice of the dual sensory impaired person (Butler 2004a, Terry 2000, Partington undated, Wolf 2004). This is significant in the light of the difficulty in identification and diagnosis of sensory impairment and the additional, and sometimes unnecessary problems which may be caused by poor communication. Particular care may be needed for those who use their hands for communication and information, such that physiotherapy, for example, may be intensively required, and that medical treatment should avoid the hands if at all possible (DOH 1997). There are examples of people with extreme difficulty in communication who were encouraged, slowly, to accept more tactile means of communication. One man's initial reluctance to touch a communication partner was gradually developed through the use of tactile letters and learning of capital letters (Wijnhoven 1998). Another man began to accept tactual cues for events after playing tactually marked dominoes with his communication partner. He now uses a few objects to signify key points of the day, such as a knife and fork before a meal (Duncan 1998). There are some examples of people with whom no acceptable communication was able to be established. Partington (undated) interviewed a number of deafblind people but was not able to establish contact by any means with one, and for others this was difficult. Duncan (Duncan and Bagley 1998) also describes a case where no communication was established with an older person with vision and hearing loss , and this person was subsequently abused by his family and died.

There may be a variety of types of communication used with a person with vision and hearing loss.   Access to printed information may be through Braille or Moon codes (tactile alphabets) or through the use of enlargement equipment . Others may be taught fingerspelling alphabets, the deafblind manual (or Spartan/Block). The acceptance of hearing aids or other amplification equipment (such as loop systems or personal amplifiers) may be important for others. Some may continue to be unable to develop understanding of such formal systems (or of course they may not be presented or taught appropriately) and for them objects as signifiers, such as a cup to represent tea time. These may be called by some 'objects of reference'. Examples of these are given by Todd (1999), Duncan (1998), Terry (2000), and Prain (2000). Carers also need help in learning to communicate (Terry 2000).   Sometimes interpretation may be required (an exact rendering of the content and tone of what is said – for example in relation to legal matters or a letter from someone else) but in other cases a communicator guide, offering communication support may for example,

describe roughly what a shop assistant said to explain why there are no tomatoes in the shop. However, this key difference (described in 'Think Dual Sensory' DOH 1997), may not be understood by other professionals and inappropriate support may be used. The need for interpretation where English is not the first language raises even more difficulties. The lack of communication also causes difficulty with isolation and inability to socialise, and prevents people from trying to take part in activities. This withdrawal can cause problems with boredom and depression. A person with vision and hearing loss can be 'isolated, even in company' (DOH 1997) because no-one is trying to communicate. Isolation remains a key issue for all people with dual sensory impairment.

There may also be gender specific issues – where men and women have different styles and expectations, or where boundaries are perceived around acceptable means of communication.

In addition to this, there are particular needs for developing interactional skills for people with sight and hearing loss. These may include, for example, how to tell other people that vision and hearing are difficult, how to speak one at a time, how to ask for repetition (Schipper 1998, an example from the Netherlands). Methods such as introduction videos may help older people with vision and hearing loss to explain for themselves about their communication needs. This allows a person to make a video about how they communicate well (and since this involves tactual methods and movement, video may be a better tool than script for demonstrating, for instance, written description only).   Terry (2000) gives a similar example.

Mobility and transport

Difficulties in getting to where they want to go are also mentioned in the accounts of older people with vision and hearing loss. Examples of these difficulties include;

- ➢ inability to read bus numbers and so to travel by bus independently (Partington, undated)
- ➢ only going out to hospital appointments (for which, presumably, transport was provided) (Terry 2000)
- ➢ difficulty in communicating with transport services; telling someone where you want to go (Partington undated)
- ➢ presence of pavement hazards such as boards, seats, and steps which are difficult to see (Partington undated, Northern Ireland 2004)

Lack of mobility is also a major theme in the accounts of people with dual sensory impairment (Partington undated). Svingen's (1998) study of deafblind people over 67 years of age in Norway shows that all of them had difficulty with movement outside their home, 80% inside their home.   Sometimes this lack of mobility is due to loss of vision, sometimes to physical and movement difficulty . Partington's case studies (undated) and interviews in Northern Ireland (2004) present problems with seeing bus numbers, costs of alternative transport such as taxis, poor quality of pavements and presence of pavement hazards, which all meant that people were very dependent, or unable to go out. Even though some specialist services (cf. dial-a-ride) might be available, the drivers of these vehicles did not necessarily understand the needs of

people with sensory impairments. Many of these services can also be run by volunteers who may not have any training and establishing communication can be difficult for even experienced workers. Lack of information (see above) limited their awareness of transport possibilities which might have helped them.

Turner (1997) in his survey of 'older people' (50+) found that only four of the 604 people he identified reported needing mobility support such as wheelchairs or transport. However, his sample was identified from people in residential accommodation or in receipt of services – and many of these were having some help with transport. He does not suggest that his sample is representative of the group as a whole.   There may be a greater need for help with transport than has yet been identified by surveys. It is not necessarily possible to differentiate clearly between the needs created by dual sensory impairment and those created by physical infirmity, or the combination of the two. It may be that people in residential care do not have access to other visits outside their home. For others, there may be few opportunities to visit places or activities where there is an appropriate environment for them to be included. They may feel that there is nowhere to go other than medical appointments (as appears from case studies, such as Partington, undated). Difficulties with travel may limit the ability to join in with social occasions or attend social groups or outings. It may be that opportunities and invitations diminish as a person finds it increasingly difficult to go out .

Kaye (1998) describes how falls in older people are frequently due to poor vision, and shows that early detection of such difficulty might limit falls, and decrease subsequent physical difficulty, such as broken bones.

Stimulation/relief from isolation
When there are difficulties with both vision and hearing, even ordinary, every day activities may be difficult or impossible. There may be nothing to do
> How do you fill your days if you can't read, watch television or listen to the radio? (Wolf 1999 pg 10)

Some quotations from older people with vision and hearing loss illustrate these difficulties
> "so used to just staying on my own. If I go anywhere I can't see a thing. I can't hear others talking. Very little I can do"
> "As regards activities, if I go anywhere, I can't see or hear, so what is the point?" (both Northern Ireland 2004 pg 6)
> "I used to be very active, knit, sew, read but now I can't do anything and I'm bored stiff" (Partington undated)
> "I'd pay almost anything to be able to go out and do things for myself again" (Terry 2000 pg 25)

There may be great difficulties in completing ordinary, every day activities for older people with vision and hearing loss, although those who have previously adapted to visual impairment may have already developed compensatory strategies and skills. As has been shown above, the typical activities of daily life may be impossible (Matthews 1998). If a person is not able to complete daily, routine activities, not only are they disempowered but they are also likely to be bored because there is nothing for them to do.   People with vision and hearing loss may feel very alone, and it may be considered that they

cannot do very much for themselves (DOH 1997). The 'activities of daily living' (Matthews 1998, Wolf 1999) may be difficult for them, which can leave them with nothing to do.

> Mrs Smith pays people to do her shopping and cleaning; much of her independence has been taken from her, along with her confidence (Terry 2000 pg. 25)

Some may need specialist equipment to complete these activities, and possibly help in learning to use it. Both of these depend on assessment, firstly assessment of technical equipment, and secondly of the person's willingness and ability to learn to manage it. Learning to do things again with help can re-empower people (Jefferson and Cutts 1999). Training for support workers and helpers may also allow a person with visual and hearing loss to take more part in activities which they cannot do alone (Roets 1998, from the Netherlands, gives an example of helping an elderly woman to take an interest in cooking again). Even in a residential home a person with combined vision and hearing loss can be very alone (Roets 1998, example from Netherlands). Svingen's (1998) study showed that people with combined sensory impairments mostly stayed in their own rooms in their residential home. No evidence relating to sheltered housing was found. This may be even more isolating, as there may be little contact with staff. Staff in a residential home may be busy with domestic tasks, and not have time to speak to an isolated person (Wolf 1999). One local Age Concern centre has employed a person especially and only as a 'social integration worker'– forbidden to do any domestic tasks, the job is to ensure that communication support is available to those who need it, thus potentially limiting continuous isolation (Butler 2004a). The isolation and lack of connection, difficulties with communication and information described need a person who is committed and interested in helping an individual, who is prepared to be flexible in communication, and to take the relevant time, and who treats each individual as a person.

The use of Guide Help (or Communicator Guide) services is also aimed at reducing isolation and increasing meaningful activities for people with vision and hearing loss, particularly those living independently or with families. Terry (2000) lists the activities which people with dual sensory impairment in Kent wished to undertake with this kind of assistance (not all of her sample were elderly, although 80% at least were 60+)

> Reading correspondence
> Writing/typing correspondence
> Payment of bills
> Communicating in groups
> Communicating one to one
> Going to GP/hospital
> Food shopping
> Other shopping
> Keeping up to date with news and information
> Joining in a day centre/club
> Going out safely and confidently (pg 9)

The need for and use of communicator-guides has been described in a number of small studies (Terry 2000, Partington undated, Northern Ireland 2004) and in case study and biographical accounts (Bashton 1998, DOH 1997)

> With the support of .. her Communicator-Guide, Annie is now able to go out.. maybe they will go out for a drive. Annie loves the movement of the car, the sun on her face and can recognise some of the landmarks in her home town. "she's ever so good, takes me all over. We have a chat, go to lunch – I love to get out," she smiles.. (Anderson 2002 pg 30)

While there are anecdotal reports about the improving lifestyle of people who receive such a service (Wolf 1999, Terry 2000) there is no evidence base for evaluating such support or the value of the different types of service provided. This is a significant area in which further research could assist local authorities and other providing bodies to organise services which are valuable to individuals as well as value for money.

Kaye (1998) suggests that there remain a very small number of such services in the UK, some provided by local authorities themselves, others contracted out to organisations such as RNIB, RNID or Deafblind UK. The provision of these services requires the very careful assessment of the needs of the individual (Wolf 1999a and b). The service requires people with particular skills and training, as Terry (2000) and Duncan (2002) recognise, people with communication skills in recognised techniques such as deafblind manual, but also in flexibility and innovation.

While such assistance is a very powerful support for many there may be drawbacks. Some people may find the intensity of this support too demanding and too personal, or they may not be able to manage the support of family alongside such a person. The family may require as much support as the person with dual sensory impairment. This support may be emotional or practical as the burdens of caring take up so much time for the regular carer. Other family members themselves may be elderly and/or have disabilities or problems and also need support which they may consider the support worker can give. In Wigan, home care assistants employed as guide helps are approved by deafblind people themselves to work with them (DOH 1997). Alternatives may also need to be considered for some individuals. Because the difficulties of the person with vision and hearing loss are complex, such support may also be needed for people in residential accommodation, as described above and below, to ensure that they are able to take part in social activities and in the activities of daily living. It is not easy for someone without specialist training, or understanding, to see how a person with difficulties with both vision and hearing can be involved in activity (Partington undated, Wolf 1999). Once again, the title 'deafblind' may work to their detriment, by encouraging people to think that a person with dual sensory loss they would not be able to take part, when in fact, with some adaptations this would not be difficult. For example, a light and a contrasting mat allowed one person to manage eating independently, (Butler 2004a) a pillow alarm can allow a person to wake up without another's help (Turner 1997) tactile dominoes allowed one person to play dominoes with Duncan (1998) and the use of a variable speed and tone tape recorder allowed the use of recorded material again (Roets 1998 – example from the Netherlands). For others, specialist help may be needed to ensure that the person with dual sensory loss has the

relevant information to choose activities (examples from Roets 1998 and Prickarts 1998 from the Netherlands).

Social work/counselling

Some of the examples in the previous section and below illustrate the isolation of older people with vision and hearing loss which may lead to depression and withdrawal.

> ➢ An 86 year old asked workers take her to the railway station, so she could jump in front of a train (Roets, 1998, an example from the Netherlands)
> ➢ An 84 year old is concerned about how much longer it will be possible to use the remaining vision and what will happen when it is lost (Partington, undated)

One of the major consequences of isolation, and thus of vision and hearing loss, is depression. 14% of the people in the Northern Ireland study (2004), (not all of whom were older people) said they were depressed. Dual sensory loss may cause boredom (Partington, case studies, undated) confusion, withdrawal, loneliness, (DOH 1997) high dependency and 'almost complete exclusion from social life' (Northern Ireland 2004), anger, anxiety, passivity, inadequacy (Butler 2004a). Such withdrawal from the social world may first be forced on individuals with vision and hearing loss by sensory impairment, and then become a way of life (examples are given by Terry, 2000 and Partington undated). There may be grieving and adjustment for the loss of senses, and for the loss of friends and contacts, and a need to adjust to change, for example to fear or embarrassment at their new needs and requirements (Chapman 2002, DOH 1997).

Issues relating to difficulties with sensory impairment are not identical with those of ageing. While many people who are very elderly have friends who have died, the situation of the dual sensory impaired person is that she loses contact with friends because

> she cannot go out alone, hear on the telephone or read their addresses in order to write to them (Terry 2000 pg. 25).

Of course, actual bereavement adds additional layers of loss. A person with vision loss may not be able to see letters or photographs as remembrances of a loved person, or be able to talk to another person about them.
Alongside this, however, moves to residential care, and increasing distance may cause less contact with family and friends. It may be difficult for someone to know what to say, not only how it can be said, when the person they are communicating with now has very poor vision and hearing. Isolation from information means they cannot keep up with world events, soap operas, or family or local gossip.

In case studies and biographies (Terry 2000, Partington undated, Butler 2004b, Schipper 1998) it is clear that people feel isolated and cut off from the mainstream of life. Some talk of 'what's the point?' (Northern Ireland 2004) Others struggle to maintain an interest in the world as described by Matthews concerning watching the world cup and Partington (undated) who describes TB who can no longer see television or read the scores in the newspaper

continues to buy the paper (although he says he does not know why). He continues to try to follow sport by listening to the radio in a quiet room.

The person with vision and hearing loss may be isolated in company (see above) and not know who else is in the room, or who they have passed in the corridor (Roets 1998). Partington (undated) says social isolation 'is the norm' for people with dual sensory impairments. But being a part of culture is vital to a sense of identity and purpose.

Older people with dual sensory loss may need assistance to become assertive, to know and understand what can be done, and what they can do. Leigh-Lewin (2001) and Duncan (2002) outline how much deafblind individuals should participate in decisions about their own situation, Bashton (1998) of the importance of autonomy. 'Think Dual Sensory' (DOH 1997) emphasises the importance of real consultation, and the need for provision of communicator guide and possibly interpreter services for this. However there is little or nothing written in detail about how to train people with vision and hearing loss in self advocacy, and this raises again the issue of how older people learn most effectively. Other people may also act as advocates for people with sensory impairments but once again, there is little information about this. Further research in this area may help to develop a greater understanding of this.

Schipper and Prickarts (1998, an example from the Netherlands) describe the importance of finding new opportunities for activity or revisiting old ones, old hobbies and domestic activities (Jeffersen and Cutts 1999 and Roets 1998). Bagley (1998) describes how she is sometimes asked what activities a deafblind person can be involved in – and she replies 'whatever they want to!' But adaptations and changes may be necessary – for example to communication methods, the addition of tactile markers, minor changes to rules and or procedures, or information in accessible formats.   Schipper (1998) also describes how a difficult it is for a deafblind person to formulate wishes/choices or decisions, because they do not have access to the examples of others. They may believe, for example, that they are complaining too much, or expecting too much. The need for advocates, who are not identical with either communicator guides or family members, is described in 'Think Dual Sensory' (DOH 1997).

Duncan (1998) encouraged one of the people she visits to join with other deafblind people, so that there was someone and somewhere to meet. Partington recommends the setting up of such groups in Bury (undated). 75% of those asked in Northern Ireland said they would like a group for deafblind people (2004). Schipper (1998) describes developing protocols for communication in such groups, such as speaking slowly and clearly, one at a time, and asking for repetition, as well as managing aids for amplification. Barnet (2001) suggests that there may be a deafblind culture, a common bond between deafblind people, a culture which recognises the increased use of touch, for instance (although she is not really discussing older people). Groups for deafblind people may use increased tolerance and flexibility in relation to communication than groups for the Deaf or people who are hard of

hearing, or for those who are visually impaired. The usual compensatory techniques may not work for the person with dual sensory impairment. But in fact, as recognised above, these older people with vision and hearing loss usually do not consider themselves deafblind. There are dangers of increased isolation by labelling them this way, suggesting that it is very difficult to communicate with them, and building an artificial wall. The fact that in a group of deafblind people, each person can only communicate with one other (see Barnett 2001) means that communication may be very slow and there may be too many people who are acting as facilitators. If the deafblind person considers herself to be an older person, with difficulty in vision and hearing, it may be best to assist her inclusion in activities for older people, perhaps with one to one help, to include her in the mainstream.

Housing/equipment

Todd (1999) describes a special housing service for older people with dual sensory impairment. The house manager explains that it is

> designed to help people maximize whatever hearing and sight they have (Todd 1999 pg 15)

Features which are brought to the attention include
- architectural factors such as the use of wooden floors in the shared sitting room so that individuals can feel vibrations when a visitor comes in
- the use of design – colour and contrast – to enhance the visual environment
- the provision of assistive technology, doorbells which flash as well as sound when rung, fire alarms which vibrate under the pillow, a loop system for listening to the TV
- the use of shared common rooms to minimise isolation
- the availability of a variety of alternative means of communication, and staff who are trained in using them
- staff who understand the difficulties of people with dual sensory impairments (Todd 1999).

The provision of suitable housing and appropriate equipment can make a great difference to quality of life. Some older people with vision and hearing loss may benefit from features of specialised environments, such as the use of contrast, hearing loops, flashing doorbells, enlarged lettering, or tactile cues (Trickett 1999, Butler 2004a). While these could be used anywhere, in fact they are frequently not present (DOH 1997, Butler 2004b). Butler's example of solving the problem of independent feeding with just a mat and light shows how these simple solutions may not have been considered. Butler gives an example of a person in a residential home being able to feed herself again after the provision of a contrasting table mat to the plate and good lighting. Again, good assessment can identify the needs of the person for such aids and equipment (Technical aids 1998). Most people in the survey in Northern Ireland (2004) used some technical aid to communication. The person with dual sensory loss is likely to need more choice and greater flexibility than a person with a single sensory impairment, to ensure that full consideration is taken of all their needs – they may need additional features, or adaptations (Kaye 1998). The provision of a ring-fenced budget for such aids (Kaye 1998)

may ensure that these aids, for older people, who are likely to have other problems, are not 'prioritised out' by the needs of younger people.

Some people may require residential care, although it may be other aspects of ageing, rather than vision or hearing loss which drive such decisions. There may be an under-identification of dual sensory loss in residential care homes, as suggested by the figures in Bury (Partington undated) and their needs may be overlooked (DOH 1997). Turner (1997) shows how some adaptations were made for older people with vision and hearing loss in their residential settings, but gives an example to show that some home managers felt they could not manage the implications of dual sensory loss for their clients. For those living in residential accommodation, adaptations may become the responsibility of the home in which they live, where people may not be well trained in issues of sensory impairment, and where costs may be a deciding factor in provision of equipment. But since many older people will develop sensory impairments, generic residential homes for older people should include awareness (in staff) and planning (in the environment) to ensure these needs are met (DOH 1997). The example of special design given above shows that where such needs are considered early on, some solutions, such as paint and loop systems, may not be expensive.

Specialist housing (such as described by Todd, 1999) with adaptations as standard, may however separate out people with vision and hearing loss from the general population of older people, with the problems outlined above.

Needs of minority communities

There is some evidences that the causes of visual impairment is different in people from ethnic minorities (Johnson 2005). However, although it is not known, it is unlikely that the incidence of vision and hearing loss in older people from minority communities is less than that of white English/Scottish/Welsh/Irish communities. However, these groups seem to be poorly represented in surveys. Partington (undated) only identified three people from non white/British groups in his survey in Bury. Moran (2005) shows that in while in white communities 70% of people who are registered blind are over 70, in ethnic minority communities, 70% of those registered blind are under 70. Among various possible interpretations one is that older people with vision difficulties do not identify themselves to professionals as having sensory impairment, and are therefore not recorded. Under-representation could also be because people from minority communities are not in touch with relevant services (DOH 1997), and do not appear on disability registers. This may indicate that they are well integrated into their local community, but there are also many reasons why this may not be so. It may be simply that their needs are less recognised (DOH 1997), or that they do not use services where the language spoken is mostly English (Butler 2004a, Narayan 2005). It is not clear how much this is representative also of older people in general in these communities, or whether there are particular issues relating to sensory loss, or to the implications of acquiring (or deteriorating) sensory impairment later in life. Additionally, while it is difficult to communicate with some people with vision and hearing loss whose first language is English, and who have experience of written English,

professionals may not be able to apply even these methods to people whose first language is not English, and who may not read or write in this language. The issue of ethnicity is not widely discussed. 'Think Dual Sensory' (DOH 1997) emphasises that ethnicity should be included in training, to banish prejudice and extend understanding. Cox, in his 1999 paper on access to information did not discuss the use of first languages other than English. There may be some concerns in groups of non-English origin about the propriety, for example, of using tactile methods for communication (DOH 1997 and 2001b). Communication is a deeply acculturated activity, and the effect of different cultures and languages needs to be considered. This is a highly under-researched area, and further work might identify the relevant issues, and then seek for good practice. There may be difficulties in contact and links between groups working with older people from ethnic minority communities and those working with people with sensory impairments and there may be a role for the voluntary sector in facilitating improved links between such services.

7 Supporting literature from other fields of study

There appears to be little published empirical work on the group of older people with dual sensory loss. The following section explores literature from other fields, such as visual impairment, hearing impairment / deafness, and older people.

7.1 *People with visual impairment*

As the review took place within a specialist centre concerned with visual impairment, we had particularly good access to specialist journals in this field. In particular, we had access to an abstracts database containing all past copies of the *Journal of Visual Impairment and Blindness* and *British Journal of Visual Impairment*. Key word searches of the terms 'deaf' and 'hearing impairment' provided very little, none of which related to topic of interest.

Searches in the area of 'deafblind', 'deaf-blind', and 'multi-sensory impairment' produced approximately 100 hits. Importantly, the vast majority of these were in relation to children and young people, or adults who had congenital deaf-blindness. For example, while Nelipovich and Naegle (1985) describe the rehabilitation process for deafblind adults, including those who are 'adventitiously impaired', (that is, they have acquired dual sensory loss in later life, rather than being congenitally deafblind), they do not explicitly discuss older people but do note that the (then) traditional vocational goal of rehabilitation may be inappropriate with this group (p107). Similarly, Barrett (1992) reflects upon community based services for adults who are deafblind, considering services throughout the previous 20 years, and considering trends for the future. Again the article makes no explicit mention of the older group of people with sight and hearing loss of concern here.

Of greater relevance, Hyvarinen (1988) offers recommendations about the visual assessment of deafblind individuals, in which she makes distinction between people with high and low levels of language. Weiner et al (1997) carried out analyses into road traffic noise and hearing loss, and the implications for this aspect of rehabilitation training for visually impaired people.

McCallum et al (1992) presents an analysis of sight and hearing loss in old age, noting that the presence of individual hearing and sight loss was linked to lower self-reported health (there was a stronger link with hearing loss):

> "controlling for age, gender and place of residence, both sight and hearing loss (versus having no disabling conditions) significantly predicted lower self-rated health, with the effect of sight loss being lower than that of hearing loss." p13.

This work links with literature concerned with ageing generally (which associates disability with depression *irrespective of age* in the older population). Many older people maintain good health and lifestyle and age itself is not the limiting or defining factor. The *combined* presence of sight and hearing loss is not mentioned by the these authors.

A further search used the terms 'older' and 'elderly'. This generated in the region of 70 hits. In light of the previous two search results, it is not surprising that most of the identified abstracts did not refer to hearing loss. Nevertheless, 17 of the abstracts appeared to potentially contain information about visually impaired people's hearing loss (in that they described seeking information about older visually impaired people's circumstances and needs, often employed a survey approach, and sometimes had a large sample size). Each of these papers was looked at in detail though only five articles discussed hearing impairment in any meaningful way. Davies (1996) presents an historical analysis of older visually impaired people, and while he says little about combined hearing and sight loss highlights,

> "Deafblindness is a complex issue in its own right, separate from both hearing and visual impairment." p55

Smith (1992) presents an interesting case study of the changing remit of a service for the 1980's and 1990's. The UK-based service was originally developed to serve deaf people who were losing their sight or blind people who were losing their hearing. However, it had adapted to cater for the different needs of those who had acquired both sensory losses in later life.

The three other (U.S.) survey-based pieces of research offer the clearest insight into this literature. Crews and Fray (1993) investigated the family concerns of 309 older blind people (55 years +). They found 8.6% reported deafness, while 35.7% reported hearing impairment (the figures were higher for men). As already reported, Crews and Campbell (2001) gained access to the very large data set of the U.S. National Centre for Health Statistics (1998). The actual sample size of the visually impaired group (who reported 'blindness in both eyes', p.457) is unclear but appears to be 386, of which 13% and 12.8% reported 'deaf in one ear' and 'deaf in both ears' respectively. Again, no further analysis across this variable is carried out. Finally, Moore,

Gieser et al (2001) reported a large scale telephone survey (N=940) of older blind 'consumer satisfaction' in response to independent living programme. The authors recognised that people who were deaf or with severe hearing loss were excluded from the survey. Nevertheless, 46.2% reported 'yes' to having a hearing impairment (only hypertension and arthritis were reported higher). This is a high proportion of the population of older blind people and indicates the importance of assessing and providing services for this group.

Similar patterns can be found in large scale surveys in the UK. Bruce et al (1991) reported 37% (aged 75+) and 34% (aged 60-74) replied 'yes' to "If you are in a quiet room with someone, would you have difficulty hearing them speak to you in a normal voice?'. This finding was supported by comments made by researcher interviewers – in 45% of interviews with people aged 75+ and 23% of interviews with people aged 60-74, interviewers reported that participants had had problems hearing during the interview.

Hanson et al (2002) report a large scale survey of 400 older people with a visual impairment (aged 60 and over) and their housing care and support needs. The research design aimed to recruit some with dual sensory loss. While they reported

> a very high proportion of informants were experiencing problems with their health, ranging form one to several long-standing chronic complaints (342, 85.5%) to one or more seriously disabling problems (214, 53.5%)' (p48),

hearing impairment does not appear to be discussed as an issue in any great detail within the report.

In spite of there being a sizable subgroup of the visually impaired sample with a hearing loss, none of the studies presented an analysis using this as a independent variable. This lack of further analysis is telling – the authors of the studies cited above cut through the data in a variety of ways but appeared to be un-interested (or had nothing interesting to report) in terms of additional hearing loss as a variable and how it made impact upon research participant's lives. Some of the research would have potential for re-analyses to look at hearing and sight loss together.

While the figures are inconsistent in terms of reported hearing loss in the visually impaired population (in part due to non-standard ways of establishing the presence /absence of hearing loss), all show significant numbers. Therefore, perhaps of greater interest is the *lack* of reference to hearing loss in the many other studies which investigated older people with a visual impairment. As examples, Casten at al (2002) investigated the impact of depression in 114 older adults with Age Related Macular Degeneration (AMD), and Marx et al (1997) investigated eye disorders amongst 100 visually impaired nursing home residents. In both these examples hearing impairment was not discussed *at all* (in spite of other conditions being discussed). While sampling bias may account for reduced numbers (e.g. deaf people either explicitly or implicitly being excluded from the sample), it seems very likely that the samples contained a significant sub-group with a hearing loss whose

particular needs may not have been included in the investigative methods. It may be that researchers are not usually aware of the effects of the combined sensory impairments and that this is not seen as a variable which needs to be considered.

In contrast, in a more qualitative study, Douglas, Willis, Pavey, and Dunstan, (2003) evaluated specialist day service provision for elderly visually impaired people. In this small study there were many references to clients' hearing loss (N=30+), e.g.:

> "Most service users interviewed reported one or more condition or disability in addition to their visual impairment, [..]. The most common is hearing loss which was often not recorded by management – hearing loss is likely to have a great impact upon the way staff engage with users, and the suitability of some activities" p18.

Importantly, this is a sizable (50 page) research report, and it may be the space constraints placed upon authors when writing journal articles that prevents discussion of hearing and sight loss.

7.2 Older people and people with hearing impairment

Time has not allowed us to inspect this literature in very much detail. Nevertheless, a useful recent scoping review by Godfrey and Denby (2004) investigated depression and older people. Of general relevance they argued the existence of a high prevalence of depressive disorders amongst the elderly population, an average of approximately 13% (depending upon definition). Of more specific relevance to this study, they go on to argue that a key 'stressor' associated with depression is the experience of ill health or disability (which would include visual or hearing loss, or both). They conclude from their analysis of the literature that it is not old age itself, or even the impairments themselves, that brings about depression, but rather the associated loss of function and participation.

While visual and hearing loss are rarely mentioned in the report (approximately twice, and then not together), Godfrey and Denby (2004) also identify a number of other studies (including longitudinal studies of older people) which offer a valuable resource for the current work. We have looked at some of this literature and, in summary, have found some reference to sensory impairment, but none to combined hearing and sight loss. The studies inspected were generally large scale surveys, e.g. Roberts et al (1997) N=2,417, aged 50 or above; Copeland et al (1999) N=5,200, aged 65 or above; Beekman et al (1997) N=3,056, aged 55 or above. All of the studies have very simplistic measures of the presence or absence of disability, and only Beekman et al appeared to have data which was sensitive enough to differentiate specifically hearing and sight loss (even so the analysis did not report any impact of them combined).

In terms of hearing impairment and deafness, we also found no literature of relevance in the short search time we had. For example searches of back issues from the last ten years in the *American Annals of the Deaf*, and *Journal of Deaf Studies and Deaf Education* gave us no hits. Some reports identified via the web searches explored the issue of older (congenitally) deaf people (including some reference to sight loss), but these focused upon people who communicated through BSL (Young and Grummitt, 2002; Pullen and Kyle, 1997). In both these cases, the reports argued for the importance of specialist residential homes for elderly deaf people.

8 Workshop

During the process of carrying out the literature review (phase 1 of the project), the authors contacted a number of organisations to (1) request any relevant literature, and (2) request attendance to a workshop on the 19th July 2005 to discuss the preliminary report.

The organisations contacted included:
- Age Concern England
- Deafblind UK
- GDBA
- Help the aged
- RNIB
- RNID
- Sense
- Sense Scotland
- Thomas Pockington Trust

Eight people attended the workshop (see Appendix). Each attendee was sent the preliminary review a week before the meeting. The meeting was split into two overlapping sessions. The morning session focused upon responses to the preliminary report prepared by The University of Birmingham team (LH and GD). Following a short presentation by LH, the meeting was asked to reflect upon the report and consider aspects that the team might emphasise, add, or remove. The afternoon session, focused upon the emerging themes identified in the report. In this case, the meeting was asked to consider the relative importance of the themes identified and what and how research and development might proceed.

LH and GD took notes and audio recordings of the sessions. A summary of the workshop was prepared, and these were distributed to the attendees for comments. The final version of the summary notes is presented in the Appendix.

The workshop proved very useful to the authors in shaping this final report. The key themes of the discussion are listed below.

Morning session:
- Staff and training, managing services
- Cultural issues
- 'Identity', identifying, and definitions
- Professional and public knowledge (including those with disabilities); Training
- Recording good practice
- Professional roles – Rehabilitation vs access to services
- Legislation

Afternoon session:

- Definition
    - The use of and application of definitions:
    - Examples of interaction between definitions in practice:
    - How to identify people:
    - Arguments for the knowing prevalence figures:
    - How this might be carried out:
- The needs of this group
- Social services, and evaluation of this work
- Evaluations beyond social services (residential homes, clinics)
- Staff and training

9 Discussion and conclusions

The evidence we have gathered through the literature review and the workshop has led us to identify a number of themes which usefully summarise areas which would benefit from research and development:

5. Population definition and prevalence
6. Needs and circumstances of older people who have hearing and sight loss
7. Service development and evaluation
8. Staff and training

9.1 Population definition and prevalence

Defining the population of older people with acquired hearing and sight loss has major implications for the direction of future research and development, and as such is intertwined with all the other themes. Unusually in the broader field of sensory impairment, deafblindness is defined in 'social-functional' terms (the DoH define deafblindness as sight and hearing loss which results in problems with access to information, mobility, and communication). The value of the definition was robustly defended by the workshop on the grounds of its inclusiveness. This definition is now recognised both by bodies in the UK and internationally after a great deal of hard work. The rewriting of this definition was considered a backwards step by the workshop.

The *use* of this definition is more pertinent and the fact that there is not accepted common practice in research and service contexts makes evidence based research difficult to interpret and difficult to carry out.

The literature and discussions in the workshop also made use of language related to 'functional hearing and vision' as well as language related to medical conditions and their impact upon clinic measures of hearing an vision. The World Health Organisation's International Classification of Functioning, Disability and Health (WHO, 2001) may be a useful unifying framework here. The classification recognises the social participation and social barriers as a central theme while also recognising that functional impacts of impairment co-exist.

The use of any term at all to describe the impact of dual sensory impairments on older people was recognised as a problem by the workshop participants and this is reflected in the literature. Older people are particularly unlikely to recognise themselves in the term 'deafblind' although they may have problems with both vision and hearing. Workshop participants who work extensively with this group said that they use terms such as 'having trouble with seeing/hearing' or 'to do with difficulties with eyes and ears'. The use of terminology becomes even more difficult when different terms are used by professionals and clients, and between professionals with different levels of expertise. This can lead to under-identification. Specialists at the workshop

explained that when the definition of dual sensory impairment was shared with non-specialist professionals, numbers identified increased. There is a tension between the specialised services which wish to maintain the term 'deafblind' and other services and the client group themselves who do not recognise it.

The range of needs represented by the term deafblind is very wide (again, supported by wide interpretation of the definition). Some of those who might be seen to meet the definition might appear to have no needs at the present time. Since objective vision and hearing measurement does not define this group, there are few measures for screening for these individuals. A screening tool is being developed between European professionals, but some specialist knowledge is required to use this.

Recommendation:
We recommend that useful work could be carried out which operationalises the current DoH definition of deafblindness so that it could be used more easily and consistently. Such work might have the following features:
1. Make use of the WHO ICF (WHO, 2001) as a framework;
2. Use language that would prove useful to a broad range of professionals (e.g. academics, policy makers, health and social care professionals), as well as incorporate lay-language to support communication with people who might not recognise themselves as deafblind;
3. Trial and recommend screening tools to be used to identify deafblind people and go some way to identifying their needs.

9.2 Needs and circumstances of older people who have hearing and sight loss

Some literature exists which describes in detail the needs and circumstances of the group. Perhaps a fundamental issue which has emerged from our review is the nature of this evidence, which tends to be in the form of professional and academic commentators as well as DoH policy documents. The identified needs are:
- Information – including public information
- Communication
- Mobility and transport
- Stimulation/relief from isolation
- Social work/counselling
- Housing/equipment
- Needs of minority communities

In the main (though not exclusively) this literature draws upon case studies, biographies, and expert views. As with much qualitative research of this kind, it has a clear validity for the specific cases, and a generalisability across other similar situations (ie. to other people in similar circumstances with hearing and sight loss).

However, such research is likely to focus upon people with the greatest difficulties in the population. Therefore, a difficulty arises when trying to scale the extent of these needs across a larger population. We found that no substantial research has taken place which seeks to quantify the impact of combined hearing and sight loss upon various aspects of quality of life (both in terms of the size of the impact for the individual and the numbers of people this might affect). As discussed, perhaps the most fundamental reason for this is the wide interpretation for the definition of the group (and consequentially the variety of figures related to prevalence, and the related terminology used). This is neatly summed up by Heine and Browning (2002):

> "Thus, only few investigations concerning the psychosocial functioning and social adjustment of older adults with dual sensory loss have been conducted. Frequently this type of research uses autobiographical or observational accounts from participants. Sample sizes are often small since it is difficult to find a large group of people with similar characteristics. Further research is therefore required so that realistic goals for older adults with dual sensory loss can be determined and incorporated in an intervention programme aimed at improving client's quality of life and feelings of well-being." p768.

There are potential opportunities to carry out analyses of existing datasets, looking more closely at groups who have self-reported hearing and sight loss. Additionally, emerging research (e.g. Network 1000 – a survey of approximately 1000 visually impaired adults, see Corcoran et al, 2004) could usefully be analysed with this in mind. Such results and analyses would provide useful information which could be combined, compared, and contrasted with existing case study information. This would reveal a more complete picture of the needs and circumstances of this group, and reveal whether the existing case studies reflect typical or extreme cases.

While secondary data analysis and linking with ongoing research projects offers a potentially practical way of generating some initial information about the population, it is likely that the methods employed by these other projects (e.g. postal and telephone surveys) would be problematic for a number of the deafblind people in which we are interested. Therefore, a more robust approach would need to be developed for identifying and consulting with older people with sensory losses. This would most likely involve face to face interviews with the people themselves and, where required, their carers. Recruitment of participants would have to be done in close consultation with a variety of social care providers.

Carrying out such research would also need to be mindful of the nature of the group, and subgroups within it. For example, there appears to be a particularly limited amount of evidence in relation to the needs of people from ethnic minorities. Under-identification, different perceptions of ageing and disability and different social and family structures may be making the picture quite different for these groups.

Of course, need is closely linked to individual circumstances and services they receive. We will unpick this further in the next section, but particularly worth reflecting upon here is that the population we are interested in here are older. There was discussion at the workshop about appropriate methods of teaching this group new skills or to undertake new activities. Little is known

(not just in the field of sensory impairment) about how older people learn and how best to encourage and develop their ability to take on new strategies. This area of research and development is of course much wider than just dual sensory impairment.

Recommendation:
We recommend that more substantial work should be carried out which seeks to quantify the impact of hearing and sight loss upon various aspects of needs, circumstances and quality of life of older people with hearing and sight loss. In the first instance, this might involve seeking secondary data sources for analysis and linking with existing research projects. Such survey data would usefully be combined with existing case study information.

A longer term approach (which would be ultimately more robust and complete) would be to carry out a survey which focuses upon this specific group. The design and methods of such a study would require careful thought, and would be informed by the first part of this recommendation. Two areas of particular consideration in such a study might be considering the needs of ethnic minorities and the preferred methods of learning for this population.

9.3 Service development and evaluation

A third identified theme is the development and evaluation of services. This covers a broad range of services including those services *for* deafblind people, and access to mainstream services *by* deafblind people.

In terms of statutory services provided by social services departments, the Local Authority Circular on social care for deafblind children and adults (DoH, 2001b) provides direction for this, and ongoing surveys by Sense (e.g. Sense, 2005) provides some powerful evidence of the (mixed) progress being made by departments. The continuation of this survey, potentially with questions and analyses focusing upon services for the older group would be an important source of data. Indications are that Sense intend to continue with this work.

Another source of evidence for the progress in the implementation of the LAC, or service impact generally, could be found by analysing local authority inspection reports.

In terms of access to mainstream services by older people with hearing and sight loss, as well as the local authority and health authority sectors, the independent sector, nursing homes, residential accommodation and voluntary organisations must be involved and included in development and inclusion (DOH 1997, Northern Ireland 2004, Kaye 1998).

For example, discussion at the workshop and the literature noted that provision of good, well resourced and planned generic services would meet

the needs of many older people with vision and hearing loss without the need for specialist services. This applied not only to those services designated as for older people, or those with sensory impairments (clubs, hospital check ups, professional groupings) but to a wide range of services. For instance, the difficulties in mobility in the literature, and examples mentioned by workshop members, could be diminished if highways or parks departments cut back overhanging branches. The use of clear print on leaflets in surgeries could save much time explaining information.

A particular problematic example which was highlighted both in literature and workshop was in relation to access to health services, e.g. in clinics, in hospital, and by medical staff who don't seem to understand or recognise the presence of a second disability. Not only is this problematic in gaining access to the actual service, but it is also a potential missed opportunity to identify people with combined sensory loss who are attending audiology or ophthalmology clinics.

While there are clear common themes in the literature and the workshop in relation to provision, there is no empirical work to draw upon for the evaluation of services. We make the general recommendation that more evaluation of services should be undertaken, and this is in line with a general concern with measuring the impact of services. While some of this would be necessarily large scale work, other equally valuable work can be incorporated into ongoing service development and the generation of helpful examples of good practice which could be shared with the field.

Such exchanges took place in the workshop. For example, since many individuals with vision and hearing loss do not recognise their difficulties explicitly, they may not know how to ask for help. Workshop participants emphasised the importance of self advocacy and some successful means of encouraging this were described. One residential home uses Age Concern as a third party to get feedback on issues from residents – among the issues they highlight to clients is communication. There is an important role for empowering clients to voice their difficulties and their own needs.

More examples of good practice in the area of service delivery would be valuable.

Recommendation:
We recommend an audit and evaluation of current specialist services provided directly to older people with vision and hearing loss. This will include Communicator-guide (guide-help) services. This will include identifying the range of services provided, and developing a method of assessing the effectiveness of the service, perhaps in relation to increased participation in community and daily life activities. This evidence will include the views of service users, gathered with appropriate communication support.

Such evaluation and audit work could be very large scale. Strategies which might be more manageable might include:

> - Continuing and building upon the existing survey work of social services departments carried out by Sense
> - Evaluating relevant local authority inspection reports
> - The generation of case studies of service development and audit.
>
> The evaluation of access to 'mainstream' services may also prove a useful insight into the circumstances of people with hearing and sight loss. Particular examples might be gathering deafblind people's views regarding access to heath services and inclusion in residential home and day care provision. Case studies based around people's experiences and examples of good practice might be a useful approach.

9.4 Staff and training

A fourth identified theme is in relation to staff and training. The appointment and employment of specialist deafblind staff for older people involve strategic and management decisions. Such a specialist service also requires leadership, which should be from a person with some understanding in this area. Again, social services departments are obliged to have such a person in place (DOH 2001b), and the surveys carried out by Sense offer evidence of progress (again mixed).

Professional groups might usefully be divided into specialist, direct care, and general workers. While there are specialists in the field, their learning has tended to be experiential as there are very few training programmes which are relevant to them. Specialists in social work departments are likely to have developed from a specialism in deafness or visual impairment. Recently, a consortium of voluntary organisations have developed and proposed a programme of study at undergraduate level which is likely to be validated by the University of Birmingham and lead to an undergraduate certificate. The consortium is hoping to develop this work further, possibly into a foundation degree. However, the programme currently spans the whole spectrum of dual sensory impairment, from children to older people, and includes congenital, adventitious and later life sensory impairments. This span means that only a small amount of time can be spent on older people. Therefore, while this programme may provide the basis for training specialists, more specific programmes related to older people may also be required.

For more general and direct care staff, working with older people for example, awareness is necessary but considering the numbers who may be affected, this is insufficient. Training in particular communication methods and some additional areas may be provided (and accredited) by CACDP (Council for the Advancement of Communication with Deaf People). Deafblind UK and Sense both offer programmes. NVQ programmes relevant to this group touch on issues in sensory impairment.

However, while such training is relevant, it may not be accessible to all staff providing direct care who are working, for example, in care homes. Training opportunities may be rare, staff turnover is rapid and staff may not invest time

in their own training for what is often a low paid and low status job.   Therefore, even if training programmes exist and providers make them available it is likely that many direct care staff will not be trained.

For staff who are likely to come into contact with older people with vision and hearing loss, but who may not have a direct care role, awareness training may be the primary need. But this has a wide scope – including perhaps people as diverse as receptionists in council offices, museum staff and meals on wheels drivers. Providing awareness training for this range at appropriate levels is also likely to be difficult. It is not clear exactly who should be trained and in what they should be trained.

Recommendation:
We recommend an investigation into current qualifications held by specialist staff and direct care staff, to discover what training has influenced the delivery of effective services. Further work could include a cross section of general services staff. The value of meetings of groups with special interest, such as LADWIG (Local Authority Deafblind Workers Interest Group) could be included to see how this group could be a part of such development in training.

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11 Appendix – Summary of the Workshop

Meeting on Vision and Hearing Loss in Older People
(funded by The Thomas Pocklington Trust)

Tuesday 19 July at 10:30am
School of Education

Minutes of the Meeting

In Attendance
LH – Liz Hodges, (University of Birmingham)
GD – Graeme Douglas, (University of Birmingham)
LD – Liz Duncan (Sense)
OM – Olga Miller (RNIB / London Institute)
SB – Sue Brown (Sense)
DP – Dave Partington (Greater Manchester Passenger Transport Executive)
TR – Trish Ricketts (Pocklington)
KW – Kevin Watts (Deaf Blind UK)
SBa – Sue Batemen (RNIB)
AM – Angela McCullagh (Pocklington)

Apologies

Stephen Craven, Thomas Pocklington Trust
Philip Hurst, Age Concern
Richard Lucas, RNIB
Tom Owen, Help the Aged

Overview

This short document summarises the information gathered in the meeting, which was split into two overlapping sessions. The morning session focused upon responses to the preliminary report prepared by The University of Birmingham team (LH and GD). Following a short presentation by LH, the meeting was asked to reflect upon the report and consider aspects that the team might emphasise, add, or remove.

The afternoon session, focused upon the emerging themes identified in the report. In this case, the meeting was asked to consider the relative importance of the themes identified and what and how research and development might proceed.

LH and GD took notes and audio recordings of the sessions. A summary of the two sessions are presented. The discussion is broken down into themes.

Session 1 (Morning) – Reflections on the report

Theme: Staff and training, managing services

Some reported that they had experienced meeting staff in care homes who had a lack of understanding of the needs of people with dual sensory loss. Staff need training may help. Some had found that if you give staff thorough induction, they speak slower, etc.

There is typically a high turnover of staff which is a problem. Such work is typically low paid.

Many staff in these jobs are recruited from overseas, e.g. Nigerian, eastern Europe. There maybe some difficulty with spoken English, or clients finding accents difficult. There may be different cultural norms of dealing with older or disabled people.

Example of Age Concern being asked by a residential care home to come in and gain feedback from residents on the service (including any problems with the staff) – such independent / 'outside' advice then can be acted upon.   This may link to Age Concern six monthly reviews.

Empowering clients to voice difficulties in understanding and, e.g., asking staff to repeat themselves.

It may be easier to to implement and manage good practice of this type in Care homes (compared with working with people individually)

Theme: Cultural issues

Cultural issues discussed in relation to different cultural views of disability, older people, and independence. This links with points raised above. Also, there may be a culture associated with the current older generation – this group may be used to tolerating hardship so we need to educate these individuals that you don't have to suffer and put up with problems.

Related, professionals and public may see "Getting old" (and associated conditions such as sight and hearing loss) as an 'acceptable' medical problem. Such a cultural view will make identification of such people harder. Such cultural norms are likely to shift - people who will be old in the future may be more likely to make their needs known.

Theme: 'Identity', identifying, and definitions

People do not view themselves as being deafblind. Perhaps the term is inappropriate here, and is rarely used.

Similarly, (non-deafblind specialist) professionals do not categorise these many people as deafblind. When a working definition is shared with professionals, then the numbers identified goes up considerably.

There was some discussion about functional definitions of deafblindness, and how this did not just link to functional sight and hearing loss. More specific 'types' of deafblind people may be more useful, e.g. those who have particular problems with communication, or rather those who have particular problems with mobility, etc. (Links with later discussion.)

There may be different terminology in each area of the country.

Theme: Professional and public knowledge (including those with disabilities); Training

In terms of individuals with hearing and sight loss, there may be a nervousness about wanting to be identified as such because a belief that they may be "put into care". Also, there may be an ignorance, people not realising they are, or are becoming, deafblind.

Eye clinics and audiology clinics may be useful locations to identify people with emerging dual sensory loss.

Professionals, such as GPs, may also be unsure about when someone might be described as "deafblind". Public services were also identified as potentially problematic, e.g. libraries, access to buildings, buses.

Training in a variety of ways was seen as an important route to overcome some of these problems. Examples of training of medical students, and sessions with public services were described.

Theme: Recording good practice

It was noted that recording and sharing 'good practice' would be very valuable. It was noted that little literature exists describing such practice.

Theme: Professional roles – Rehabilitation vs access to services

A key distinction was made between professionals who offer an 'enabling service' by providing *access* to information and services, compared to professionals who offer some type of *rehabilitation*. This was confused because of an inconsistency between names professionals are given by different agencies. Definitions varied, E.g:

- 'Communicator Guide' provides day to day help which includes interpretation to undertake daily living tasks and leisure activities (Sense). For the RNIB the term may have a broader definition, including teaching deafblind manual.

- 'Communication development' is something different and should not be the responsibility of the Communicator Guide. *Developing* communication with someone is very important. Within Sense it would be skilled Outreach Officers doing this work. Within Deafblind UK this job title would be Rehab Guide.
- For people who are congenitally deafblind an 'intervenor' may work to develop communication as part of a developmental, learning programme. This is less likely to be appropriate with older people who already have communication systems, albeit systems which they can no longer access.

The existence of a number of titles might cause confusion. In addition the distinctions in professional roles might cause fragmentation of service, and perhaps a professional with all these skills might be the ideal.

It was also highlighted that very often the person who acts as a guide and a communicator, (usually unrecognised and unpaid) is in fact a relative (e.g. partner) of the deafblind person. Often a crisis point is when such a carer dies – the person left behind has to cope with bereavement while simultaneously being cut off from their main support.

Theme: Legislation

The DDA (2005) and Age Discrimination Act were highlighted as important and relevant legislation in this context.

Session 2 (Afternoon) – Emerging report recommendations

Definition

There was a lengthy discussion about the merit of definitions for this group, with positive arguments being presented for the usefulness of the 'functional social' definition as presented by DoH, a 'functional hearing and sight' definition, and a 'medical / impairment' definition.

- The use of and application of definitions:

The DoH 'social functional' definition (sight and hearing loss which results in problems with access to information, mobility, and communication) has been a long time in coming, and is now accepted nationally and internationally. This cannot be changed. It is the understanding and implementation of the definition which requires attention. It may be that services are defined by this definition.

A 'functional hearing and sight' definition may also be useful – some discussion about those who may have sight and hearing loss, but are not 'deafblind' in terms of the 'social functional' definition. Establishing the numbers who are 'deafblind' in this sense can only be achieved by "going out and talking to people", i.e. it's not possible to decide based upon medical information. Some method of assessing may be useful.

This distinction highlighted that that people could be more ,or less, 'disabled' in different contexts, e.g. they may function happily and successfully in a quiet, well lit room, but nevertheless struggle in a supermarket. However, the 'social functional' definition does not specify 'when' or in 'what circumstances' – so the definition is quite clear. But the challenge is working out what the definition means in practical terms (this point was reinforced in the context of talking to service providers who appear to find it difficult to apply and it and identify people).

A challenge is that it is commonly perceived that 'deafblind' people cannot see or hear anything. Perhaps examples are useful in making the definition more transparent – linked with everyday activities.

- Examples of interaction between definitions in practice:

Some discussion about different 'types' of deafblindness, and the distinction between 'severe' and 'less severe' was used for purposes of discussion, and illustrated by examples (further discussed below).

Example – people with industrial-related hearing loss (e.g. having worked in heavy industry), many of whom will have hearing aids. In older age this will often be accompanied by loss of vision through AMD, cataracts. They are "not extreme examples" of deafblindness. Often they are getting on with things (linked to notion of 'coping'). At 86 they're probably doing OK. At 90

when they physically become a little bit more frail they may become the "extreme" example of deafblindness.

Such people are deafblind, but become a greater concern when their coping mechanisms or support systems fail.

Such support mechanisms are linked to design of the environment (e.g. in residential care homes the lighting may be poor, poor colour contrast etc.), support from family members, support from social services / voluntary organisations. But ability to cope may be linked to changes to hearing or vision, as well as other disabilities.

A useful contrast might be between a 'measure of vision and hearing' versus a 'measure of difficulty' (e.g. how difficult to get over the front door threshold, communicate, access information).

- How to identify people:

Linking with some method of screening with other services who are likely to come into contact with this group, e.g. eye clinic, optometrist, audiology unit.

A 'screening' questionnaire (devised in UK, then developed and piloted by a Swedish and Norwegian academic) which has proved to be reasonably useful. Measure professional and individual views of their situation. Is about to be piloted in the UK in an SSD. Note: It requires some knowledge / experience. (Action LD, LH, GD to communicate about this)

- Arguments for the knowing prevalence figures:

Economic argument. Waiting until something 'goes wrong' is not cost effective, (cf. having the person identified, and 'in the system' – ie a more 'preventative' approach).

People are hidden. There was a belief there are larger numbers of people who are deafblind than recognised (the 40K figure). The figures relating to people over the age of 80 were particularly highlighted. Concern that the perception of this being a 'low incidence' condition may be unhelpful.

- How this might be carried out:

Some discussion about looking at existing datasets for working out numbers (combining figures for populations as per the report), also looking at older populations in greater detail. Some consultation with local authorities to establish numbers with hearing loss on registers of blind and partially sighted might be useful – though noted by a number that this is not straightforward.

Noted that the screening mechanism perhaps offered a method of having a shared understanding and clearer working model of deafblindness. Perhaps it also offers objectivity and believability which might be important because of perceived vested interest of the professionals/organisations.

The needs of this group

There was some discussion about the tension between focusing in upon the needs of the group vrs the specific needs of the individual.

Further contrasts were made between 'extreme deafblind case' (e.g. communicates by deafblind manual) with the other older group – say those who have hearing aids, glasses. Similarly, there was some discussion about whether we know about how to effectively work with older (deafblind) people? Perhaps these clients may not be used to learning new skills, and lack motivation to do so. Some discussion about how the needs of these groups differ.

A large number of examples of needs were generated:
- example of people with vision and hearing loss in warden controlled housing, go down stairs for coffee mornings but people don't talk to them because it is seen as hard work. So they become isolated, while one-on-one communication may not be a problem.
- example highlighting the difficulties of hearing aids in the group setting with a television on in the background.
- batteries going on hearing aids, ears bunged up with wax, incorrect/old ear-moulds.
- some discussion about the apparent breadth of needs which perhaps can't be covered by a single person. E.g. overcoming isolation may be dealt with, but changing lighting is not. E.g. overcoming isolation through encouraging other residents to talk to someone with sight and hearing loss is often unsuccessful (people often do not have the skills, patience, etc.)
- mental health issues / depression.
- commonly people may require support with personal hygiene, particularly kitchen hygiene.
- links with falling (Action LH/GD – follow-up reference).

There was discussion about the notion of 'coping', and potentially individual differences in 'resilience' and motivation.

This discussion highlighted that need was, of course, linked with support and services available. Positive and negative examples of service availability being linked to the presence of deafblindness:
- example of cataract operation not being carried out
- example of priority for digital hearing aids to those who are blind.
- example of a residential home (specialist VI), having built up a good relationship with an audiologist, and the local hospital clinic.

There appears to be little empirical evidence of impact of hearing *and* sight loss upon quality of life. A general feeling that such data was important, but difficult to be generated from the 'deafblindness field' directly as it is relatively small and 'young'. Linking with other projects, and secondary data sources may be efficient ways to proceed.

There have been studies about the 'correctable sight loss', and there was discussion about parallel studies regarding hearing impairment / deafness:

- noted that hearing aids cannot 'rectify' hearing loss (in the same way that glasses *can* in some cases)
- example a hearing impairment team often referring clients to an audiologist who clients had previously not seen.
- Perhaps 'uncorrected' hearing loss will be higher than for uncorrected vision loss. This may be linked to a greater reluctance to accept a hearing loss; and different cultural perception of deafness. RNID study (1980s?) on who and why people are wearing hearing aids may be useful (Action: LH/GD – follow-up reference).

Social services, and evaluation of this work

Sense research into this was described by SB. Four year rolling survey of what SSDs do in this area. Some questions have been repeated each year, but not all. The data shows some inconsistencies (e.g. year on year authorities reporting same numbers of deafblind people, suggesting the data is not regularly updated). In spite of these problems there are some clearer messages, e.g. identified people is going up; some areas are improving dramatically, while others are not. Sense intend to continue to do this, although it is very labour intensive (nb. Year 1 carried out by phone and had high response rate; subsequent years by post and responses rate dropped dramatically – makes year on year comparisons more limited). Some of this data is on the Sense website.

Discussion: Deafblind UK, Sense, and RNIB work with a number of social services, sub-contracted to provide services. Also other voluntary organisations (e.g. local societies for blind and deaf). Under-16 work is often covered by Sense. Therefore some of the data gathered for the survey comes indirectly from the voluntary sector.

There was some questions raised as to whether some sensory team managers have the necessary knowledge/experience to run deafblind services. Also, is the budget ring fenced for deafblind services, or might it go to sensory services generally?

Evaluation: There appears that limited work has been carried out on service evaluation / impact of services. Inspections are now beginning to incorporate statutory guidance of deafblindness – may be a useful source of data in the future.

Evaluations beyond social services (residential homes, clinics)

Discussion not really linked to the final two themes – time was limited, and people were tiring. Nevertheless the following interesting pints were raised.

As well as 'people services', it might be useful to consider equipment, e.g. IT. A recent survey of technology uptake (e.g. mobile phones) by Sense on the website (most of the respondents were older – Action: LH/GD follow-up reference). Other issues regarding access to technology were discussed, e.g. operating washing machines, visual displays, non-feedback buttons.

There was some speculation about the misdiagnosis of dual sensory loss as dementia. This might be linked to:
- assessment criteria, and access to assessments
- potential links with visual hallucinations associated with some visual impairments
- social isolation and depression, and its association with dementia and deafblindness.

There was some reported work on deafblindness awareness training in the geriatric and psychiatric sector.

Staff and training

There was some discussion of informal / non-accredited training in which many rehabilitation officers are trained in communication skills, deafblind manual. Much of the discussion was orientated around people of working age (this also links with some awareness training described above).

While 'standard' deafblind awareness, and training of Communicator -Guides is very important, perhaps the infrastructure for this work already exists. The emerging certificate and diploma is a step forward in the development of formalising training routes, but there was a concern about building a literature so that the field didn't just rely upon the professions 'experts', perhaps the more formal use of mentoring.