



Policy Briefing: Older People and Dual Sensory Loss

Summary

Deafblindness or dual sensory loss among older people must be addressed by a full range of policy-makers and service providers. Sense estimates that almost 1 in 20 people over 75 are sufficiently sensory impaired to be considered deafblind. Action must be taken throughout the older people's sector to meet the needs of deafblind older people. These actions should aim to:

- Implement the statutory Deafblind Guidance for deafblind older people in England and Wales;
- Provide all required health and social care assessments, including specialist assessments;
- Offer services, aids and equipment that meet the needs of deafblind older people, whether this be for support in the home, group settings or care homes;
- Make sure personalisation of social care includes deafblind older people;
- Ensure preparations for an ageing society recognise and provide for the prevalence and impact of dual sensory loss.

Mainstream policy and services must be able to meet the needs of deafblind older people, but supporting deafblind older people effectively can require specialist input and older deafblind people should have a specialist assessment of their needs. This policy briefing addresses deafblindness among older people in England, Wales and Northern Ireland and is based on information from deafblind older people, their carers and the professionals who work with them, as well as independent research. There are several references to the Deafblind Guidance which is statutory guidance issued in England and Wales only.

1. Introduction

About deafblindness

Deafblindness is a unique disability commonly defined as a combined sight and hearing impairment which causes difficulties with communication, access to information and mobility. This is rarely complete loss of both senses. The commonest cause of combined sight and hearing loss is ageing. The older you are, the more likely you are to have both a hearing and a visual impairment. Sense estimates that 4.6% of over 75s, or almost 1 in 20, are sufficiently sensory impaired to be considered deafblind.¹ This is approximately 186,000 people in England, Wales and Northern Ireland. Older deafblind people use a range of communication techniques to both give and receive information, including voice, written, signed and tactile communication; methods may also vary according to the situation and environment.

Deafblindness and the ageing population

As the population ages, the number of deafblind older people will rise. Indeed in 2029, we estimate that the number of deafblind older people in England, Wales and Northern Ireland will have risen to over 334,500.² This is an estimated increase of 74% in the number of deafblind older people. Government, local authorities and other organisations' plans to address the needs of an ageing population must include identifying deafblind older people and providing appropriate services. If this does not happen, these plans will fail, deafblind older people will be excluded and they will receive reduced outcomes.

About Sense's work with older people

With over 50 years of experience, Sense is the leading national charity working with, and campaigning for, children and adults who are deafblind. Sense provides expert advice, support, information and services for deafblind people, their families and professionals. Sense has been working with deafblind older people for a number of years. While Sense can offer specialist advice, one key aim of Sense's work is to greatly increase awareness of deafblind older people and support others to recognise and meet their needs. Sense has produced a range of freely available publications about deafblind older people that include information on making sure their needs are met. Sense is committed in the long-term to supporting and campaigning for deafblind older people.

2. The impact of deafblindness on older people

Lack of awareness, age discrimination and attitudinal barriers

The attitudes of older deafblind people themselves and those around them can prevent them from seeing deafblindness as leading to support needs. Sensory loss is seen by many as a natural and inevitable part of the ageing process. Unfortunately this can lead to the attitude that there is nothing which can be done to maintain or regain quality of life. When older people become deafblind, the erroneous assumption can be made by individuals themselves, their families or professionals that they need to give up activities that they enjoy when in actual fact appropriate support could be put in place to facilitate continued participation.

Isolation

“From leading an enjoyable, full and active life – I am now down to nothing...now I can only watch TV (close seat) and have to make up my own dialogues. Strange but friends do desert you when you cannot communicate.”³

As people lose their hearing and sight, they are likely to become increasingly isolated. Many everyday activities such as shopping or meeting friends become difficult and individuals can lose the confidence to leave their own homes. Communication becomes harder; people may need to access information in different ways and may need to learn new communication tactics or methods. People may not feel safe going out of their house alone; yet inside the house they may be unable to read, watch television or listen to the radio.

Higher rates of additional health needs and conditions

Research has found that older people with dual sensory loss are more likely to develop certain additional health conditions, stroke, arthritis, heart disease, hypertension and depressive symptoms. They are also more likely to have falls.⁴ By definition, deafblind older people will be more likely to have difficulty with moderate exercise, mental stimulation, maintaining social contact and healthy eating. We estimate that the cost to the NHS of these additional health conditions is £365,000,000; offering deafblind older people the right support could reduce this cost.⁵

Mental health

Deafblind older people are likely to have significant mental health needs. Enforced isolation, loneliness, coming to terms with sensory loss and boredom are just some of the factors that can contribute to this. Deafblind older people can develop low self-esteem, depressive symptoms or anxiety and withdrawal. Research has shown that a significant percentage of deafblind older people can have a much higher level of mental distress.⁶ Deafblindness can also compound mental distress at a time of a major event such as moving into a care home or bereavement.

Addressing the impact of deafblindness

With the right advice and support, such as one to one support, mobility and communication training or equipment, deafblind older people can be enabled to live active and healthy lives that can help prevent or reduce the negative impact of dual sensory loss.

3. Health and social care assessments

Appropriate health and social care assessments are crucial in improving the lives of deafblind older people. Professionals assessing deafblind older people should allow enough time for effective communication. This may necessitate giving individuals double length appointments or consultations. Referral routes must be clear and good communication should be developed between different professionals and services. English and Welsh local authorities' plans for implementing the Deafblind Guidance must include older people.

Sight and hearing tests and aids

Older people should have access to regular sight and hearing checks and both audiology and low vision assessments must take account of the impact of dual sensory loss.

Case study

Jenny was given two hearing aids. All went well for a short time until the first set of batteries ran out. Due to her visual impairment, Jenny found it hard to replace the batteries. Jenny became frustrated and stopped using the hearing aids. No-one at the audiology clinic had considered that replacing the batteries would be a difficult task.

Audiology services must recognise the difficulties that deafblind older people may face. Simple advice could include keeping and replacing the batteries in a place where there was good even light and good colour contrast. Services should support individuals to develop necessary skills and plan for any appropriate follow-up. Audiologists must also be aware that deafblind older people may have problems with dexterity that are compounded by their visual impairment. Given that deafblind older people cannot use their vision as effectively in order to make up for hearing loss, deafblind older people should also have prioritised access to both digital and bilateral aids.

Specialist assessment under the Deafblind Guidance

In England⁷ and Wales,⁸ deafblind older people are entitled to a specialist assessment of their needs and appropriate services. The statutory Deafblind Guidance clearly state that local authorities must:

- Identify, contact and keep a record of deafblind people that live in their area;
- Ensure that a deafblind person is assessed by a suitably qualified person;
- Provide services that are appropriate for deafblind people;
- Provide one to one specialist support as appropriate;
- Provide information and services in a way that is accessible to deafblind people;
- Ensure that a senior manager is responsible for services for deafblind people.

Every deafblind older person should be offered a specialist assessment under the Deafblind Guidance. Many deafblind older people and their families do not know about the kind of positive interventions that can provide support to deafblind older people. This is where a suitably trained specialist can offer guidance and advice on making sure support options take full account of the impact of dual sensory loss. Assessments must look beyond the scenario of an older person sitting in their chair at home; they should look at individuals' ability to stay healthy, active and involved in their community. Sensory awareness training for older people's team can highlight the needs of deafblind older people and encourage referral to sensory teams.

Recognising deafblindness as part of mainstream older people's assessment

The Single Assessment Process (SAP) for older people in England, the Unified Assessment Process (UAP) in Wales and the Single Assessment Tool (SAT) in Northern Ireland do not explicitly recognise dual sensory loss. They look at vision and hearing but not in a way that would necessarily trigger recognition of dual sensory loss and referral for a specialist assessment. Sense has produced a simple checklist to help professionals, families and others to identify dual sensory loss. Any changes to the assessment process (such as a Common Assessment Framework or Resource Allocation System) should explicitly recognise dual sensory loss and identify the need for a specialist assessment.

Dementia, confusion and delusions

"It gets completely ridiculous sometimes when you can't understand what people say. You answer something or other and then people think you're becoming senile"⁹

There have also been cases of professionals or others thinking that deafblind older people have dementia when actually it is dual sensory loss that has triggered confusion. Tinnitus, delusions or withdrawal can also be mistaken for signs of dementia. Older people's and mental health teams are unlikely to have expertise in sensory loss and may not have a clear relationship with sensory teams or providers of sensory services. It is paramount that these two groups share knowledge and expertise. The fact that the same age group is at a higher risk of developing both dementia and/or deafblindness means that it is even more important to ensure that assessment of these different conditions is clear. Deafblindness can also make it challenging to assess whether someone has dementia; again assessors should be aware of this and request specialist support where appropriate. This will ensure that Objective 2 of the national dementia strategy, good-quality early diagnosis and intervention for all, is achieved.¹⁰

Preventive services for deafblind older people

Deafblind older people often may not receive services at an early stage. Early intervention is crucial in lessening the impact of deafblindness as outlined above. For example, providing support with communication and mobility so that they do not become isolated and develop poor mental health. Assessment that leads to preventative services in both health and social care is a key part of effectively supporting deafblind older people. It is imperative that health and social care professionals try to identify deafblind older people as early as possible.

Older people will often have increasing levels of sensory loss so it is important to support older people with more moderate hearing and sight loss. Planning ahead can also assist an older person if they need to start learning a new communication method before their sensory loss increases.

Falls prevention

Deafblindness as a risk factor for falls must be included in local falls prevention strategies. The NICE falls guidelines call for a multifactorial assessment to investigate why older people fall as well as multifactorial interventions to prevent falls. It must be clear that this assessment should look at whether older people have a dual sensory loss and the impact that this could have. The interventions for deafblind older people must recognise the unique impact of deafblindness. Where appropriate, individual professionals working on falls prevention should seek specialist support from professionals working in deafblindness. Fear of falls can prevent individuals from leaving the home therefore contributing to and compounding the isolation and inactivity that many deafblind older people are confronted with.

Case study

John is a deafblind older man who has had several falls. The older people's team identify that his dual sensory loss is a risk factor. They contact the deafblind worker in the sensory team who is able to advise them on action. The worker notices how John's combined sensory loss is causing him difficulties both with locating his walking frame as well as dizziness and balance problems. High visibility hazard tape now helps John to see where to support himself on his walking frame. John is also given some mobility training to improve his ability to move about independently.

4. Provision of appropriate and accessible social care services

A positive and common sense culture can ensure that deafblind older people receive the right kind of services and make the most of any remaining hearing and vision and ensure that professionals feel confident in their roles. Individuals with multiple impairments can challenge services or make professionals uncomfortable or unconfident. Steps to take include developing reflective practice, for example where professionals consider how to adapt practice to develop positive attitudes or successful communication. Not all sensory services sit in-house within local authorities so joined-up work between all relevant statutory and voluntary agencies is essential.

Case Study

Rose, an older deafblind person living alone, was identified by the local authority as a vulnerable person. Rose was visited by the local authority hearing impairment team who left her a hearing loop. However, because the team were unable to communicate with Rose, they left the loop in its box. Rose was unable to read the instructions and the loop remained unused. The visual impairment team then paid Rose a visit. The representative was unable to communicate with Rose, so he left her a cane, without telling Rose how to use it. Rose used the cane to wave at traffic as she stood on the side of the road to warn them that she was there. The local authority identified Rose as an isolated person and arranged for her to attend a service for older people. Rose sat in the corner at the centre alone as no-one was able to communicate with her. Eventually Rose developed psychiatric problems and was admitted to hospital.

This is a classic example of well intentioned but disastrously managed care services. Rose needed a specialist assessment that would have looked at dual sensory loss in a holistic way, promoted effective communication, and planned for support which was appropriate for her needs. This could have saved the local authority money and possibly averted the end result of this failure to provide appropriate care and protect Rose's wellbeing and dignity.

The National Service Frameworks for Older People in England¹¹ and Wales¹² establish standards for health and social care for older people. They do not provide a specific framework for sensory impairment, but if local authorities are going to meet these standards for services for all older people, they must address sensory impairment. Listed here are three suggestions of how to ensure services for deafblind older people meet the standards:

- Rooting out age discrimination – recognise that loss of vision and hearing is not simply a normal part of the ageing process and that providing support can increase independence;
- Person-centred care – this could involve providing information in an appropriate format, including individuals' assessments and care plans;
- Falls – increase awareness that dual sensory loss increases the possibility of a fall.¹³

Strategies for Older People in Wales¹⁴ and Northern Ireland¹⁵ set out some similar aims that will only be met for all older people if deafblindness is taken into account.

One to one support from a communicator guide

Deafblind older people may be able to take care of their own personal care but may need support in performing other essential tasks, accessing information and being active members of their community. For some people this may require a number of hours of communicator guide support. A communicator guide is a worker with specialist knowledge of deafblindness who can support a deafblind older person with tasks in the home and in the local community. A few hours a week of one to one support can transform the life of a deafblind older person. However, we know that many deafblind older people are not getting these services, even when they ask for them.

Enabling deafblind older people to live independently in their own homes

Many older people want to be enabled to remain living independently in their own homes.¹⁶ Through a personalised and common sense approach deafblind older people have choice, control and respect as outlined in the Independent Living Strategy.¹⁷ This means that existing resources can be more effectively deployed to meet the needs of deafblind older people. There are some simple and economical ways that deafblind older people can be supported to live independently. A combination of one to one support, skills training, equipment or adaptations can support a deafblind older person to maintain their independence and dignity.

Case study

Colin receives regular support in his home. The only exchange he has with his care worker is when she taps him to make him lift his feet so she can vacuum under them. He is unsure when she has arrived or when she has left.

No one should have to live like Colin; domiciliary care workers supporting deafblind older people have a key role in preventing isolation and must have a level of deafblind awareness and communication skills. For example they should be able to communicate effectively and understand the importance of not moving items, such as kettles, fragile items or essential equipment.

Equipment can work alongside such support to create independent and safe environments. Older people can value technology but it should enable rather than only keep track of them and should also aim to simplify rather than complicate life.

Case study

A visual impairment worker sets up a Talking Books service for Jim, a deafblind older person. She recognises that she needs to make this accessible. She makes sure that Jim can amplify the sound and adds some tactile bump-ons to the buttons on the machine so that he can operate it independently.

Support for deafblind older people in community settings

Many older people can be offered a service based in a group setting. However, for someone with poor vision and hearing, a group environment can be a very isolating place. There can be high levels of background noise, and staff and other users of the service may not know the best way to communicate. Deafblind older people should not be excluded from such groups, but it is vital to

consider how they will be included in a group setting or group activities and whether an alternative would be more appropriate.

Case study

One social services department provides a monthly drop-in day for people with both single and dual sensory loss. The majority of attendees are older people and their carers. Staff present include specialist workers in visual impairment and dual sensory loss. This means that individuals are able to easily access information and equipment that can help them to meet needs triggered by single or dual sensory loss. Individuals often come seeking help for their predominant loss but workers' awareness of dual sensory loss can ensure that needs related to a secondary sensory impairment are addressed. The presence of a specialist worker in dual sensory loss ensures that people with these impairments can be easily identified. Deafblind older people benefit as they can start to have their needs met after this single visit (rather than by separate visits to address individual sensory impairments) and start to build relationships with workers that have specialist knowledge.

Group and peer support for deafblind older people

Some deafblind people will enjoy and benefit from attending groups made up of other deafblind people. There are a number of local groups for deafblind older people or older people with sensory loss, run by a range of organisations including local authorities and Sense.

Case study

A local group for deafblind people meets regularly. Communication support and induction loops are available. The events are used for a range of informative and accessible activities as well as visiting speakers and displays. This helps deafblind older people to have access to information about the support or equipment that they may be able to access. Individuals also enjoy the social element.

Case study

Steven wanted to be part of a regular conference call with other visually-impaired people. He uses an amplified telephone and other members of the group have been given tips on clear speech and trying to speak one at a time.

These types of support groups provide an extremely valuable support mechanism for deafblind older people and their carers. We strongly recommend an increase in the level of peer support and accessible group activities for deafblind older people. Such groups require a relatively low level of resources considering their positive and multi-faceted impact.

Mental health services

Deafblind older people should have access to the full range of mental health services. It is crucial that conditions such as depression do not become normalised. Deafblind older people should have access to talking therapy where professionals should have a minimum of basic communication skills.

Information provision

Information must be accessible to deafblind older people. This will facilitate access to services and other support. It is also vital in ensuring that deafblind older people maintain regular contact with professionals. Deafblind older people can miss appointments simply because information is not provided in the right format.

Personalisation of services

Sense supports moves to give individuals more control and choice over the support they receive. Deafblind older people should be offered the choice to receive more personalised support through direct payments or a notional or cash personal budget. For personalisation to work for deafblind older people, information and support must be provided at appropriate levels. Both the Department of Health¹⁸ and CSCI¹⁹ have recently noted that information and appropriate assistance to plan support are crucial if personalisation is going to work for older people. It is fundamental that any system for allocating resources meets the cost of any specialist needs of deafblind older people. Any system to allocate resources, such as the Resource Allocation System (RAS) does not change any underlying legislation or the need to comply with guidance such as the statutory Deafblind Guidance. Local authorities must be aware that under a self-assessment system, many older people will under-assess their needs and deafblind older people or their carers may not know about possible support solutions such as communicator guides. Compliance with the duty to provide a specialist assessment will help to prevent such issues arising.

The local care workforce and local authorities' role as place shapers in an ageing society

As well as commissioning appropriate services, local authorities have a duty to monitor and encourage the local market for independent support services. Government was right to encourage local authorities to look at the changing demographics of the area they cover.²⁰ However this must go further. Given that Sense estimates that 4.6% of the population over 75 are deafblind, local authorities should analyse the demographics of their local area and plan for the current and future population of deafblind older people.

Residential care home providers

Due to the prevalence of deafblindness in people over 75, it is inevitable that the majority of residential care homes will provide support to deafblind older people. Many care providers do not identify deafblind older people that they support. This can result in lack of communication with and isolation for deafblind older people. Increasing staff awareness is vital to improve outcomes. Indeed care providers will only be able to provide a high level of services if they recognise deafblindness and adapt services accordingly. Assessment or review appointments can be ideal opportunities for input but it is important that staff at all levels of a care setting are deafblind aware.

Case study

A deafblind specialist from social services visited a care home and identified that Elizabeth was deafblind, distressed, and that communication was very poor. The deafblind worker tried different communication techniques, asked to give staff deafblind awareness training and contacted the local audiology clinic. As a result, there is a regular communication group for staff exploring communication methods. Staff set up a checklist system to ensure that Elizabeth was always using her hearing aids. The lack of colour contrast between different furnishings was also causing some difficulties. Staff purchased cushions in a contrasting colour which enable Elizabeth (and other residents) to move around the room safely and independently. Staff now feel more confident in communicating with Elizabeth and she is able to receive the support she needs more effectively.

Case study

Miriam recently moved into a residential service. The service was keen to provide a service that would meet her needs. She was provided with a ground floor room and staff received deafblind awareness training. She had a specialist assessment that identified that she needs several hours of weekly support from a communicator guide who supports her to access her local community. The residential service is unable to provide this so the service is provided additionally to her residential placement. She attends a regular craft class, computer lessons and services at her local church.

5. Conclusion

With an ageing population, sensory loss must not be ignored when planning services for older people. People providing services to older people, including social services, care providers, group setting managers, housing officers and the voluntary sector, need to be aware that dual sensory loss is common among the people who use their services, and to think about how they can make what they do accessible. Local authority plans for meeting the needs of an ageing society must recognise dual sensory loss in order to achieve aims around information provision, prevention, health promotion, active ageing, supporting carers, dignity, respect, and preventing isolation.

Sense would welcome support and assistance in voicing our serious concerns relating to older people with dual sensory loss across the membership of both Houses of Parliament and devolved assemblies, relevant government departments, the Welsh Assembly Government and Northern Ireland Executive, local authorities and Health and Social Care Trusts, older people's champions, service providers, relevant organisations and the wider public. We believe that in working in partnership with others, we will be able to ensure that deafblind older people receive the services they need, retain their independence, maintain important relationships and are part of their local communities.

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6. Resources

Sense

www.sense.org.uk

Tel: 0845 127 0060

Text: 0845 127 0062

Email: info@sense.org.uk

Fill in the Gaps: A toolkit for professionals working with older people

Fill in the Gaps: A checklist for assessing older deafblind people

Seeing Me: Guidance on sight and hearing difficulties for staff who care for older people

Seeing Me: A checklist for identifying older people with dual sensory loss

It All Adds Up: A pack for healthcare staff

The Good Life booklet: Information for older people and families.

The Good Life poster (A4)

Short film about Edith, a 96 year old deafblind woman

Department of Health

www.dh.gov.uk

Social Care for Deafblind Children and Adults LAC (DH) (2009) 6

National Assembly for Wales

www.wales.gov.uk

Circular No.10/01: Social Care for deaf blind children and adults.

Moving Forward: Services to Deafblind People

Counsel and Care

www.counselandcare.org.uk

Guide 39: If you can't see and/or hear well: what help and support is available?

Social Care Institute for Excellence (SCIE)

www.scie.org.uk

Research briefing 21: Identification of deafblind dual sensory impairment in older people

Thomas Pocklington Trust

www.pocklington-trust.org.uk

Occasional paper 20: The needs of older people with acquired hearing and sight loss

Occasional paper 11: Dementia and serious sight loss

Visual Impairment Centre for Teaching and Research (VICTAR) -

<http://www.education.bham.ac.uk/research/victar/>

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

Endnotes:

¹ Figure calculated by Sense in 2006 using Fletcher, A, 1990, The MRC trial of assessment and management of older people in the community: objectives, design and interventions, Centre for Ageing and Public Health, London School of Hygiene and Tropical Medicine

² Based on population projections from the Office for National Statistics

http://www.gad.gov.uk/Demography_Data/Population/2006/uk/wuk065y.xls

³ VICTAR, 2007, Secondary data analysis with a focus on the needs of older people with acquired hearing and sight loss: An analysis of the 'Network 1000' and 'Cambridge' datasets, 45

⁴ Crews J.E., Campbell V.A., 2004, Vision impairment and hearing loss among community-dwelling older Americans: implications for health and functioning.

American Journal of Public Health; 94 (5); 823-9

⁵ Sense, 2008, Sense paper on the health of deafblind older people. Cost estimates are based on government statistics for specific conditions.

⁶ VICTAR, 2007, Secondary data analysis with a focus on the needs of older people with acquired hearing and sight loss: An analysis of the 'Network 1000' and 'Cambridge' datasets, 35

⁷ Department of Health, 2009, Social Care for Deafblind Children and Adults LAC (DH) (2009) 6

⁸ National Assembly for Wales, 2001, Circular No.10/01: Social Care for deaf blind children and adults

⁹ Göransson, L., 2008 'Ageing with Deafblindness' in Deafblindness in a Life Perspective, Mo Gårds, 146

¹⁰ Department of Health, 2009, Living well with dementia: A national dementia strategy, 33

¹¹ Department of Health, 2001, National Service Framework for Older People

¹² Welsh Assembly Government, 2006, National Service Framework for Older People

¹³ See Sense, 2006, Fill in the Gaps, 13 and Fill in the Gaps (Wales version), 13

¹⁴ National Assembly for Wales, 2008, The Strategy for Older People in Wales (2008-2013)

¹⁵ Office of the First Minister and Deputy First Minister, 2005, Ageing in an Inclusive Society

¹⁶ Care and Social Services Inspectorate Wales, 2009, Annual Report 2007-08, 13

¹⁷ Office for Disability Issues, 2008, Independent Living: A cross-government strategy about independent living for disabled people

¹⁸ Department of Health, 2008, Making personal budgets work for older people: developing experience, 8

¹⁹ Commission for Social Care inspection (CSCI), 2009, The State of Social Care in England, 139

²⁰ HM Government, 2005, Opportunity Age, 31