

Sensory loss in the adult population in Wales

May 2012

This report addresses the needs of people with sensory loss to ensure that they are recognised across the spectrum of public services and that we ensure that as services are reconfigured in Wales we can better meet the needs of this group services.



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Contact

Welsh Local Government Association

The WLGA's primary purposes are to promote a better local government, its reputation and to support authorities in the development of policies and priorities which will improve public service and democracy. It represents the 22 local authorities in Wales, with the 4 police authorities, 3 fire and rescue authorities and 3 national park authorities as associate members.

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Sensory loss in the adult population in Wales

Introduction

Sensory loss is a significant issue affecting one in five people in Wales. As people live longer the number of people with sight loss alone can be expected to double in the next 25 years. As users of public services it is important that the needs of people with sensory loss are recognised across the spectrum of public services and that we ensure that as services are reconfigured in Wales we can better meet the needs of this group. Ensuring that standards of service are both appropriate and deliverable poses a challenge to all providers of services.

Cross sector partnership

In recognition of this growing challenge the WLGA, RNIB Cymru, Sense Cymru and Action on Hearing Loss, have embarked on a cross sector partnership approach with a senior manager from RNIB providing 2 days a week support within the WLGA's Equalities and Social Justice Directorate, as Sensory Loss Partnership Manager.

Briefing and website

The initial task of the role was the production of a briefing on sensory loss in Wales and production of a web based sensory loss resource on the Social Services Improvement Agency website. <u>http://www.ssiacymru.org.uk/</u>. The website resource will also be accessible through the Good Practice Wales online portal, a single access to Welsh Public Services good practice and knowledge. <u>http://www.goodpracticewales.com/</u>

Purpose of report

The purpose of the report and website is to assist in the delivery of high quality and accessible services to people with sensory loss in Wales by;

- raising awareness of the prevalence and impact of sensory loss in Wales
- providing statistical information to inform service delivery in Wales
- raising awareness of the experiences of people with sensory loss

Key themes and recommendations

There are a number of key themes raised by people with sensory loss which should be addressed by service providers;

- Communication
- Access to information
- Awareness raising
- Environment
- Engagement of people with sensory loss in service planning

Sensory loss in children in Wales

A separate briefing will be issued specifically in relation to children with sensory loss.

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1.1 Hearing loss

Prevalence

- 500,000 people in Wales, 1 in 6, are estimated to be affected by hearing loss.
- 300,000 plus of those with hearing loss would benefit from hearing aids. 10 per cent of the population.
- 44,500 of those with hearing loss are severely or profoundly deaf.
- The majority of people with hearing loss are older. The prevalence increases with age.
- 41.7 per cent of over 50 year olds have some kind of hearing loss.
- 71.1 per cent of over 70 year olds have hearing loss.

Figures based on the most comprehensive study into hearing in the adult population (1) with prevalence rates applied to population estimates, 2010. (2).

Increase in prevalence

- 14 per cent increase every 10 years, correlating to an ageing population. Medical Research Council.
- By 2030 adult onset hearing loss will be in the top 10 disease burdens in the UK, above diabetes. The World Health Organisation.

Local Authority Registers

• 12,500 people in Wales were registered with hearing loss as at March 11, based on data provided by 21 Local Authorities. (3)

The Statistical Directorate of the Welsh Government recognises that as registration is voluntary figures this may therefore be an underestimate of the numbers of people with physical or sensory disabilities.

1.2 Sight loss

Prevalence

- 115,000 people in Wales are estimated to be living with sight loss that has a significant impact on their daily lives. (4)
- A further 200,000 over the age of 65 have a visual impairment that could be cured simply by wearing glasses. (4)

The above figures are based on prevalence statistics and applied to population estimates, 2007. (4)

- Every day 5 people lose their sight in Wales.
- Over half of all sight loss is preventable and avoidable.
- Sight loss affects people of all ages. However, the prevalence increases with age.
- 1 in 9 people over the age of 60 are living with sight loss.
- 1 in 3 people over the age of 85 are living with sight loss.

Increase in prevalence

11.25 per cent in the next 10 years. Correlating to an ageing population and a growing incidence in key underlying causes of sight loss such as obesity and diabetes.

Local Authority Registers

16,300 people in Wales were registered with a visual impairment as at March 11, based on data provided by 21 Local Authorities. (3)

The Statistical Directorate of the Welsh Government recognises that as registration is voluntary figures this may therefore be an underestimate of the numbers of people with physical or sensory disabilities.

1.3 Deafblindness

Definition of deaf blindness

Whist there is no generally accepted definition of deaf blindness there is a working description that has been accepted over many years –

'Persons are regarded as deaf blind if their combined sight and hearing impairment cause difficulties with communication, access to information and mobility'. Deaf blindness can be found in all age groups, including children, but the incidence is greatest for older adults. (5)

The multiplier effect

Dual sensory loss is not just a deaf person who cannot see or a blind person who cannot hear. The two impairments impact on each other and multiply the total effect.

Prevalence (6)

- It is estimated 18,850 people in Wales are currently affected by both visual and hearing impairments.
- 500 people in every 100,000 population will have some level of cooccurring sight and hearing loss and 212 per 100,000 will have a loss of a severity to classify them as deafblind.
- 62 per cent of the deafblind population is aged over 70.

Increase in prevalence (6)

- The number of people who are both deaf and blind is estimated to grow by 60 per cent in 20 years (2030) largely driven by general demographic change.
- People over 70 will be most affected with an 87 per cent increase by 2030.

Local Authority Registers

206 people in Wales were registered as Deafblind as at 31st March 2010.

As 68 per cent of those registered were registered within just two authorities the figures are likely to be vastly underestimated.

2.0 Health and wellbeing



The effect of sensory loss, single or dual, is underestimated in relation to social isolation, loss of independence, mental ill health, nutrition and wellbeing. People with sensory loss are more likely to have difficulty with moderate exercise, mental stimulation, maintaining social contact and healthy eating resulting in poor health outcomes.

The common perception that sensory loss in older people is an inevitable part of ageing should be resisted. With the right information, advice and support people with sensory loss can be enabled to live active and healthy lives, maintain independence, be socially active and maintain good mental health. Many older people's sight and / or hearing can be enhanced or maintained, and a great deal can be done to help someone to use the remaining sight and hearing that they do have.

Although the level of sensory loss is higher in the older population sensory loss affects people of all ages.

2.1 Depression and suicide

Sight loss

- 35 per cent of older people with sight loss are living with some form of depression. (7)
- Older people with sight loss are three times more likely to experience depression than people with good vision. (8)
- The British Medical Journal reports that sight loss is one of the top three causes of suicide among older people. (9)

Hearing loss

• Older people with hearing loss are 2.45 times more likely to develop depression than those without hearing loss. (10)

2.2 Social isolation

People with sensory loss are likely to withdraw from or be unable to access social groups and activities within their communities, due to a range of factors such as; lack of confidence, lack of information, lack of awareness of their needs, lack of money, lack of support.

Sight loss

- 43 per cent of people with sight loss would like to leave their house more often. 3 out of 4 older people with sight loss cite their visual impairment, mobility issues or a lack of confidence as the main barrier. (11)
- Nearly 50 per cent of people with sight loss report that they feel 'moderately' or 'completely' cut off from people and things around them. (12)

Hearing loss

- People with hearing loss are likely to withdraw from social activities involving large groups of people and where they do take part communication difficulties can result in feelings of loneliness. (13)
- Hearing loss can mean a decrease in intimate talk and joking with family (14) and a distancing between couples. (15)
- Hearing loss can distance couples as a unit from wider social networks; partners of people with hearing loss feel frustration and loneliness and report missing out on social activities and companionship. (16)

2.3 Lack of accessible information or communication services

Lack of accessible information or communication services have a huge impact of people's lives and can compound social isolation, financial exclusion and living health lives.

Sight loss

- Less than 7 per cent of books are available in accessible formats. This does not include e-books, which are increasing usable for people who are confident users of technology.
- 79 per cent of participants in a survey for Guide Dogs for the Blind reported having difficulties with identifying food and medicine labels. (17)

Hearing loss

- People with hearing loss find it hard to access information about services. For example, lack of accessible information is a significant barrier to people using public transport.
- 79 per cent of people, when fitted with hearing aids, did not receive any information about other services or potentially useful technology.
- Lipreading classes help people with hearing loss to maximise communication, build confidence and increase their independence. However, there are currently only 21 lipreading classes in Wales. The cost for classes is varies between authorities, ranging from £77 per term, to free of charge. It would be helpful to have a consistent approach across Wales. (18)

2.4 Abuse and harassment

- People with sight loss are 4 times more likely to be the victim of physical abuse, and of repeat abuse. Nearly half are abused by someone they know. (19)
- 1in 5 blind and partially sighted people never go out alone, citing fear and lack of confidence as major factors. (19)
- Disability harassment is widespread and a daily experience for many disabled people who routinely experiencing different forms of harassment such as name calling, physical violence, bullying and cyber-bullying, sexual harassment, domestic violence and financial exploitation. (20)

 100,000 disabled adults were crime victims in Wales and England last year. 19 per cent of the population (The British Crime Survey 2009/10. Not all crime experienced by disabled people is related to their disability. Equally, however, much disability-related harassment does not involve criminal behaviour, so the numbers experiencing harassment are likely to be much higher.

2.5 Falls

Historically, falls were accepted as an unavoidable problem of advancing years and frailty. However, there is now a large-body of evidence based research that considers that such events can be predicted and prevented. Effective interventions are important and can result in significant benefits with regard to improving individual wellbeing.

- Poor eyesight is one of three major risk factors contributing to falls among older people leading to accidents and death. (21)
- Older people with sight problems are almost twice as likely to have a fall, and have 90 per cent higher odds of multiple falls than a person without visual impairment. (22)
- Falls are believed to be a contributing factor in 40 per cent of admissions to nursing homes. (23)
- Approximately 60 per cent of people living in care homes experience recurrent falls each year. (24)
- 60 per cent of people who have a stroke will have visual problems and falling has been identified as a major complication in people who have had a stroke. It has been estimated that up to 70 per cent of individuals who return home after a stroke will fall, especially during the first few months and this could result in a move to long term care. (25)
- Many falls happen in people's own homes. Nearly 50 per cent of people with sight loss indicated that they trip or fall on the stairs, with a third rating the light level for finding the stair edge as 'poor' or worse. (26)

- 1 in 4 people using the Wales Low Vision Service reported that they had fallen 4 times or more in the last 12 months, over 50% had fallen once.
- People with hearing loss are highly likely to have problems such as tinnitus and balance disorders which contribute as risk factors for falls and other accidental injuries. (27)
- 35 per cent of people aged 65 and over who live in the community fall each year, increasing to 45 per cent for those 80 years and older. (24)

2.6 Additional disabilities and long term health problems

Due to the prevalence of sensory loss with age many people will have additional disabilities and long term health problems.

- It is estimated that 35% of people with sight loss have an additional health problem or disability. (29).
- It is estimated that around 50 per cent of people with hearing loss have an additional health problem or disability such as arthritis and mobility problems. (30)
- Older people with dual sensory loss are more likely to develop additional health conditions such as stroke, arthritis, heart disease, hypertension and symptoms of depression. They are at increased risk of falls and often have higher rates of mental distress. Sense estimates the cost of treating these additional conditions to be £365 million per year in the UK.

2.7 Associated risk factors: deprivation, poverty, obesity and smoking

Sight loss

The link between poverty and poor health is now well recognised and it is common for people who have lost their sight to also have the burden of chronic conditions such as cardiovascular disease, diabetes, arthritis or respiratory disease. Living with these conditions is more difficult for people who struggle to exercise because they cannot see and struggle to eat a healthy diet because they are living in poverty. Attending an outpatient appointment is difficult if you can't read the letter from the hospital and taking medication without supervision can be dangerous.

- Chronic eye disease is worse in areas of multiple deprivation and low income. Glaucoma and Diabetic Retinopathy, both major causes of preventable but irreversible sight loss in working age groups in the UK, present at more advanced stages with worse prognosis in areas of high deprivation.
- Poorer older people are much less likely to seek early attention for the onset of visual disturbance and are much less likely to visit an optometrist leading to a likely differential risk of blindness from neovascular Age Related Macular Degeneration in poorer people.
- Smoking doubles a person's chance of sight loss and there is a proven link to obesity and eye disease / sight loss.

2.8 Dementia

Hearing loss

- People with mild hearing loss have nearly twice the chance of developing dementia compared to people with normal hearing. The risk increases threefold for those with moderate and fivefold for severe hearing loss. (31).
- There are no validated assessment tools in British Sign Language for diagnosis of dementia among Deaf people and using assessments designed for English speakers with an interpreter can lead to misunderstandings; some terms do not mean the same thing to people from different cultures.

Sight loss

• It is estimated the number of people over 75 years with dementia and sight loss, based on the data for each individual morbidity, to be 2.5 per cent of this older population. (32) However, this figure is likely to be an under-estimate because visual impairment studies will not have accounted for individuals that are considered 'untestable'. There has been no comprehensive study covering this area, and serious sight loss is not part of the standard diagnostic features of Alzheimer's disease. It is important to diagnose both dementia and sight loss in order to maximise the treatment and care of the individual, as the degree to which a person with dementia is able to cope will be influenced by sight loss.

- Dementia combined with sight loss can lead to:
 - profound disorientation and isolation
 - increased risk of falls
 - difficulties moving between light and dark
 - difficulties learning to use new equipment
 - more visual mistakes
 - less independence
 - misperception and misidentification
 - increased worry for carers and relatives
 - visual hallucinations may be associated with dementia or sight loss. They may be distressing for those affected, and may precipitate a move to a care home.

2.9 Stroke

- 60 per cent of people who have a stroke will have visual problems (33). with those who have had a right-sided stroke more likely to experience visual difficulties.
- Falling has been identified as a major complication in people who have had a stroke. It has been estimated that up to 70 per cent of individuals who return home after a stroke will fall especially during the first few months and this could result in a move to long term care (25).
- Deafblind older people are nearly four times more likely to suffer a stroke.
- Stroke has a greater disability impact than any other chronic disease. Every year the cost to the UK of handling stroke sufferers is $\pounds 6$ billion.

2.10 Early diagnosis of sight and hearing loss

Sight loss

- Every day 5 people lose their sight in Wales.
- Over half of all sight loss is preventable and avoidable.
- 200,000 people in Wales over the age of 65 have a visual impairment that could be cured simply by wearing glasses.

Hearing loss

Diagnosis of hearing loss in adults is opportunistic and ad hoc.

- An average10-year delay in people seeking help. (27)
- Research suggests that GPs fail to refer up to 45% of people reporting hearing loss for any intervention such as a referral for a hearing test or hearing aids.
- There is no national adult screening programme in the UK, and the government does not offer public health information on hearing loss, its impact, and the benefits of early intervention.
- A cost benefit analysis of a hearing screening programme, showed that the benefits of hearing screening for older people clearly outweigh the costs. At a cost of £255m (UK) over 10 years, a hearing screening programme for over 65s could save £2bn, representing a benefit cost ratio of more than eight to one (34).

Sight and hearing loss are viewed by many as an inevitable part of ageing, however much can be done to limit the negative impact of sensory loss with appropriate interventions. E.g the significant benefits of hearing aids. Hearing aids use can reduce isolation, (35) depression, anxiety and improve emotional stability and independence (36).

3.0 Financial exclusion



3.1 Poverty

- RNIB estimates that 3 out of 4 older people with sight loss live in poverty compared to 1 out of 4 sighted people (37). In Wales alone this would suggest that over 75,000 older people with sight loss are living in poverty.
- People with hearing loss may also incur additional costs in daily life through paying for additional communication support.

3.2 Employment

Sight loss

- People with sight problems are less likely to be in employment than the general population and they are more likely than other groups to be unemployed for 12 months or more (38).
- Registered blind or partially sighted people with a degree or higher still only have the same chance of getting a job as someone with no qualifications in the general population (39). A number of factors contribute to this. Most significant is that of employers' attitudes and lack of awareness of the Access to Work programme.
- The Labour Force Survey identifies that 48 49 per cent of long term disabled people with a seeing difficulty are in employment (38) whilst the Network 1000 study identifies 34 per cent of working age people who are registered blind or partially are in employment. (39) The reason for this discrepancy is that the two studies use different criteria for identifying the blind and partially sighted population.

Hearing loss

- At a time of near full employment, deaf people were 4 times more likely to be unemployed than the general population, with negative attitudes from employers seen as the main barrier to getting a job (40).
- RNID's 2010 annual members' survey found that 60 per cent of respondents were employed when they lost or began to lose their hearing. 45 per cent told their colleagues about their hearing loss, and even fewer, 37 per cent, chose to tell their employer. 40% found their hearing loss made them less confident in their abilities (30).

Further information on Access to Work

Access to Work can help individuals if their health or disability affects the way they do their job. It gives the individual and their employer advice and support and support with extra costs which may arise because of the individual's needs, for example, additional equipment costs.

http://www.direct.gov.uk/en/DisabledPeople/Employmentsupport/Work SchemesAndProgrammes/DG 4000347

3.3 Access to benefits

The benefits system provides vital support for people with sensory loss. Disability Living Allowance in particular is a crucial benefit for disabled children and adults to help with extra costs they incur. It is estimated to cost around \pounds 200 per week in extra expenses if you are blind or visually impaired, for example, taxis, additional help in the home, ready made meals. (Centre for Research in Social Policy at Loughborough University)

However, access to benefits is often marred by poor decision-making and little understanding of sensory loss. Research conducted in 2009 by Action on Hearing Loss showed that 85 per cent of people who were refused Disability Living Allowance and took it to appeals tribunal were successful in their appeal (41). RNIB Cymru's Specialist Home Visiting Welfare Rights Service has evidenced that over 60 per cent of people with sight loss accessing the service are under claiming their benefit entitlement. In 2010/11 alone the service secured just under £1million in unclaimed benefit entitlements, including back dated payments, for just 484 people. This money is from the national exchequer. In addition the service is reporting an increase in the number of appeals and Tribunals it deals with.

Many people with sight loss do not access the benefits to which they are entitled to for a number of reasons:

- Lack of accessible information
- The completion of forms and follow up documentation is often extremely difficult, if not impossible
- Questions are aimed at physical rather than sensory disabilities
- People with sight loss are very poor self advocates
- People often say they don't need any help for fear of being taken from their home
- Mobility and access to services is extremely difficult

Welfare reform

On 16 February 2011 the Welfare Reform Bill was introduced to Parliament. The bill introduces a wide range of reforms including the replacement of Disability Living Allowance for people of working age with a new benefit, Personal Independence Payment. The introduction of Universal Credit, which aims to radically simplify the system to make work pay and combat worklessness and poverty, and changes to Employment Support Allowance.

Disabled people are concerned at the current proposals and may lose an important source of income when these changes come into effect.

Mitigating the impact of Welfare Reforms

The Welsh Government is developing a Framework for Action on Independent Living. The Framework will set out the action to be taken to promote the rights of disabled people to live independently and exercise the same choices as other citizens. It will contribute to the Welsh Government's Strategic Equality Plan and support its efforts to mitigate the effects of the UK Government's welfare reform plans.

4.0 Digital exclusion



Almost a third of people in Wales do not have an internet connection in their home and statistically fewer people in Wales than the UK are online.

People do not access the internet because of lack of awareness, knowledge and confidence and because of lack of access to equipment and cost. When deciding to go online, financial reasons are significantly less important than social, family and employment-related reasons.

As in the general population, computer usage amongst blind and partially sighted people is linked to age. 53 per cent of working age blind and partially sighted people use a computer at least once a week or more compared to only 8 per cent of people of retirement age (11). Amongst both these age groups, the frequency of computer use is significantly lower then comparable age groups in the general population.

An increasing number of public services are expected to be delivered online in the future. This raises a significant challenge as to how the needs of those who are currently offline might be met. This is all the more pressing because the individuals and households who do not currently use the internet are generally those who are already the most disadvantaged in society. As such they are likely to be more dependent than other groups of people on the very services that they could well be excluded from through a wholesale move to online delivery (42).

5.0 Public transport



Public transport is essential for providing access to employment, social events, health services, education and leisure pursuits.

Hearing loss

In 2009 RNID Cymru, now called Action on Hearing Loss, received funding from the Welsh Assembly Government to undertake a research project into the everyday inclusion barriers facing people who are deaf or hard of hearing in Wales. The report "Open to All" (43) identified the main barriers to using public transport as:

- Lack of deaf awareness 65 per cent of respondents
- Lack of accessible information 28 per cent of respondents
- Attitude of service providers 24 per cent of respondents
- No real-time visual information displays

Sight Loss

The 2009 report on Travel, Transport, and Mobility of people who are blind and partially sighted in the UK (44) outlined the experiences of people with sight loss.

- 32 per cent of people with a visual impairment using buses experienced some degree of difficulty, 10 per cent found them very difficult
- Accessing information related to public transport was a common theme participants described difficulties in reading bus numbers and train/flight destinations on overhead screens, and the absence of audio announcements on journeys.

• The quality of the help received from transport staff was mixed and often linked to awareness of visual impairment. Some of the participants felt that this was often because they did not 'look' visually impaired and so people did not understand why they were asking for help. Many considered that having a cane or guide dog usefully signalled that they had a visual impairment.



6.0 Access to public services and service providing organisations

The RNID "Open to All" report, 2009, commissioned by the Welsh Assembly Government identified the following:

- 89 per cent of respondents believed that being deaf or hard of hearing makes it harder for them to use services
- 80 per cent of respondents identified that a lack of deaf awareness was the main barrier to using services
- 36 per cent identified the attitude of services providers as a barrier.
- 23 per cent said it was difficult to get information about services provided by local authorities. When discussing local authority services, open forum participants raised the need for specialist social workers for deaf people in every local authority as well as the lack of lipreading classes across Wales.
- 15 per cent said it was difficult to get information about health services. The figure rose to 45 per cent of respondents who use British Sign Language and Sign Supported English.
- 10 per cent of respondents said it was difficult to get information about services provided by post offices and banks. However, the figure rose to 33 per cent of respondents who use British Sign Language and Sign Supported English.

For above figures see ref (44)

7.0 Learning Disabilities



Sight loss

- People with learning disabilities are 10 times more likely to have serious sight problems than other people. People with severe or profound learning disabilities are most likely to have sight problems (45).
- 6 in 10 people with learning disabilities need glasses and often need support to get used to them. People with learning disabilities may not know they have a sight problem and may not be able to tell people. Many people think the person with a learning disability they know can see perfectly well (45).
- The estimated number of adults, aged 20 plus, with a learning disability in Wales, 2011 is 49,600 (45).

Hearing loss

It has been suggested that almost 40 per cent of adults with a learning disability will have a hearing loss yet for many people the loss will not be diagnosed because audiology services are not accessible to them. For many, the loss will be identified but the support they receive may not be adequate for them to benefit from a hearing aid. The consequences can be a double disadvantage, their learning disability precludes them from receiving adequate support for their hearing loss and the failure to address their hearing loss will in turn exacerbate the effects of their learning disability. More research needs to be undertaken in this area to ensure the provision of adequate services.

Dual sensory loss

There are no statistics available for people with a learning disability and dual sensory loss because most people do not distinguish between people who have a learning disability and people who have a dual sensory loss. Presentation can be similar. This lack of statistical data clearly will impact on the delivery of appropriate services.

Local Authority Registers

As at the 31st March 2011 there were 14,440 people registered with learning disabilities in Wales.

The registers of people with learning disabilities may be an underestimate of the total number of people with learning disabilities as registration is voluntary.



8.0 Black and Minority Ethnic Communities

Sight loss (Ref 46)

- People from black and minority ethnic communities are at greater risk of some of the leading causes of sight loss.
- 1 in 10 people from ethnic minority background over the age of 65 will experience serious sight loss.
- Black and Asian communities have a greater risk of developing diabetic eye disease compared to the white population.
- Cataracts are twice as common in Asian communities and occur ten times earlier in people with diabetes.
- People of South Asian descent are six times more likely to develop diabetes than the general population.
- People of Asian descent are at particular risk of developing acute glaucoma.
- The risk of glaucoma is much higher for the black population compared to the white population.
- People of African and African-Caribbean descent are four times more likely to develop glaucoma.
- The black population has a greater risk of developing age-related macular degeneration (AMD) compared to the white population aged under sixty whereas the white population has a greater risk of developing AMD in the later years of life.
- Overall Asian people are at lower risk than the white population of developing AMD.
- The white population has the greater risk in developing refractive error compared to the black population.

Hearing loss

There are currently no reliable prevalence stats for the prevalence of hearing loss in BME communities.

9.0 Residential Care



Sensory loss is a common occurrence in the general elderly population. It is therefore reasonable to predict that there will be a significant incidence of sensory loss in the elderly population in residential care. However, sensory loss is rarely viewed as a need in itself, more often a complicating factor in other needs and there is evidence that it is seldom specifically addressed.

Recent research by Sense into hearing and sight loss amongst older people in care homes (47) found;

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

Action on Hearing Loss's research "Older people who use BSL – preferences for residential care provision in Wales" (48) evidenced that that the needs of people who used BSL are being significantly overlooked. Consequently services are being provided which may not be tailored to individual need, leading to unnecessary isolation, depression, mental ill health and wellbeing.

In 2012 the National Assembly for Wales' Health and Social Care Committee is undertaking an inquiry into residential care for older people.

RNIB Cymru, Sense Cymru and Action on Hearing Loss will be working with the CSSIW, Care Council Wales and Registered Care Homes from 2012 to address sensory loss in Care Homes.



10.0Main causes of sensory loss inadults

Sight loss

The five leading causes of sight loss in the UK are refractive error, agerelated macular degeneration, cataract, glaucoma and diabetic retinopathy."

- 53.5 per cent have sight loss equivalent to partial sight or blindness due to refractive error. (Uncorrected refractive error is a correctable form of sight loss.)
- 16.7 per cent to age-related macular degeneration
- 13.7 per cent to cataract
- 5.3 per cent glaucoma
- 3.5 per cent diabetic retinopathy
- 7.4 per cent have other eye diseases.

Hearing loss

The single biggest cause of hearing loss is age related damage to the cochlea, or presbycusis. This process occurs naturally as part of the ageing process. Other causes and triggers of hearing loss include:

- Regular and prolonged exposure to loud sounds
- Ototoxic drugs that harm the cochlea and/or hearing nerve
- Some infectious diseases, including rubella
- Complications at birth
- Injury to the head
- Benign tumours on the auditory nerve

• Genetic predisposition: at least half of all childhood deafness is inherited

Deafblindness

- **Congenital deafblindness** is when someone is born with combined sight and hearing difficulties. Examples of this include conditions such as Rubella or CHARGE.
- Acquired deafblindness is when people develop these problems later in life. This may be due to an accident, illness or as a result of ageing in later life, see information above.
- **Genetic deafblindness.** This is where there is a genetic condition such as Usher Syndrome, which may mean that they progressively lose their sight and hearing.



11.0 Key themes and recommendations

There are a number of key themes raised by people with sensory loss which should be addressed by service providers.

Communication

Poor communication is one of the key concerns raised by people with sensory loss. Ineffective communication can have a very significant adverse impact upon individual's lives, their ability to access public services and consequently can poses significant risks to individuals.

All authorities / services should have an Accessible Information Policy outlining how individual's communication needs, including the needs of people with sensory loss, will be met. This should include:

- ensuring that information, both written and face-to-face, is accessible and delivered in a way that meets the needs of people with sensory loss,
- staff, in particular front line staff in services which have high numbers of people with sensory loss using them, are trained in communicating with people with sensory loss and able to meet their needs,
- ensuring the Accessible Information Policy is included in induction training and customer service training,
- ensuring a system is in place to capture feedback from people with sensory loss on the effectiveness of the authority's communication systems and that the data collected is routinely used to further improve communication.

Access to information

Information should be made available in a variety of formats and communication support should be available, where necessary,

Awareness raising

Sensory loss awareness training should be part of initial and regular staff training.

Environment

Environments in which services are delivered should be accessible, safe and appropriate to the needs of people with sensory loss, including colour and tonal contrast, appropriate lighting and noise insulation. Loop systems and fire strobes need to be in all communal areas, kept in good working order and how to maintain them included in training.

Engagement of people with sensory loss in service planning

A robust mechanism should be in place to ensure that the needs of people with sensory loss underpin service planning. This should include setting up of sensory loss expert panel.

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