Health and Social Care Committee

HSC(4)-07-12 paper 3

Inquiry into residential care for older people – Evidence from Action on Hearing Loss Cymru, RNIB Cymru and Sense

About us

Action on Hearing Loss Cymru

Action on Hearing Loss Cymru is the new name for RNID Cymru. We're the charity working for a Wales where hearing loss doesn't limit or label people, where tinnitus is silenced – and where people value and look after their hearing.

Care & Support Services is the largest component of the Action on Hearing Loss group. We support Deaf and hard of hearing adults, some of whom have additional needs such as learning disabilities, mental health, physical disabilities and dual sensory loss. Nearly a third of our service users (27 per cent) in residential care in Wales and the South West of England are over the age of 60.

RNIB Cymru

RNIB Cymru works on behalf of an estimated 115,000 people in Wales with sight loss. We campaign to create a society more inclusive of people with sight loss and we promote eye health by running public health awareness campaigns. We also work in partnership with organisations across Wales to provide local services, providing practical solutions to everyday challenges.

Sense

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

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

Vocabulary
Throughout this response we use the term 'people with hearing loss' to refer to people with all levels of hearing loss, including people who are profoundly deaf.

This response uses the term ‘people with sight loss’ to refer to any people who are living with significant sight loss, and some have vision which is equivalent to people who are partially sighted or blind.

People with hearing and sight loss are referred to in this response as people with dual sensory loss.

The term ‘people with sensory loss’ is used to refer to people with hearing, sight or dual sensory loss.

Our response
As laid out in the introduction (below) there is a high proportion of people with sensory loss in Wales. As the population ages there will be an increase in the levels of people with sensory loss, together with a likely increased need for residential care. It is critical that current and future providers of residential care are able to meet the needs of people with sensory loss in Wales – providing people with an exemplar service and meaningful choice in terms of residential care provision.

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.

With the right advice and support, such as one-to-one assistance, mobility and communication training or equipment, people with sensory loss can be enabled to live active and healthy lives, maintain independence, be socially active and maintain good mental health.

The common perception that sensory loss in older people is an inevitable part of ageing should be resisted. 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.

Sense have provided this powerful example of what the process of entering residential care can be like for someone with dual sensory loss.

“Sheila is an elderly deafblind woman who lived alone for the whole of her adult life. Until her sensory impairments degenerated significantly in her early eighties, Sheila had an active life, took part in the W.I. and helped with the reading programme at a local school.

Sheila was only given 2 hours per fortnight of a combination of paid and voluntary support. She became increasingly confused due to her deafblindness and the decision was made, against Sheila's wishes, to place her in residential care.

The staff at the home do not know how to support her, for example they leave her food on a tray in front of her but don't communicate with Sheila to tell her that her food is there and as a result Sheila may go hungry. Sheila has depression and talks of suicide.

The Sense professional working with Sheila firmly believes that if Sheila had been given 2 hours per day of communicator guide support at an early stage to help her to readjust to her sensory impairments and thereafter 3 hours twice a week of one to one support, then Sheila could have remained in her own home."

The following example, also from Sense, highlights the impact of inadequate recognition of sensory loss on an individual:

Sense Cymru has recently been involved with an elderly lady with 'challenging behaviour' who was placed in a North Wales residential care home by an English Local Authority. On investigation, this 'challenging behaviour' was found to largely emanate from frustration. The person was deafblind, but she could read Braille fluently and communicated by using deafblind manual alphabet. However, none of these skills/needs were picked up during the assessment or provided for in the residential establishment. The case was brought to the attention of Sense Cymru not through any systematic process, but by a basic grade care worker who had some personal knowledge of deafblindness. The lady died before the situation could be rectified.

Our response will focus on key issues that relate to people with hearing loss, sight loss and dual sensory loss.

We have set out a series of recommendations which, if implemented, would help people in residential care in Wales lead more full and active lives.

We cannot answer every question but have chosen to respond to the part of this call for evidence where we feel we can add value to the Inquiry.

We are happy for the details of this response to be made public.

Introduction

Sense has recently carried out some research into hearing and sight loss amongst older people in care homes (Sue Pavey, Manveet Patel, Liz Hodges, Graeme Douglas, and Anna McGee (2011) The Identification and Assessment of the Needs of Older People with Combined Hearing and Sight Loss in Residential Homes, University of Birmingham). They plan to submit a full copy of the research findings to the inquiry, but these are some key points from the findings:

- 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.
- Medical and clinical appointments related to hearing and vision are very important in monitoring deterioration in sight or hearing. Many residents were unaware of when they had last seen, or would next see, a clinician.
- 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.
- 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.

Prevalence of hearing loss

- It is estimated that there are 534,000 people with hearing loss in Wales.
- More than 300,000 people would benefit from using hearing aids – 1 in 10 of the population (10%).
- Almost two out of three people (65%) with hearing loss are over the age of 65.

Because of the ageing population, the number of people with hearing loss is set to grow by 14% every 10 years.

About people with hearing loss

Depression, anxiety, stress

Research reveals that people with hearing loss have a higher prevalence of depression, anxiety and stress. A recent study shows that older people with hearing loss are 2.45 times more likely to develop depression than those without hearing loss.[1]

Dementia

Recent research also shows that 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.[2]

Falls

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.

Learning Disabilities

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[1] Saito H, Nishiwaki Y, Michikawa T, Kikuchi Y, Mizutari K, Takebayashi T, Ogawa K '*Hearing handicap predicts the development of depressive symptoms after 3 years in older community-dwelling Japanese'* J Am Geriatr Soc. 58(1):93-7. 2010

[2] Lin, Frank, E Jeffrey Metter, Richard O'Brien, Susan Resnick, Alan Zonderman and Luigi Ferrucci *'Hearing Loss and Incident Dementia'.* Arch Neurol 68(2), 2011

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 their 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 problem 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 appropriate services.

On average, there is a 10-year delay in people seeking help with their hearing loss

Early diagnosis and intervention is fundamental to preventing and reducing the impact of hearing loss, supporting independence and wellbeing and preventing mental ill health. However, on average, there is a 10-year delay in people seeking help with their hearing loss.

Prevalence of sight loss

- There are an estimated 115,000 people with sight loss in Wales.
- 1 in 5 people over the age of 70 have a significant sight loss.
- 1 in 2 over the age of 90.

The number of people with sight loss will double in the next 25 years.

Sight loss isn't confined to those who are registered blind and partially sighted. It includes people who are waiting for, or having, treatment such as laser or other surgery to improve their sight. And it includes people whose vision loss could be improved by wearing the right glasses.

About people with sight loss

Depression and suicide

- 35 per cent of older people with sight loss are living with some form of depression. (Hodge, Barr and Knox (2010) Evaluation of Emotional Support and Counselling within an Integrated Low Vision Services. University of Liverpool.

- Older people with sight loss are three times more likely to experience depression than people with good vision.

- The British Medical Journal reports that sight loss is one of the top three causes of suicide among older people.

Stroke and sight loss

There is a high prevalence of sight loss amongst people who have had a stroke. A systematic review of prevalence of sight loss in stroke patients is due for publication by RNIB shortly, but visual impairment is reported in the region of 70% of stroke survivors.

Dementia and 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. However, this figure is likely to be an under-estimate because visual impairment studies will not have accounted for individuals that are considered 'untestable'. 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

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 well-being.

- Approximately 60 per cent of people living in care homes experience recurrent falls each year.

- Poor eyesight is one of three major risk factors contributing to falls among older people leading to accidents and death.

- 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.

- 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.

- Recurrent falls are associated with increased disability and are the leading cause of death resulting from injury in people aged 75 years and over. Age UK reported in 2010 that an older person dies every five hours as a result of a fall.

Learning Disabilities
- 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

- 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.

The BME population
People from black and minority ethnic communities are at greater risk of some of the leading causes of sight loss. 5 per cent of the population of Wales may fall into this category.

Prevalence of people with dual sensory loss

- It is estimated 18,850 people in Wales are currently affected by both visual and hearing impairments.

- 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

- 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.

Figures based on prevalence statistics and the Centre for Disability Research, 2010 report: Estimating the Number of People with Co-Occurring Vision and Hearing Impairments in the UK.

The terms of reference
As described above, we cannot answer all the terms of reference, but have included relevant terms of reference to make clear which point we are referring to.

- **the process by which older people enter residential care and the availability and accessibility of alternative community-based services, including reablement services and domiciliary care.**

Care and Social Services Inspectorate Wales (CSSIW)
During 2012-2014 Action on Hearing Loss Cymru, RNIB Cymru and Sense Cymru will be working with the CSSIW and the Care Forum Wales on how residential care homes can better meet the needs of people with sensory loss. We hope this partnership will include different strands of work including an expert users group and help make sure that CSSIW are aware of the needs of people with sensory loss in residential care in Wales. The paper submitted to CSSIW is attached to this document.

Person centred planning
We believe that it is important to make sure that people with sensory loss are given choice and control. Service users need to be at the centre of the Care Planning process from the beginning and they need to be provided with clear information so they can make informed choices . This will mean that not only are people's needs catered for in terms of their sensory loss, but also in terms of their other needs (eg. medical, cultural, social etc). We believe that

everyone with a sensory loss should be able to plan and be in control of the support they will receive.

The Person Centred plan should be drawn up with the full involvement of the service user. This is not possible unless you can establish meaningful communication. It must also be recorded in a format which is easily accessible to the service user.

Regular eye and hearing checks
Regular checks should be part of the individual's Personal Plan. This should be recorded and monitored. This applies to all service users within residential care, not just those with a previously diagnosed sensory loss. Diagnosis is essential in terms of ensuring the appropriate care and support.

Information
Information should be made available in a range of formats, so that people are kept informed and given a meaningful choice. Information should be produced as standard in Clear Print, Plain English / Clir Cymraeg and be available in Braille, large print, audio, electronic, British Sign language (BSL) and Sign Supported English (SSE).

It is important this information is available in an appropriate format and in a timely fashion. It is also important to consider that friends and family who are helping the individual to make a choice about residential care, or may in some instances be taking that decision for them (for example, if they have Power of Attorney), may have sensory loss. Their needs must be considered along with the service user.

One of the factors causing people with sensory loss to enter residential care is the lack of adequate support in the community to meet specialist needs related to sensory loss, as illustrated by the example of Sheila in the introduction to this response. Rapid identification of sensory loss and provision of adequate reablement and long term support could reduce the need for residential care.

- **the capacity of the residential care sector to meet the demand for services from older people in terms of staffing resources, including the skills mix of staff and their access to training, and the number of places and facilities, and resource levels.**

Given the prevalence of sensory loss amongst older people it is essential that any provider of services to this group, including the residential care sector, has the skills and knowledge to meet their needs. The research quoted earlier indicates that staff have little training in this area. Sense produced some guidance for care home and home care providers on supporting people with dual sensory loss, called **“Seeing Me”**.

Sensory loss will affect many aspects of a person’s life in residential care:

Training and equipment

Training for staff is absolutely crucial to ensure that they are able to meet the needs of people with sensory loss in residential care. This includes communication techniques, understanding of sensory loss, how to operate and maintain equipment, including hearing aids and loop systems.

Service users should have the specialist equipment they require to maximise their independence. For people with a dual sensory loss this will include a range of high and low tech equipment. Loop systems can help anyone who uses a hearing aid to hear speech or the TV. Magnifiers can help with reading. A specialist assessment may be necessary to identify the best solutions, including tactile markers, vibrating alarm clocks, task lighting.

Action on Hearing Loss Cymru has also worked with CSSIW and the University of Manchester to create the attached report: **"Older people who use BSL – preferences for residential care provision in Wales" (2010**). This extract from the report makes the case for deaf awareness training in residential care:

"Deaf awareness within residential care homes
Whilst being able to communicate in one's own and preferred language within a residential setting was the main concern of those interviewed, all in different ways also highlighted the importance of Deaf awareness within the living environment of residential care homes.
When the one current resident we interviewed was asked what she enjoyed doing in the home, she at first could not answer. When prompted that she might like watching television with the other residents she said 'no' because the subtitles on the TV were never switched on and in fact the staff did not actually know how to do this. Other respondents also raised the issue of inaccessible television within the broader context of communication isolation.

However, not all Deaf people of that generation would necessarily be good readers as one respondent pointed out, thus further reinforcing the significance of face to face communication. Television as a proxy means of keeping up with what was going on in the world, or simply for entertainment, was not for some Deaf people a viable option, even if subtitles were to be switched on.
However, good Deaf awareness in residential care was also strongly linked by those we interviewed, to supporting residents' independence and sense of control within their living environments. For example, several respondents discussed the provision of vibrating pagers/alerters to residents so they could be aware if there was an emergency or a fire alarm and so they could alert staff in a timely manner to their distress."

Social contact and activities
Keeping active is vital to keeping healthy as we get older. Enabling people to maintain leisure and social activities and cultural interests will require thought about what support the person needs to do this. People who appear to no longer be interested in activities they previously enjoyed may simply be finding them too difficult due to sensory loss and steps need to be taken to make these activities accessible again.

Food, meals and mealtimes
For people with sight loss, eating can be difficult. Dining rooms can be noisy, making speech difficult to understand. If a person's hearing and sight loss is severe, it is essential that they know the food is there.

The environment
It is critical that the environment is suitable for people with sensory loss – taking into account the need for good colour contrast to help, for example, identify doorways and preventing falls.

Good environmental design aids independence and reduces the risk of falls. It has also been reported by a large Care provider in England that utilising good design principles also reduced the levels of incontinence.

The environment must also be suitable for someone with a hearing loss – with loop systems maintained to aid communication. Without this people may become isolated and unable to participate in group activities.

RNIB have also produced guidance **"Seeing it from their side".** A guide to recognising and supporting sight loss in your care home, which is attached.

RNIB Cymru have designed 'Visibly Better', an accreditation scheme developed to meet the needs of the increasing numbers of people with sight problems who live in sheltered housing and extra care homes. While RNIB assumes that tenants living in sheltered housing receive a quality service in all aspects of life within their housing environment, 'Visibly Better' is focused on improving the service and equality of rights for clients who have sight loss.

This type of scheme could be used in residential care to ensure they are meeting the needs of people with sensory loss.

- **the quality of residential care services and the experiences of service users and their families; the effectiveness of services at meeting the diversity of need amongst older people; and the management of care home closures.**

Equality Act 2010
Residential care homes need to take the needs of people with sensory loss into account. If due regard is not taken of residents' sensory loss, residential care homes will be in breach of the Act by;

- not removing or minimising disadvantages experienced by people due to their protected characteristics
- not taking steps to meet the needs of people from protected groups where these are different from the needs of other people

Commissioning
Providing for the sensory loss of an individual is not currently seen as a significant factor in current commissioning processes. Consequently services are being provided which may be totally unsuited to individual need, leading to

unnecessary isolation and additional risks to the individual, commissioner and the provider.

British Sign Language residents
The **"Older people who use BSL – preferences for residential care provision in Wales" (2010**) report calls for a specific provision for BSL users in Wales in order to meet the needs of BSL users in residential care.

Currently people who are deaf can either be placed in a care home where they are likely to be the sole resident who is a BSL user or sent to one of the few specialist care homes in England – away from their family, as highlighted by the report:

"Arguments for specialist residential care
The establishment of specialist residential care provision for Deaf older people was strongly supported by those who participated in the research. It was not regarded as the one size fits all solution, but the requirement for it to be resourced and available was argued because of:

• inadequacies of current provision which do not meet Deaf people's linguistic and cultural needs that are fundamental to their well being, safety and basic human rights

• the potential growth in demand as a result of the ageing population in general which equally applies to Deaf people

• the long standing lobbying by Deaf citizens themselves

• the clear advantages for the maintenance of personal independence, mental well being and happiness that a supportive signing care environment could create with other Deaf people."

A copy of this report is attached.

- **the effectiveness of the regulation and inspection arrangements for residential care, including the scope for increased scrutiny of service providers' financial viability.**

See work with CSSIW, described above.

Recommendations

Awareness training
It is essential that social care staff be aware of how to communicate with people who have sensory loss and that their needs are taken into account in the design and management of residential care services. Sensory loss awareness training should be part of initial and regular staff training.

Training packages already exist that can quickly improve practice, both with staff in residential care and with those who commission such services in line

with the mandatory requirements of the new Qualification and Credit Framework [QCF], operational from 01/01/11.

Access to information
Information should be made available in a variety of formats and communication support should be available, where necessary, at all stages of a person's dealings with social services. For instance, service users should be able to make an appointment with social services via email or SMS text. All written information should be produced as standard in Plain English/ Clir Cymraeg in at least size 12 arial font (Clear Print). Information should be made available in audio; electronic, large print, BSL, SSE, Easy Read and Braille formats.

The environment
The environment needs to be appropriate for people with sensory loss, including colour and tonal contrast, appropriate lighting and noise insulation. As a minimum, 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.

Policy and procedure
Residential care homes need to include sensory loss throughout their policies and procedures, which could be included in the contract from the commissioning body. This would also ensure compliance with the Equality Act and should be included in CSSIW inspections procedure.

Person centred plan
Service users should be central in the planning of their stay in residential care. The plan should be drawn up with meaningful communication with the service user and made available in their preferred format. This plan should be shared with all staff and people involved in the care and support of the service user as appropriate.

Sensory Champions
The development of a ‘Sensory Champion’ in each home would have a very positive effect in motivating colleagues and keeping this on the establishments/company’s agenda.

Accessing external services and support
Care Homes often do not access the wide range of external organisations that could support residents, e.g local Visual Impairment societies, Age Cymru and Sense. This support could reduce isolation and help individuals to maximise wellbeing. Care Home providers should be encouraged to engage with external organisations through individuals' Person Centred Plans.

CSSIW Inspector Training / Awareness raising
Inspectors should undergo training / awareness raising on sensory loss issues. This has been agreed with the CSSIW for 2012.

Maintenance of hearing aids

Staff should be trained in maintenance of hearing aids and regular maintenance recorded and monitored.

Regular eye and hearing checks
Regular checks should be part of the individual's Personal Plan. This should be recorded and monitored.

Wales Low Vision Service
Care Homes should be expected to utilise the Wales Low Vision Service if appropriate to ensure that individual's vision is maximised.

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