

## Health and Social Care Committee Inquiry into residential care for older people

RC54 – Action on Hearing Loss Cymru, RNIB Cymru and Sense



## Health and Social Services Inquiry into Residential Care for Older People – Joint response from Action on Hearing Loss Cymru, RNIB Cymru and Sense Cymru.

### 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.<sup>1</sup>

### **Dementia**

Recent research also shows that people with mild hearing loss have nearly twice the chance of developing dementia compared to

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<sup>1</sup> 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

people with normal hearing. The risk increases threefold for those with moderate and fivefold for severe hearing loss.<sup>2</sup>

## **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**

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.

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<sup>2</sup> 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

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 underestimate 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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# **SENSORY LOSS AND RESIDENTIAL CARE**

## **BACKGROUND PAPER FOR CSSIW**

### **November 2010**

**This discussion paper has been prepared to aid colleagues in CSSIW when considering the desirability and manageability of including an additional sensory element to their annual inspections of Residential Care for the Elderly in Wales 2011/12.**

**The paper has been jointly prepared by RNID, RNIB and SENSE Cymru.**



## **Background Information**

### **1. PEOPLE WITH HEARING LOSS AND RESIDENTIAL CARE.**

- There are 480,000 deaf and hard of hearing people in Wales – one in seven of the population.
- 70% of people over 70 have a hearing loss.
- With the increase in the ageing population this figure will rise significantly, driving the need for services to be delivered in an appropriate and safe manner to meet the needs of people with hearing loss.

Manchester University have prepared a report for the Welsh Assembly Government into residential care provision for deaf people who use British Sign Language (currently in draft format). This Report highlights poor provision for deaf people in residential care and poor practice such as lack of TV subtitling, lack of visible alarms and lack of deaf awareness training for staff etc.

#### **Case Example:**

**RNID is routinely made aware of people in residential care left without working hearing aids - effectively cut off in silence - because staff are not trained in the most simple of maintenance tasks such as changing of batteries.**

### **2. PEOPLE WITH A SIGHT LOSS AND RESIDENTIAL CARE**

- There are 115,000 people with sight loss in Wales. These numbers will double in the next 25 years
- 1 in 5 people over the age of 70 have a significant sight loss. 1 in 2 over the age of 90
- Sight loss is directly correlated with falls, poor mental health, poverty and poor access to health and social care services.
- If detected early a significant proportion of sight loss is preventable.

Up to 40% of an individuals sight can be lost before a carer or the individual may begin to notice. Peripheral vision is often the last areas of sight to be lost so a person may still be able to read but be at high risk of a fall through tripping over objects at ground level which they cannot see.

**Case Example:**

**In a visit to one care home in Wales by RNIB staff, 9 out of 14 residents, 64%, were identified as having sight problems that placed them at potential risk of harm.**

### **3. PEOPLE WITH A DUAL SENSORY LOSS AND RESIDENTIAL CARE.**

In 2010, the Centre for Disability Research [CeDR] at the University of Lancaster produced a report “Estimating the Number of People with Co-Occurring Vision and Hearing Impairments in the UK”. This work focussed on analysing results from 12 existing UK and National Surveys (e.g. General Household Survey) where sensory loss was reported by the participants. This Report estimated that there are 572 people per 100,000 population who have a co-occurring sight and hearing loss. Approximately 212 per 100,000 would fall within the WAG and DoH definition of deafblindness. This prevalence rate is taken across all age groups. Therefore, the rate of dual sensory loss amongst the elderly population taken in isolation is likely to be substantially higher.

The CeDR Report estimated a total of 9285 people in Wales aged 70+ with a significant co-occurring sight and hearing loss, with this number predicted to rise to 27,442 in the year 2030 in line with general population demographics.

**Case Example:**

**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.**

## **Current Situation.**

- ✚ The above figures all clearly indicate that **sensory loss is an extremely common occurrence in the general elderly population.**
- ✚ This being so, it is reasonable to predict that there will **be a significant incidence of sensory loss** amongst the elderly population **in residential care.**
- ✚ The **numbers** in this population are **likely to increase significantly** over the forthcoming decades.
- ✚ The **effect of sensory loss**, single or dual, is **underestimated** in relation to social isolation, depression/mental ill health, nutrition and physical wellbeing.
- ✚ 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.
- ✚ This **situation will be occurring every day in residential homes** for elderly people across Wales.

## Key Points for Future Action

- ✚ **RNID, RNIB and SENSE** can help CSSIW in this work by **bringing together people with sensory loss** to ensure the work delivers the results that would meet their needs. For example they could use their first hand experiences **to shape the questions that need to be asked of residential care providers.**
- ✚ For many elderly people in residential care who have a sensory loss, their **situation can be improved dramatically at very low cost** to the provider.
- ✚ **Much can be achieved** in terms of **improving the physical environment** for people with a sensory loss **within the establishment's existing refurbishment programme.**
- ✚ **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.
- ✚ Such training / information packages can be **delivered on an individual, corporate or geographical basis**
- ✚ **Dealing with a resident's needs emanating from their sensory loss should be as 'routine'** for staff **as dealing with the individual resident's physical care needs** - but can be much more rewarding for all parties.
- ✚ The **development of a 'Sensory Champion'** in each home can have a very positive effect in motivating colleagues and keeping this on the establishments/company's agenda.
- ✚ A **validated assessment tool** for use by residential care staff to assess residents' sensory needs is currently being trialled in a large metropolitan area and should be **available for use in autumn 2011.**
- ✚ The **sensory needs** of an individual **should be a significant element in the commissioning process** to ensure that the facilities provided are adequate and that staff are trained to delivery those services appropriately.
- ✚ **RNIB, RNID and Sense Cymru are committed to working with the Provider Sector** in assisting in the development of services for people with a sensory impairment.

## **RNIB, RNID and SENSE Cymru would urge CSSIW through its programme of inspections to ensure that;**

Staff in residential care homes are trained to meet the needs of people with hearing / visual / dual sensory loss through:

1. Being trained in Deaf / Visual impairment / Deafblind awareness and associated communication skills
2. Ensuring that information is provided in accessible formats
3. Being able to support basic maintenance and usage of hearing aids and other simple assistive technology.
4. Ensuring the physical environment is appropriate e.g. Health and safety provision such a fire warning systems are accessible through visual alarms; Hearing loop systems are provided and working; TV has subtitles; information is provided in an accessible format; décor has sufficient contrast; etc
5. That activities are developed within and by the establishment that are appropriate for people with a single or dual sensory impairment, noting that large group activities are often inaccessible for people who cannot see and/or hear their fellow residents.
6. That a 'Sensory Champion' is appointed in each establishment. This person should be at a level that allows them to have a meaningful input into the development of policies and services in each establishment. This person should be aware of services and support from specialist sensory loss providers/organsiations
7. By ensuring that the needs of people with sensory loss are built into the commission process for residential care in Wales.

RNID Cymru  
SENSE Cymru  
RNIB Cymru

November 2010

## Older people who use BSL - preferences for residential care provision in Wales

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## 1. Introduction and Background

This research study is about older Deaf people living in Wales. It concerns specifically whether and why there might be a case for the provision of a specialist residential care facility as an available option for this population. It does not consider the full spectrum of older people's care (such as domiciliary care, intermediate/continuing care) which lie outside the research brief.

The consideration of a population-specific facility arises in the context of Deaf citizens who use British Sign Language as their first or preferred language (conventionally referred to by the designation of capital 'D' to distinguish them from the larger populations of deaf people who might use spoken language, be they hard of hearing or those who have lost their hearing as a result of the ageing process). By contrast Deaf people use a visual, spatial language that is grammatically distinct from either spoken English or spoken Welsh. BSL was formally recognised by the Welsh Assembly Government as a language in its own right (WAG, 2005). There is a strong community of Deaf people united by a common language, shared histories and culturally distinct characteristics (Ladd, 2003). Over 90% of Deaf people choose another Deaf person as their life partner and over 90% of children born to Deaf couples will be hearing.

Thus the potential range of support needs, lifestyle preferences and adult safeguarding concerns associated with ageing for this population are inextricably bound up with linguistic and cultural identity. The extent to which Welsh medium or English medium services are accessible or suitable is a key concern. The provision of information to assist informed choice about care needs and preferences becomes a critical issue for BSL users. The cultural sensitivity and suitability of any aspect of older people's care requires scrutiny.

In one sense such considerations are no different from those associated with the provision of services to any minority language using group within the Welsh context. However in a society more attuned to recognise deafness as loss of or impaired hearing, being Deaf is not necessarily a gateway to linguistically and culturally sensitive service provision. In terms of population numbers, there are very few Deaf people in Wales; approximately 3000, of all ages, (WAG, 2005) out of a total population of just under 3 million (BSMHD, 2006). Consequently demand for services by older Deaf people will be disparate with few coming to the attention of Authorities at any one time. Without significant numbers there is little momentum for the development of specialist services, or specialist aspects of current services.

Nonetheless there is a small but significant number of older Deaf people who will require residential care provision. At the moment in Wales there is no other option than for them to be accommodated within mainstream services where they are likely to be the only Deaf person.

Wales is not alone in its concerns about whether existing provision would be appropriate for older Deaf people and how best the needs of older sign language users might be met. The state of Victoria in Australia, for example, is carrying out a very similar piece of research as has previously, the Canadian Deaf Association. At the same time, some specialist provision in the UK that has previously existed such as Craigholme (previously run by Deaf Connections, Glasgow), has closed down.

## **A brief review of literature**

Literature concerning older Deaf people who are sign language users and residential care provision is rather sparse. There is a very small amount of relevant research evidence, some web-based literature generated by specialist residential care providers overseas and a small amount of guidance provided largely by third sector organisations in the UK. Current UK providers of specialist residential services for older Deaf people have also been consulted and relevant information inserted in this brief literature review.

The following is based on five key issues that arise in the literature from specialist residential care providers overseas (and their associated service user groups of older Deaf people). These are discussed in light of additional evidence from other literature sources and relevant policy and practice initiatives specific to Wales.

### **(i) Older Deaf people are vulnerable.**

Older Deaf people who use sign language may be regarded as vulnerable for a number of reasons. Economically they may be vulnerable because they are of a generation whose educational outcomes were not good and who consequently were unlikely to be in financially rewarding employment in their lifetime. Poverty therefore may be a significant factor in older age. Its consequences, however in terms of older people's care may be more acutely relevant to countries like the USA without universal health/social care. Remaining 'safe' is also mentioned by many specialist providers as an important factor (e.g. Fremont Gardens). The physical frailties of older age and associated personal safety concerns are exacerbated if living alone in a situation where communication with (hearing) others might be problematic. Although it is claimed that older Deaf people are also vulnerable because of a greater likelihood of experiencing mental ill health, including dementia, there is no good evidence to support this supposition. The lack of evidence arises not from the fact that studies have been carried out which contradict the supposition, but rather that no studies have been done in the first place.<sup>1</sup>

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<sup>1</sup> The first ever study of dementia amongst signing Deaf people is currently being funded by the Alzheimer's Society in the UK led by SORD (Social Research with Deaf people programme) at the University of Manchester, in partnership with DCAL (Deafness, Cognition and Language Research centre) UCL, City University and RAD.

However, in the Welsh context specifically, concerns have been raised that d/Deaf people in general (including older Deaf people) may experience poorer mental health outcomes because specialist mental health service provision cannot meet their needs effectively (BSMHD, 2006). The report's recommendations encompassed how integrated health and social care pathways should be responsive to Deaf people although specific attention was not given to older Deaf people other than within the wider adult services models proposed.

## **(ii) For optimum health and well being older Deaf people need to be in a signing environment**

Specialist care providers such as De Gelderhorst in the Netherlands and Fremont Gardens in California, USA argue that being in a care environment that is linguistically accessible (everyone signs) and where the Deaf individual is not isolated as the 'only one' will promote positive mental well being. Older people will not become communicatively isolated, they would remain socially stimulated, and they would continue to experience being in community with others like themselves. As the Bay Area Coalition of Deaf Senior Citizens in San Francisco, USA argue:

"The lack of American Sign Language (ASL) in conventional senior housing facilities, for example, is a significant barrier to the deaf population's ability to access proper services or communicate with other residents or management staff. Area Agencies on Aging indicate that isolation for the elderly population is an ongoing problem; for deaf seniors it is often insurmountable. "

Two first hand accounts from carers of older Deaf people have provided moving examples of how being in a residential care environment where there is no sign communication can impact on the well being on Deaf residents who have dementia and their families (Conrad 2004; Parker et al., 2010).

"My mother only lived for 3 years after being diagnosed with Alzheimer's. Looking back now, I can see how the disease really affected her vocabulary, which became severely limited very quickly.... I also feel that her decline was hastened by the lack of resources available to her. There was nothing offered to help stimulate her mind, meaning her faculties faded quickly, along with her vocabulary. She even stopped saying thank you or hello and was reduced to just smiling a lot of the time. By the end, she could barely speak or sign at all." (Parker et al., 2010)

Although not carried out specifically in relation to residential care, a study of older Deaf sign language users in Sweden did find a statistically significant relationship between subjective well being and social activity within the Deaf

club, where social activity included both unstructured informal activities like meeting friends and specifically structured leisure activities (Werngren - Elgstrom et al., 2006).

### **(iii) Older Deaf people's cultural needs and heritage**

Specialist providers also argue for the significance of meeting Deaf people's cultural needs - to be with others like themselves, with shared values, experiences and histories. Part of such cultural needs are the preservation and continuation of culture passed down from older generations to younger generations.

"By having safe environment Deaf elders feel at home, this protects Deaf culture" (De Gelderhorst)

Additionally, as the Canadian Association of the Deaf argue, it is important to respect older Deaf people's heritage in its own right as they were often the generation of pioneers who through their lives had contributed to the struggles for equality and the recognition of linguistic rights.

"The Canadian Association of the Deaf recognizes the special talents and knowledge of Deaf seniors. It was their generation which fought for the right to recognition, dignity and acceptance of the Deaf languages and cultures in Canada. They led the long fight for better quality Deaf education, better jobs and training, more accessibility to universities and to society in general. They demanded the captioning of television and video/DVD programming, the construction of telephone Message Relay Services, and the accessibility of transportation services and stations. They kept the Deaf culture alive and thriving at a time when non-Deaf society still resisted accepting its existence and its legitimacy."

### **(iv) Without specialist provision older Deaf people's independence is likely to be eroded**

Several specialist providers emphasise the importance of creating the optimal conditions to facilitate Deaf individuals' independent access to support and ability to make their own decisions about their care. It is argued that within a signing environment, Deaf older people are able to make their wishes known independently, share their concerns without an intermediary (e.g. interpreter) and have a sense of mastery over their environment. If placed in a mainstream/hearing environment with little or no direct communication in sign language then it is likely that a Deaf person will become dependent on others rather than be able to exercise their independence of mind and access support and services directly. One provider suggests that older Deaf people are also more likely to lose their legal independence as well meaning relatives might assume that they could not manage their own affairs if they were placed in a

non-signing environment where they were effectively prevented from carrying out their own decisions because of lack of appropriate communication (CAD, 2010).

The National Service Framework for Older People in Wales (WAG, 2006) includes the standard the prevention of dependency (which was not in the English version) and gives a helpful context for these considerations of potential erosion of independence.

#### **(v) The effects of being placed in a hearing/mainstream residential care environment**

Some specialist providers emphasise that residential care in an environment that is not deaf aware and not Deaf accessible is akin to a breach of individual human rights through being held in a restrictive environment. A study by the Canadian Association for the Deaf in 2001 also raised concerns about elder abuse if older Deaf people were in environments where it was not possible for them to communicate their concerns independently or report with ease an abusive incident.

In 2005, in the wake of the government consultation on Mental Health and Deafness, DH (2005) produced some best practice guidance. Under the section on older people they raised serious concerns that the specialist needs of Deaf sign language users were being overlooked in being presumed to be synonymous with those with acquired hearing loss. They also drew attention to how small national provision was for this group of service users.

"Deaf people, like everyone else, may need residential care when they get older and become frail. Most now go into residential or nursing care where their needs are not distinguished from those with acquired hearing loss. Understandably, staff do not differentiate between Deaf elders and those whose deafness has come later in life, despite the fact that they will have very different communication needs.

There are 24 nursing home places nationally for Deaf people and it is likely that this represents significant under-provision.

Recommendation

That local Needs Assessments take account of the number of Deaf elders who may require residential care." (DH, 2005, p.17)

In 2008 RNID produced extensive guidance for those managing/working in sheltered accommodation or residential care facilities, concerning hearing loss and how to ensure the environment is accessible and deaf aware. This includes information on specialist equipment, hearing aids and communication. However, although Deaf sign language users are mentioned in the body of the



guidance, none of the recommendations or good practice guidance actually addresses the linguistic or cultural needs of sign language users.

Although not specifically about residential care provision, the Deaf Mental Health Charter (SIGN and MHF, 2005) draws specific attention to the importance of an accessible environment for all d/Deaf people in receipt of services. In respect of placements, including within care homes and nursing homes, they go on, unequivocally to recommend the following:

"Any placement decisions should take into account the deaf person's preferred communication method and language. For instance, users of BSL should not be placed in environments where there is no effective communication with staff or other service users. This applies to care homes, nursing homes, secure accommodation, psychiatric services and prisons as well as in managing transitions, e.g. from hospital or supported accommodation to independent accommodation." (SIGN and MHF, 2005)

The issue of placement is firmly linked in the charter to an individual's rights, not just an individual's needs.

## **Research Questions and Methods**

Against this background, the Welsh Assembly Government have begun to consider whether there is a case for the establishment of a specialist, Sign Language medium, residential care provision for Deaf people in Wales. In 2009, they commissioned a scoping study involving Deaf people in Wales and other stakeholders drawn from professional service providers. The following is a report of the study, its main findings and a discussion of their potential implications.

### **Research questions**

The research study set out to explore three questions:

- (i) How can the needs of older Deaf people who use BSL be best met in residential care provision?
- (ii) What might constitute good practice for Deaf older people who use BSL and are in residential care/considering residential care?
- (iii) What influences preferences amongst older Deaf people in Wales who use BSL for specialist residential care provision within a signing environment, in contrast to a local residential placement?

### **Methods**

The study was approved by the University of Manchester Research Ethics committee. It consisted of 4 parts:

## Literature review

A literature search was carried out to identify pre-existing literature and good practice guidelines concerning older Deaf BSL users including grey literature. The data bases within Web of Knowledge were searched using the terms Deaf\*, old\*, people, sign language, resident\* care and the search restricted to the past 10 years. In addition, the same terms with the addition of the Americanism 'seniors' were used in a google search to identify any commercial or user web sites that may be relevant. Also a hand search was done of grey literature, Deaf-related web sites, government web sites and policy/practice documents produced by Deaf-specific voluntary sector organisations. A full list of identified literature is provided in the References and Sources Consulted list at the end of the report. Background information was additionally sought through a visit to a pre-existing specialist residential care home for older Deaf people in another part of the UK.

## Community Consultations

4 focus groups<sup>2</sup>, involving 32 people in total, were held with members of the Deaf community in Wales aged 55 and over. Participants were recruited by advertising (in BSL and English) in various Deaf community fora, with the assistance of Deaf community officers in Wales and through 'word of mouth'. All recruitment, information and consent materials were produced in BSL. The focus groups were facilitated by a Deaf researcher using BSL. Discussion was triggered by the use of a fictional scenario on DVD that the group watched then were invited to comment on followed by a structured discussion. English copies of all materials used are available in the Appendix A, B, C & D. A current time interpretation into spoken English of the focus group discussion was audio recorded and later transcribed into written English for purposes of analysis.

## Stakeholder Interviews

Six stakeholder interviews (one of which involved two people) were held with representatives of relevant organisations in Wales. One interviewee represented a statutory service, the rest represented voluntary organisations/charities. All information and consent materials were available in BSL, Welsh and English. Three interviews were carried out in BSL and three in spoken language. Interpreters were provided as required. The interviews were video recorded for later analysis purposes.

## Individual interviews with older Deaf people

Seven individual interviews were carried out, two with older Deaf people already in a residential care provision in Wales and five with older Deaf people actively considering a move to residential care. Participants were recruited by means of community officers passing on information materials (available in BSL and English or Welsh) and by 'word of mouth'. Participants wishing to be

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<sup>2</sup> The groups took place in Cardiff, Neath Port Talbot, Wrexham and Mold

involved then contacted the research team directly. All interviews were carried out in BSL by a Deaf researcher. Contemporaneous notes were taken of the main considerations discussed in the interviews for later analysis purposes. It had been hoped to recruit up to 10 participants for these interviews, however, it proved very difficult actually to locate Deaf people who were in residential care who could be approached for participation. Also because the study had not sought approval through ADASS, Social Services Departments could not be approached directly to pass on information to potential participants without being in breach of required social care governance arrangements<sup>3</sup>.

## Analysis

All data from the focus groups and stakeholder interviews were translated into English and transcribed verbatim, however the data in source language was also maintained for purposes of cross referencing back to the original expression in context. The English version of the data was read by at least 2 members of the research team who independently identified recurring themes. Identified thematic categories were then compared to arrive at the final thematic coding framework. These themes were to some extent influenced by the specific focus of the research questions the study sought to answer (e.g. 'communication'), however, some were generated as a result of unanticipated emphases in the data (e.g. 'abuse'). A full list of thematic categories applied to the different data sets is given in Appendix E. Given the relatively small data set, themes were applied to relevant parts of the data by hand, rather than with the use of a computerised sort and retrieve programme such as NViVO.

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<sup>3</sup> The decision not to recruit through social services departments was taken because of the short timescale and the limited funding available which restricted the scope of the project.

## **2. Individual interviews with older Deaf people: “They must remember I am not a number but an individual ‘til I die.”<sup>4</sup>**

Seven individual Deaf older people were interviewed about their thoughts on residential care. Two were already resident in care homes, the others were of the age and personal circumstances where they were beginning to consider it might have to become an option for them. The following summarises the main concerns and priorities of those who were living independently, plus one of those currently in residential care.

We discounted the data from the other person who was interviewed in residential care because it became clear during the course of the interview, that she had quite severe dementia. We were not convinced that she had been able to give informed consent but equally she was very comfortable chatting with another Deaf person (the researcher) and it would have been rather harsh simply to stop the interview once it was clear she was unable to consent properly. Therefore the researcher stayed with her and chatted in BSL during the course of which it became apparent that she thought she was back in her residential Deaf school and was happy in her surroundings. There were however no other Deaf people in the residential care and at best there were a few staff with minimum sign language skills. The care home manager confirmed that the resident had dementia but that currently she was having no treatment, no specialist support and staff did not have access to any training concerning Deaf people or those with dementia.

### **Communication, identity and loss of self**

For all 5 respondents not yet in residential care, concerns about communication were their top priority. They were all aware that it was unlikely that any staff would be able to use BSL or to be able to communicate with a Deaf resident to the same extent as they might with a hearing resident. Basic signs or gestures did not amount to ‘communication’ as respondents were accustomed to using their language fluently with other people in their current social circles.

Poor or non-existent communication was explicitly connected with both fear and isolation. The impact was not thought of in abstract terms (e.g. not having someone to talk to) but in highly emotional terms as a deterioration of the self. One respondent likened it to a living death:

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<sup>4</sup> This comment is particularly powerful because of the practice some older Deaf people will have experienced from their childhood of being referred to in residential schools by their allocated number, rather than being referred to by their name. To this day, it is possible to see older Deaf people who were at school together greet each other in Deaf clubs by ‘their number’

"I can't see any benefits for a deaf person living in a hearing care home. I know someone who does - very upsetting to see the state she's in ... I know a Deaf man, who loves travelling and goes to Deaf club regularly, he has some problems with his legs so he had to move into a local care home (hearing)... He is very frustrated and so unhappy at the moment. Because of no communication in the home, he said he would rather be dead" (i07)

Another, asked about their expectations of daily life in a residential care home replied: "Low, lonely, fearful" adding:

"Deaf people need company and like signing around to block any isolation" (i03)

None of the 5 were concerned that they would not be able to get across their basic wants and needs if they were looked after in a care home. After all they were all experienced in living in a hearing world where people generally did not sign. Their main point was that such basic communication was not enough. To not use their language everyday and engage in true social interaction through that language would gradually destroy who they were as individuals. In practical terms, some pointed out that living in a non-signing environment would mean that one's sign skills deteriorated as one literally forgot one's language through its lack of use.

"From experience, I tried to ask one Deaf person [about her life in a residential care home] but she was unable to talk to me because she had been too lonely and lost communication skills. She mixed with hearing people which I think is not right" (i03)

The resident who participated in the research who was already in a care home, was to some extent a living example of these other respondents' worst fears. She was the only Deaf person in the care home and none of the staff or other residents could sign. She had been married for many years to a Deaf man. He was now dead and she had no social contact at all with any Deaf social events and no Deaf friends ever visited her. When the Deaf researcher arrived to interview her, she became very excited and introduced her as her "friend", although those around her would not have understood what she was saying, and the researcher and respondent had never previously met.

The researcher observed that her signing skills were very poor (despite the respondent having been a fluent signer all of her life). It was unclear whether her communication difficulties were linked with not having used her language for a long time, or whether they were indicative of early stages of dementia, or indeed both. When the researcher who was a sign language user herself tried to discuss her concerns with care home staff, this proved very difficult as none were able to communicate effectively with her. Even when she used pen and

paper to write down what she wanted to say, the first staff member she did this with could not understand written English.

The absolute centrality of communication through respondents' own preferred language was also evident when they were asked explicitly "How would you prefer to communicate with staff and residents". All replied through Sign Language, for example:

"BSL is a big must!" (i07)

"Signing! Remember some Deaf people can't write! (i07)

"Signing, no interpreters please, as it has to be one-to-one" (i06)

However, one respondent, pragmatically considering that the home was likely to be a hearing environment, insisted on the provision of interpreters to be able to communicate with those around him (i05).

### **Maintaining contact with the Deaf community**

All those interviewed were culturally Deaf people whose first or preferred language was BSL. All had strong links with the others in the Deaf community either through their local Deaf clubs, Deaf organisations for those sharing common interests, and/or just through their circle of Deaf friends. All 5 respondents not currently in residential care considered such ties to be absolutely vital. Therefore concerns about their potential loss, through moving into residential care (should that ever happen) weighed heavily on their minds.

A part of their worry concerned the loss of communication opportunities such as outlined above. But more fundamentally, and linked with communication, was the potential loss of *belonging*, associated with being alongside other Deaf people like themselves in all of these social networks. Involvement did not just represent a leisure activity (a club that one is part of to pursue a hobby or interest) but rather involvement was a signifier of their identity, a marker of being a Deaf person. Belonging was a way of both sharing their cultural identity and expressing their cultural identity. It was also a means for gaining access to a range of personal and social activities on their terms in their own language (such as Deaf Church), rather than as a minority within a bigger hearing majority.

INTERVIEWER: "What factors will influence your decision whether to choose residential care in the future?"

RESPONDENT: "Communication is a key factor - I would want to be with other BSL Deaf people and staff who can sign so I can fit into social activities with them. I would like to be taken to Deaf club and Deaf church. I also like local chaplain with Deaf people

to visit regularly and give me Holy Communion as faith is important to me." (i06)

As this respondent went on to say when asked how important it would be to her to keep her links with the local Deaf community should she move into residential care:

"I have a motto - I would not move to Russia, but will do if moving into a mainstream care home was the only option here for me!" (i06)

### **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.

INTERVIEWER: "When choosing a residential home, what equipment specifically for Deaf people would you expect them to have?"

RESPONDENT: "Depending on budget - television with subtitles in each room so you have peace watching on your own or be with friends... A flashing light for emergency use (personal pager). Carry a medical care in hand, a self tracking device. Staff have to make sure they stay alert to pay attention to any resident for their welfare which is very important - no delays, no waiting" (i07)

Others talked about the necessity of visual doorbells on residents' rooms to protect their privacy. Just because a resident could not hear someone knock at a door, it does not give another the right to walk straight in, if a means could be supplied of a resident knowing someone was outside their room and seeking access. In the case of the Deaf person we interviewed who was already in a care home, we established from the staff that she had no adaptations or equipment whatsoever within her living environment, not even a visual doorbell on her room.

Deaf awareness was not just about the provision of equipment to support independence. It was also about the sensitivity of staff and their level of understanding about basic things such as how to attract a Deaf person's attention and how to avoid unnecessary shocks for example if a Deaf person cannot hear someone is behind them and therefore is unaware they are about to be touched. One respondent told the following story:

"I know one Deaf woman living in a mainstream care home. I paid her a visit and she was distraught. I asked her what had happened. She explained when she couldn't sleep one night, she decided to take a stroll around in the home and she was grabbed from behind by staff and taken back to her bedroom. She was badly shaken after, as she wasn't aware that there was someone behind her. I think that is terrible and that she is quite fragile." (i06)

Deaf awareness and understanding of cultural norms amongst Deaf people was also vital from a health perspective. The same respondent expressed concern that failure to understand Deaf people (both linguistically and culturally) could result both in falsely labelling someone as ill when they were not, and failing to recognise when they might need help. She said:

"Also labelling Deaf people as aggressive/agitated isn't helping either. What if staff who are not Deaf aware report [a behaviour] to the GP and they give out medication to Deaf residents and they [the residents] will become disorientated or a zombie? That's my biggest fear!" (i06)

## **Deaf Staff**

Respondents were enthusiastic in their support for Deaf staff within residential care facilities (whether these be mainstream care homes, or Deaf-specific environments). Their support largely arises from the three concerns already discussed. Deaf staff would ensure that Deaf residents had someone on site with whom they could fluently communicate. Also other Deaf people (in this instance staff, but this was also important in respect of other Deaf residents) would share and understand the priority they gave to social activities with



other Deaf people. The sense of cultural belonging would thus be reinforced. Also Deaf residents would be confident in terms of Deaf awareness.

One respondent added another reason for her support of Deaf staff in residential care facilities, namely that they would benefit from having a job.

### **How desirable would it be to have a Deaf-specific residential care facility?**

At the end of each interview, respondents were asked to speculate on how desirable they thought it might be to have a Deaf-specific residential care home in Wales. The respondent who was already in residential care found it very difficult to understand what we were asking and we did not pursue the point with her because we were concerned that she might worry that she was going to be moved from her current place of residence. Earlier in the interview, she had said she was 'comfortable' and felt 'safe' where she was (notwithstanding what was observed about her extreme communication isolation and total lack of contact with any Deaf people). Her response was understandable because the alternative of living alone at home was not one she regarded as personally safe.

The other 5 people we interviewed each gave the proposition of a care home for Deaf people some serious consideration. Opinions varied depending on personal circumstances therefore we have chosen to present respondents' views as a series of mini case studies. In all cases we have used false names and removed identifying features.

#### Josie (i06)

Josie lives alone and has no family, but regards her Deaf friends as her family. She has limited mobility but is still active in the Deaf community, regularly attending the Deaf club and other Deaf social activities. She manages at home with the assistance of a close friend who lives nearby. She believes that she is going to have to seriously consider residential care as an option quite soon, because she has no confidence that services could appropriately support her in her own home, which would be her first preference. From her point of view, no domiciliary care services are staffed by anyone who can communicate with her. There is no social worker with Deaf people in her area who might be able appropriately to assess her needs and reassure her. She finds it stressful to think that there is nobody in an official care capacity who would be able to communicate with her directly. She does not look forward, however, to the prospect of residential care if, as she fears, she might be placed somewhere where she is the only Deaf person, where there are no staff who could sign and as a result of which she could not keep in regular touch with her social activities in the Deaf community. She said that if she could not have those priorities met then "I would feel the same as if I am in prison or in a foreign country". Consequently, if there were a care home in Wales for Deaf people she would enthusiastically welcome it and move in (even if it were outside of

the area where she is currently living). Her only concern would be if the Welsh Assembly's charter meant that spoken Welsh had to be used there as well as she finds lipreading in Welsh rather challenging.

#### Muriel (i07)

Muriel is from Wales but has lived her working life elsewhere in the UK. Her health has recently deteriorated and she is considering moving back to her homeland to be near her brother who still lives in Wales. She is very strongly involved in the Deaf community locally and nationally. From a personal perspective, she does not think residential care is for her and would want to exhaust every other available option for independent living before considering it. However, communication in BSL and being in the social company of other Deaf people remain a key priority in thinking about her future care needs. She suggests instead, that there would be some advantages in having a Deaf only residential care facility that also had warden controlled flats that were linked to it. This would be her preferred option but if her health seriously deteriorated and she did have to go into residential care then a Deaf-specific facility would be her preference. Family considerations would not prevent her moving away from relatives to take up residence there, but she sees that the location of a Deaf care home may be an issue for others who might prioritise family ties over and above a Deaf residential care environment.

#### Grace (i04)

Grace is a widow and lives alone in a flat. She has some physical mobility problems, but manages quite well. Her family live some distance away but she chose to continue to live where she does after husband died because she wanted be near her Deaf friends and her local Deaf club. The maintenance of strong links with the Deaf community is her number one priority in old age. She would have no hesitation in moving into a Deaf residential care home when the time came, regardless of its geographical location in relation to her current home or her family. Being with other Deaf people and sharing communication and a social life with them is more important than anything else.

#### Louisa (i03)

Louisa is a widow and lives alone. She likes being close her Deaf friends and her local Deaf club so would not consider moving to be closer to her family who live elsewhere, even though her husband has died. She has not seriously considered her future care needs and what she might do if she found it more difficult to live independently. She thinks that if she had to move into residential care in the future, she is sure she would prefer it if it were somewhere with other Deaf people in order to avoid feeling isolated.

#### Michael (i05)

Michael lives with his partner who is younger than him. They have recently moved into the area where they live now. He sees strong links with the local Deaf club as a current priority. He has not given future care needs much consideration but is adamant that he would not want ever to move into any

kind of residential care facility. He would prefer to move to live close to his daughter who lives outside Wales if he needed care. Consequently a specialist care home for Deaf people in Wales is not something he would see as being particularly relevant.

### 3. The views of focus group participants on residential care provision for Deaf people in Wales

#### Communication, Communication, Communication

“Communication, it’s absolutely vital”.

It will come as no surprise that good communication in BSL was overwhelmingly the issue of importance identified by Welsh Deaf people when considering future options of support as they grew older. Communication was in and of itself of major importance, however it has many facets and a multitude of implications as focus group members identified. Almost everyone who participated had a shocking story to tell of someone that they knew, or who was a friend of a friend, who was almost totally isolated as the only Deaf BSL user in an otherwise hearing residential home or supported housing unit. Participants were only too well aware that lack of opportunity to communicate would lead to deterioration in a person’s mental health - they had seen it happen; they speculated that this isolation would lead to deterioration in physical health as well. This awareness gave rise to fears of what could all too easily happen to them in the future and dreams of what they, as Deaf BSL users in Wales, would like to be available. Experience had shown them that in Wales a Deaf person was usually the only Deaf resident in the particular residential home or supported housing unit and that staff were unable to sign. Knowing of Deaf residential homes (Blackpool) and clusters of Deaf people in supported accommodation (Bristol) where BSL was used by staff and residents allowed participants to envision similar Deaf provision for themselves.

Clearly Deaf people had lived their lives in a predominantly hearing world and had always found ways of communicating in the dominant culture. In considering the future Deaf people realised that other means that they now used to get by in everyday life would perhaps no longer be available to them.

“I tell you the truth, my eyesight is poor and my hands are shaky so I feel like how do I write? I would feel absolutely lost if I lost the communication through Sign Language.”

In addition they could foresee that reduced mobility would prevent them travelling to the normal Deaf social events that they had been used to accessing all their lives, thus leaving them totally isolated and reliant on the occasional visitor who could sign. Additionally, they were aware of Deaf people in very poor situations, at best because of ignorance and at worst because of neglect. Experiences were related of Deaf people trying to watch TV with no subtitles, Deaf people being seated by care staff such that it was difficult to read subtitles and Deaf people being told not to sign. There were a plethora of concerns about the quality of every day life if Deaf people were cut off from

their signing friends, their usual activities and knowledge of what was happening around them without even being able to make their needs and preferences known easily to carers and other staff.

The process of how and by whom decisions for their future were made was also of concern. Here good communication was vital. Focus group participants questioned how much decision making power they would have when the time came to move from their current homes. They doubted that they would be given accessible information, but rather information in written English or Welsh. They doubted that they would be assessed by workers with sign language skills or cultural knowledge of Deaf people, and therefore they feared the outcomes. It was this inaccessible process that they felt would lead to isolation as the only BSL user in an otherwise hearing establishment that they dreaded.

### **The fear of isolation and deterioration in mental (and physical) health.**

Fear of isolation and lack of opportunity to communicate with other BSL users leading to mental deterioration loomed large and was a real fear for many focus group members. It should be noted from the outset that some focus group participants found this topic distressing to discuss:

“That’s quite hard; I don’t want to think about it at the moment.”

Participants were clear that without frequent and regular opportunities to communicate in BSL they would be lonely and isolated. Obviously a Deaf resident would be surrounded by others, residents and staff, but without the possibility of chatting, catching up on news and gossip and the minutiae of being with others in a companionable way:

“It’s your first language and if you’re in a care home and you’re the only deaf person, then you’re going to have no communication with anybody”

“I feel it would be lonely. There’s no staff that can sign or no nursing staff can sign”.

Worse still, participants imagined that a Deaf resident in a hearing home would be aware of the every day exchanges going on around without being able to participate, thus intensifying any feelings of isolation and exclusion.

Distress arose as many participants had witnessed what had happened to their friends or to Deaf people older than themselves when they had entered residential care where other residents were not BSL users and staff were unable to sign. It should be emphasised that participants were not drawing

attention to a lack of stimulation, but rather to what they clearly identified as communication deprivation and its consequences:

“They move to a care home...all the other people are hearing so they’re just sitting there isolated...you know, so if...for Deaf people they get worse and worse because they haven’t got any interaction and they’re not being visited and their mental health deteriorates because you know, they’re isolated, they’re depressed, they haven’t got access to the world”.

“‘Cos if there’s only one Deaf person and everybody’s hearing and you can’t speak...you never get to speak to anyone and then that means that you would just go downhill”

“I think if there was no Sign Language there then I think you might actually deteriorate quickly, you might feel worse, you know, because there’s nobody there to communicate with”

“You’d get very lonely which would then become very, very stressful and I think it could lead to illness”

This was a fate which they did not want to share:

“And I’m thinking for myself, no thanks, I don’t want that”

### **Cultural Issues**

For Deaf people use of BSL is not just a means of communication, although this is extremely important, it is also part of Deaf culture and a marker of identity. For focus group participants, Deaf social life had always included mixing with other people who used BSL and with whom they had a shared history, shared experiences and shared community. The role of Deaf Clubs here is extremely important: Deaf clubs give not only the opportunity to chat informally in BSL, but a chance to meet and be with life-long friends, to gain information in BSL and to be confirmed, supported and valued as Deaf people. As one participant said, imagining themselves in residential care:

“I’d definitely want to go to Deaf Club and I’d definitely want a lift to go to Deaf Club”

Consequently, when discussing residential care options, continued contact with Deaf clubs was high on the agenda. Attendance at Deaf Clubs would enable Deaf BSL users to continue with activities they had always enjoyed such as Bingo, outings, coffee mornings, trips to other Deaf clubs, and annual social events. It would enable residents to maintain contact with friends:

"I think that's very important because you've got friendships, you've got friendships within that Deaf community, you know, you want to hear the news, you want to know what's going on, you want to...and that would lift your spirits as well, it would keep you happy"

Even if there were other Deaf people where they were living, participants felt that they needed to maintain links with the wider Deaf community:

"If I was living in a residential home and there were Deaf people living with me I would still want to keep contact with the outside Deaf community as well."

"It's so important to keep Deaf links".

For a BSL user, attendance at Deaf Club is not equivalent to a hearing person entering residential care and maintaining a hobby; rather it is akin to a person who is unable to speak English having access to native speakers of their first language and their language community with its customs and traditions. Therefore its importance is even greater to those envisaging a future where they may be the only Deaf person in an otherwise hearing and non-signing environment.

For focus group participants the maintenance of cultural identity for those in residential care was a clear priority. They had many stories to tell of the personal experiences of people they knew. Lack of knowledge of Deaf cultural needs led to restrictions being placed on Deaf people which effectively made it very difficult for them to maintain their cultural identity. For example:

"Eventually M went into a home, but nobody there could use Sign Language and she wasn't allowed out, she had to stay there, she wasn't allowed out at specific times, you know, she felt like she was in a prison, you know she couldn't even come along to the Deaf Club. I think perhaps there were not enough staff available to accompany her."

Similarly, an experience of someone in supported accommodation:

"And when we decided to take her out she said, 'I have to be back by nine o'clock' and she was really worried about going out because of this getting back for this certain time. And I thought 'oh, that's not really on is it?' You know, if we had a party or something, she'd have to get back by nine o'clock. I mean we used to ask the warden if...you know, it was possible to stay out a bit later. And I'm thinking all this meant that she couldn't go out

and enjoy herself because she could only go for a couple of hours and then was worried about getting back on time.”

To someone unaware of how essential it is for residents to maintain social contact with culturally Deaf people, the full impact of these rules would not be appreciated. They might simply seem expedient to those in charge of the residential facilities instead of placing restrictions on meeting a resident's cultural needs.

Restrictions on the maintenance of cultural identity did not just arise from unintended consequences as in the examples above. Focus group participants also gave examples of deliberate actions which severely restricted Deaf residents' cultural and/or linguistic expression. For example:

“the staff have actually asked them ‘stop signing around here because it's not allowed to sign here because other older people, hearing people, don't like you signing’. So they've actually been stopped signing and they've cried a lot.”

It might be suggested that in these situations the Deaf residents had misunderstood what was being asked of them. If this were the case, it emphasises the point that communication between staff and residents is inadequate. On the other hand, a deliberate intention to disallow signing may be regarded as tantamount to the abuse of an individual's human rights to communication.

### **The loss of BSL as a part of everyday life**

For Deaf BSL users, chatting in BSL is part of every day life. The majority of BSL users choose a life partner who also communicates in BSL. For one isolated BSL user in a residential setting, easy, relaxed communication in BSL would not be possible. Rather, any communication would be difficult, requiring a struggle with lipreading or reading and writing in English or Welsh. A common experience of several focus group participants was that when visiting BSL users in residential homes, the resident would be extremely distressed when the visitor came to leave and would beg the visitor to stay or visit again.

“I went to visit someone in a home and they were the only one. And for an hour we were there just signing, signing away and they were unhappy. And when it was time to go they were saying ‘please stay, please stay. Please stay for another hour.”

“And when I've actually gone to visit them, they've erm...they've actually said to me ‘please could you stay because I don't want to be left alone’”.



The experience of a resident begging for visitors to stay or to visit again is a common scenario for hearing people in many residential homes. However, the importance of contact with someone who communicates in BSL for a Deaf resident cannot be overestimated. That visitor is likely to be quite literally the only person they will be able to communicate with in their own language. When they are gone, the resident becomes communicatively isolated once again in stark contrast to their previous life experience where BSL was just a part of everyday life.

Failure to take into account linguistic and cultural needs as part of a resident's original assessment of need can further restrict others who may be doing their best to support that resident. In the latter quote above the visitor was herself prepared to visit to provide company, but she could not afford the transport to get there and there were no other funds available. Such funds could have been made available if due attention had been given in the resident's original assessment. Alternatively, Deaf visitors have themselves been so distressed by the situation of the Deaf resident that they have been reluctant to visit again and distress themselves further.

### **Processes - communication is power**

The whole process of moving from living totally independently is for many people disempowering; for BSL users, it is potentially even more so. Focus group participants felt that they had little access to information available to them now in any arena, and none that would allow them to consider their future options of support:

“there isn't enough information available to us. I mean we can't access information from the news like hearing people do. There's not enough information on the news or widely available for Deaf people.”

Comments such as this were made in all the focus groups and resulted in general agreement from the whole group.

“information is mostly spoken or it's in written form and deaf people need that translating into Sign Language”

As a result Deaf focus group members felt that decisions would be made on their behalf without consultation:

“I feel it's terrible. They don't ask you where you want to live, they just pick you up and basically take you. So you could be the one deaf person in a hearing environment and you could feel isolated” .

Participants' expectations were that Deaf BSL users' social, cultural and linguistic needs would be marginalised when entering any kind of supported living or residential care. For example, experience was that in the case of a hospital discharge, the worker doing the assessment, through ignorance about Deaf people, would neither be able to communicate directly with the Deaf person, nor be able to assess cultural and linguistic need appropriately. These expectations were based on two things: the experience of acquaintances and their own current experience that generally the systems and procedures recently implemented by Local Authorities had reduced the direct access to staff who could communicate in BSL which they had previously enjoyed, and such access was becoming more and more restricted.

"[Before] I could pop in but they've now moved offices ... so if I wanted a social worker it's difficult, they say, 'well you're not allowed to come straight to the office...you have to go in and say which team you want.' You can't go in and see your social worker directly"

Participants were concerned that when workers other than specialist Social Workers with Deaf People were making assessments, interpreters would not be used, cultural and linguistic issues would not be taken into consideration and BSL users would thus be wrongly placed and/or inadequately supported leading to the situations of isolation and deterioration described earlier.

### **Dreams and Nightmares**

So far we have looked at what Deaf BSL users see as being important to them when considering future options of support as they grew older. We have seen that communication by means of BSL was an absolute priority, with other cultural aspects also being recognised as important in their lives. This led on to focus group members' dreams of the perfect residential situation and nightmares of what could potentially happen to any Deaf person or to any one of them. One focus group member had a vision:

"I've always said that if I won the lottery I would definitely buy a residential home for deaf people and put all the deaf people in there, you know, when everybody becomes an OAP ... I've felt that's really important."

A Deaf home is important because it would automatically provide what BSL users felt that they needed - culture, language and appropriate assistive technology; thus loneliness, isolation and consequent deterioration in mental health would be limited. As focus group members said:

"Yes, you would have shared experience with other people there, you would all share the same culture, communication".

“Yes, because you won’t be isolated, you won’t be lonely; it would be good stimulation for your mind to be able to have... communication with other deaf people” .

In the focus groups there was very little dissent from these views although there was some discussion as to whether to prioritise a Deaf home over all other considerations. This uncertainty was based on two things. Firstly they did not believe a Deaf residential home was a real possibility, so found it difficult to imagine what it would be like. Secondly, they themselves were aware of the small number of people in the Deaf community in Wales and were nervous that perhaps they would be placed with one other Deaf person, and that other Deaf person would be someone that they really did not like.

For potential Deaf residents, it was important that any setting was properly equipped to meet the specific needs of Deaf people and to give them equal access to all that was going on. This would include subtitles on the TV (permanently on), visual alert doorbells combined with a webcam system so that residents could see who was at the door, and technology such as a minicom or webcam enabling residents to communicate directly with signing friends and family. Again many participants had stories to tell of Deaf people in care situations where their needs were not met, for example trying to watch TV with no subtitles.

Focus group members were able to make comparisons as several people had Deaf friends who were isolated in residential establishments in Wales and knew Deaf people in facilities in England where there were other Deaf people and signing staff. For example:

“The person that lived in [place in Wales] went to this residential centre, there was nobody to talk to, there weren’t any other Sign Language users, it was all spoken communication that took place. Whereas this friend in Blackpool has got other Deaf people there and there are people that they can communicate with and I do think we need something like that in Wales, you know, for the Deaf community here”

Two other examples of facilities in England were also cited as comparisons. If a Deaf home were not possible, then at least a group of Deaf residents would be helpful as that would ensure some communication and the numbers might mean that staff would learn some sign language:

“I think loneliness would be a big issue, yes, you can provide all the equipment that a Deaf person needs but if nobody can communicate with them. I think if there was a care home or a residential home where there were perhaps two or three other Deaf people then that would be much better.”

In other words, two components had to go hand in hand: a fully accessible physical setting (in terms of equipment enabling equal access to the environment) AND other Deaf people. One without the other was not regarded as optimal.

### **Communication with care staff and professionals**

Communication with staff was another vital component from focus group participants' perspectives. In a perfect world, therefore, all staff in a residential facility should be able to sign, ideally to 'Stage 3'<sup>5</sup>. As a minimum, all staff should at least have basic skills.

"Because you need Sign Language, you need somebody to talk to, you need somebody to sign with, for the staff, doctors, hairdressers, you want staff in the care home, you need Sign Language because that's the first language of a Deaf person the majority of the time".

"I feel that all the Deaf community do want the staff to sign, all the staff to sign first because that's my first language".

In addition, it was thought that an additional benefit of Deaf people being together in the same facility would be that it would act as an impetus for at least some of the staff learning to sign. Maintaining a reasonable number of signing staff was recognised as potentially difficult because of staff turnover.

The nightmare scenario was clearly the opposite to the dream. Focus group participants were not convinced that they would be able to communicate at even the most basic level in a residential setting if there were not staff who could sign reasonably well. This was important not just for the social purposes we have previously discussed but also in terms of personal care, safety and the expression of concerns and preferences. They envisaged having to wait perhaps a month for someone who could sign to visit in order simply to make a comment or request:

"Well this is it because a Deaf person wouldn't be able to get in touch with the social worker or perhaps they couldn't communicate their issues to the members of staff, are they going to wait for somebody they know to come and visit them before they bring attention to it?"

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<sup>5</sup> This phrase 'stage 3' refers to a level of BSL competency that would be regarded as intermediate to advanced. It is an important caveat because the various stages of BSL proficiency are not always clearly appreciated by employers/care providers who may claim that staff can sign. It is also referred to as 'level 3'.

## **Additional Benefits**

In discussing the dream of a Deaf residential home or a Deaf supported housing unit, focus group participants also brought up its potential positive impact on the wider Deaf community. They discussed, for example, how older Deaf people could act as role models for younger Deaf people who might visit. A community of older Deaf people would be able to pass on knowledge and experience and enable younger Deaf people to have some positive ideas about their own future aging. Also the shared stories of older Deaf people were identified as important to the maintenance of cultural values and Deaf heritage.

“I think it’s important for deaf young people as well because they would...you know, if they see happy older Deaf people then they know that they’re going to you know, grow up and be happy as well. It’s learning from different experiences as well, you know, old Deaf people have got a lot to share, particularly with the younger community coming through. There’s advice that can be passed down as well” .

## **The same, but different**

Focus group members were asked to prioritise a range of considerations that might be thought to be important for someone entering residential care (see Appendix B). Whilst some related to aspects of life that might be different for older Deaf people, many were the same as for any older person considering residential care. Others might have been the same consideration, but as focus group discussions revealed, could have a different meaning or emphasis from a Deaf perspective.

Deaf focus group members rated privacy in a residential setting as extremely important. This meant having one’s own room. One’s own room was important, at least in part, because it would allow a Deaf person to meet personal needs such as having subtitles on their own TV when having time alone

“you need the subtitles on your television in your own bedroom so you can have some time on your own.”

Privacy would also necessitate the appropriate technology, such as a visual alert that someone was knocking on the door, rather than people simply walking in and surprising the resident.

“I would want a visual alert for the doorbell and for the telephone because I wouldn’t want somebody to come in and me not know that they’re coming in to my room.”

Pleasant surroundings were valued, as in the summer, it would be nice to have a garden to sit and sign in, just as hearing people would value sitting in the sun and chatting verbally.

Focus group members had the usual fears of entering care, such as having money or possessions stolen. Many of the options offered in the question were thought to be highly desirable, for example quality of food and healthcare provision, but all these were secondary to good communication in BSL.

"Well when I visited this old lady, a friend of mine, it was a nice clean place and she had her own room and bath and everything. There was a dining room, small dining room, but the staff, bit difficult because no signing and no-one spoke to her, she was very isolated so it meant she had no-one to sign with."

When focus group participants were asked to put in *rank order* various priorities in potentially choosing residential care provision, the significance of good communication in BSL within the facility was clearly evident, over and above remaining close to one's home Deaf community (see below).

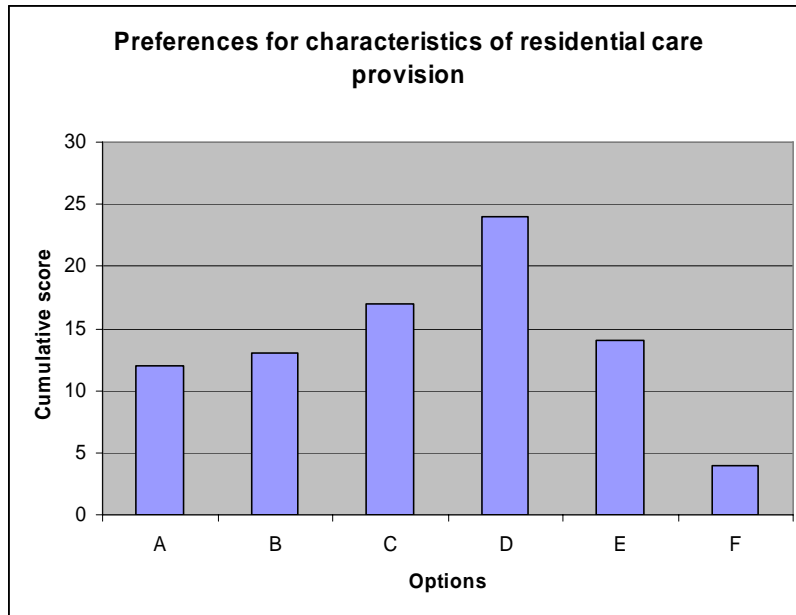
### **Priorities in choosing residential care provision**

[Participants in the focus groups were asked to put *in rank order* six potential characteristics of residential care provision based on their preferences. Groups had to arrive at a common consensus of the appropriate order. The six options were:

- A to live in a residential home near family/friends
- B to live in a residential home near local Deaf community
- C to live in a residential home with other Deaf people
- D to live in a residential home where the staff are Deaf aware, can sign and there are specialised Deaf equipment/facilities available
- E to live in a residential home with a high standard of nursing care
- F to live in a residential home with cheap/low fees

Although these 6 options are not necessarily mutually exclusive, the aim was to force an order of preference for these characteristics, rather than to ask participants to choose between different kinds of provision.

In analysing the results, a score of 6 was given to first preference, 5 to second and so forth. Overall results can be displayed as:



## Facing Reality

However, focus group participants were only too well aware of the problems of critical mass. They realised that having sufficient BSL users in need of the same level of support whether this be a sheltered housing /supported living scheme or a residential home in the same area at the same time would be difficult to achieve in areas that were sparsely populated anyway. All focus groups, regardless of the locality in which they took place, thought a Deaf residential facility might only be realistic or possible in areas with larger populations and good transport links.

Another reality check was that although they appreciated the consultation and were enthusiastic about giving their views, there was doubt as to whether anything would come of it. Focus group members had previous experience of responding to an issue which had no obvious resulting benefits for them.

## 4. The Views of Stakeholders

Six stakeholders<sup>6</sup>, specific to services for Deaf people in Wales, were interviewed to discuss their experience and perspective on residential care for older Deaf people. In this context, 'stakeholder' refers to representatives from an organisation or service who have some interest (current or potential) in the provision of care for older Deaf people in Wales. Those individuals who took part were chosen for their strategic-level overview of issues. Although directed to consider residential care provision specifically, conversations ranged over the spectrum of older people's care services thus placing the question of specialist residential provision in its broader service context.

### **Is there a need for specialist residential care for older Deaf people?**

All stakeholders agreed that there was a pressing need to consider and to improve services for older Deaf people including the provision of suitable residential care if required. A range of factors influenced the identification of this priority: (i) demography; (ii) serious concerns about existing provision; (iii) impetus from the Deaf community.

#### (i) Demography

Stakeholders were only too aware of the changes in demand that would be brought about by an ageing population in general, trends that applied to Deaf people too.

"I feel that we're going to have an explosion of people soon because our Deaf community is quite old and it's getting older, we're an ageing society and we've got a lot of Deaf people in their mid-sixties at the moment and as they age it is going to become an issue for us and I don't know what the answer is."  
(SH1)

Although there are no reliable figures for the number of older Deaf sign language users in Wales and stakeholders were unaware of any figures specifically in relation to those who might need residential care provision, many knew of Deaf people who were already in care homes:

"I think there are ten Deaf people at least that I can think of already, so I'm sure there would be the demand..." (SH7)

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<sup>6</sup> This equates to seven actual participants because in one case two people were interviewed together representing the views of one organisation. Both Deaf and hearing professionals were interviewed as stakeholders.



## (ii) Serious concerns about existing provision

From a stakeholder perspective, the current situation is woefully inadequate. Older Deaf people in mainstream services are seen to be isolated and deteriorating as a result of that isolation.

"I know one older Deaf woman who is well-known in [place name] and she now lives in a mainstream residential home. I just feel for her because she has no one there who can communicate with her (nor staff) and I have seen her a few times slashing out with frustration and trying to run away because she is so unhappy. I don't feel that is right as it was her hearing daughter who made her live there." (SH6)

As service providers, stakeholders are providing services as best they can to relieve that isolation, but feel that what they are able to do does not meet needs, but merely makes the situation a little better for the Deaf individual. Areas of concern raised were similar to those raised by members of the Deaf focus groups: lack of communication, separation from the Deaf community and Deaf culture, and the effects of social and linguistic isolation.

Whether older Deaf people were in their own homes or in residential care it was common practice for Deaf organisations to try to provide visits from people who could sign to militate against some of these detrimental effects.

"We can visit clients within their homes, so it means they're not losing their homes. But the reason we do visit them there is because of the communication, because if they are with hearing staff, obviously there's no communication and it can upset them and they can become frustrated." (SH7)

"We have a couple of clients ... they live in a generic older people's service in Wales and our outreach team go in and provide, erm, additional support in their language, not ideal." (SH2)

With stretched resources, even occasional visits were not prioritised:

"in an ideal world you'd like to employ somebody with sign to go to their house, but erm...that's not always possible, if at all possible." (SH1)

Whether within mainstream residential care provision, or supported at home, serious concerns were raised about the detrimental effects of older Deaf people being in effect cut off from their own community by not being able to visit the Deaf club or participate regularly in Deaf community social life and events.

"I'm sure you know that forty per cent of all deaf people suffered some time during their life from mental health problems. It would seem to me logical to expect that if somebody is isolated and doesn't see people they can communicate with from one end of the week to the next, eventually it will play on their mind, they become stressed and I would imagine they would suffer from mental ill health." (SH4)

"In my personal experience, they would get depressed and might want to give up living if they are cut off from their local Deaf community and not able to keep in touch - it's a double blow. It's important to keep up their personal and social needs."(SH5)

### (iii) Impetus from the Deaf community

Five of the stakeholders made mention of specific campaigns from within the Deaf community that had focused on older people's care in Wales. It was presented very much as a grassroots issue and whilst it had been around for some time, it was gaining momentum as the issue was becoming more obvious, giving the ageing profile of the population:

"But people do say to me that they're worried about the future and what's going to happen and they ask me will I be in a care home? I didn't actually bring this up, people are bringing this up themselves because they're seeing their family or older friends did and who's going to care for them when they become old?" (SH7)

"About fifteen years ago our Deaf members suggested we set up a residential home for deaf BSL users ourselves and we thought it was a good idea because there is a model for this, RNID do this in England or they used to. ... But the idea is still out there and my view is it's really important that they do have something like that, that they have choice, if they want to live in a home like that then they can." (SH4)

The fact that this research project was being supported was seen as a positive response to those community based concerns:

"I think that is why this project has been funded because Deaf people have been campaigning that they want a care home for Deaf older people" (SH5)

### **Specialist residential care is only part of the picture**

Some stakeholders pointed out that even if there were to be consensus on the importance of specialist residential care provision for older Deaf people it did not mean that it was the only option or only concern to be addressed. Drawing on notions of the importance of the prevention of dependency and the

promotion of autonomy, some stakeholders emphasised the importance of improving domiciliary care services and community based interventions both to promote greater individual choice and in order to prevent the necessity of residential care admissions.

"I think most people if they were given a choice, would rather stay in their own home than go into residential care. And that needs to be looked at and focused on as much as the needs of deaf people when they are actually in residential care." (SH3)

"Deaf individuals [should] have the range of services available to them in the same way as ...a hearing person." (SH2)

Whilst nobody was against improving community based provision for Deaf people, it was pointed out that measures used to prolong older people's independent living might not have the same consequences or benefits for Deaf people as for hearing people. For example, domiciliary care services provided by care staff who could not sign (or could sign only to a basic level) whilst meeting some essential physical needs only served to reinforce the isolation of Deaf people. In effect such services prolonged the amount of time that an older Deaf person would be cut off from others with whom they could communicate fluently whereas moving into residential care with other Deaf people would not. Paradoxically culturally relevant and linguistically accessible residential care could be the best solution to prolonging independence if by that one meant an active mind, social enjoyment and a sense of belonging. In this respect, one respondent reflected on whether providing care at home on an occasional basis, even if from someone who did sign, was actually helpful:

"You know, the rest of their communication in their day, there are huge gaps, huge, huge gaps ... nobody can communicate and...buying outreach packages, going in to support those individuals in those homes is not ideal by any means, whilst you know, you're talking twelve hours in a day, they might get an outreach worker for one hour, the rest of the time we have examples where individuals are not able to communicate with anyone else..." (SH2)

Whilst views differed on the degree of priority and how realistic a specialist Deaf residential care provision might be in Wales (see below), the discussions nonetheless revealed some consensus on key factors that overrode questions of what kind of care provision. These were: (i) recognition of the key priority of communication to older Deaf people's health and wellbeing; (ii) taking seriously the duty to meet the cultural needs of Deaf older people; (iii) the importance of the community, not just the individual, in the planning and provision of older Deaf people's care. These are discussed in the following sections.

## Could specialist residential care meet older Deaf people's needs?

There were many positive aspects identified as to how and why a specialist residential provision for older Deaf people would meet their needs well. The overriding one was communication and the many and varied positive consequences of being in a care environment where Deaf people could understand and be understood without effort or restrictions.

"To live in a residential home with other Deaf people...so they can communicate with them, so they have a full and satisfying life."  
(SH4)

A communicative, signing environment was identified as important because of its positive effects on mental well being, both in terms of avoiding isolation and in terms of the beneficial effects of socialising with other Deaf people.

"I can only talk from experience in England where we have a number of residential care homes for older Deaf people and having specialist services works really well. It means there is a community of people who can communicate fluently with those individuals, twenty four hours a day, seven days a week and if you're an older Deaf person who needs care, whether that's nursing or residential, having the ability to communicate fluently, express your needs, be supported emotionally and physically is really important and that's what the services in England offer".  
(SH2)

By contrast, many respondents told stories of the negative effects they had seen first hand when Deaf people were not placed in such an environment:

"He's living in a residential care home, where you know, eighty percent of the time his kind of cultural and social needs aren't being met and that actually is probably contributing to the dementia moving along rather rapidly, if you're not able to sit and be stimulated and motivated and communicated with, you know, to try to maintain those erm, skills that you've got when you're suffering from an illness like that then actually unfortunately that actually you know, makes it much more prominent and his deterioration has been rapid" (SH2)

One respondent in particular linked the importance of a signing environment where good communication could be assured to the requirement that older people's emotional, social and cultural needs are also met:

"In Wales, because there is no specialist service provision it means that older Deaf people are being required to access mainstream services in Wales and then their communication and emotional

need are not being met... I think care is not just about physical needs, it's also about emotional wellbeing and social inclusion and having high quality of all of those things so I think that having staff that are able to understand the culture and the language and communicate is a crucial part of that standard really." (SH2)

Specialist residential care provision was also regarded as important in terms of safety and the avoidance of fear and anxiety that could result from not being able to communicate one's needs and wishes.

"Mainly, they would move if they feel safe and know they will be with their peers." (SH5)

"For example, if they moved into a residential care home with was primarily hearing residents, then they're going to feel very lonely, very isolated, quite often left to last if the one signer on the shift isn't on for three days and can't explain what's going on" (SH1)

Good communication without restrictions was also seen as vital to ensuring that care could be optimally tailored not just to what a resident might need but how they might best thrive and achieve a good quality of life and happiness within residential care.

"I mean the obvious advantage is that the Deaf people in the residential accommodation can all communicate with each other and socialise together. And... there would have to be a specialist worker there as well who could sign so that there would be clear understanding of what each individual person's needs were but there are a lot of benefits from that." (SH3)

Vital to that quality of life was the preservation of Deaf identity, that is to say being in an environment with others who share the same language and culture. Whilst the meeting of cultural needs is in no way an uncommon consideration in relation to older people, in respect of Deaf people it has an added component. Failure to do so can result quite literally in communication deprivation and being cut off from meaningful contact with others around them.

"Very important to keep the links with the local Deaf community. That can be done by bringing those who live in the care homes to the Deaf club or on OAP trips to motivate them, otherwise their mental state would go downhill because of lack of communication. It is vital to do that regularly" (SH6)

## Should we be cautious about specialist residential care for older Deaf people?

Although there was clear support from all stakeholders for the provision of specialist residential care for older Deaf people, some problems were also identified that might make one more cautious about seeing residential care as an ideal solution.

First and foremost was the issue of choice and how one could be assured that Deaf older people were being truly informed about the range of support services that might be available to them of which residential provision was one, but not the only available option.

"I think yes, if people don't have information to make informed decisions about things. Then they will go with whatever perhaps their friends or family or people around them are suggesting is the right thing to do because it's in the absence of knowing anything else." (SH2)

Concerns were raised both from the point of view of older Deaf people choosing to enter residential care without understanding the potential consequences (when this care was within a mainstream provision) and Deaf people wishing for specialist residential care provision without having considered other available options first (such as domiciliary or community based non-residential care options).

In either instance choices might be made or options stated as preferred without the individual being in a position to really consider the pros and cons of their stated preference.

"In my experience mostly they [older Deaf people] don't really know what is available to help them, they don't know where to go." (SH4)

"We might think it's the best thing for the, but you know, they have the choice at the end of the day. And I think in a situation like that I would get an advocate in so they won't want to be pleasing, like a lot of the people would want to do, it would be about what they wanted, not what they think other people want. (SH1)

However, the exercising of informed choice was seen as problematic because of: (i) how poor available information was - very little was in BSL;

"But we're by no means in a position where everyone is accessing everything that they need to be accessing in their own language, I think that...we're a long way off from that." (SH2)

"I know there's a lot of people in the Deaf community who don't even know that they got those things [care options], that they're managing and struggling and they're not aware of the services that are out there to help. So it's about information giving as much as it's about creating a range of services that people can then access." (SH2)

(ii) how uninformed the Deaf community in general was, partly because of the failure of services to reach out to them to assist in awareness raising and accessible information provision; partly because of the consequences of not hearing:

"There is much less information for Deaf people because on the streets, people share information where Deaf people don't have that resource - usually they only have access to general conversations unless someone is generous enough to explain any new information in detail. Also hearing people use radio every day where deaf people cannot so much less access to information for them." (SH5)

"I really feel that the information needs to be Sign Language led, it needs to be clear, avoiding jargon and it needs to be promoted on a regular basis with older Deaf people what their choices are." (SH1)

"In my experience mostly they [older Deaf people] don't really know what is available to help them, they don't know where to go" (SH4)

(iii) the diminishing number of social workers who worked specifically with Deaf people or in roles that enabled them to work with the Deaf community. The overall number of specialist social workers was reducing and of those that remained, many were seen as being redeployed into roles that restricted how much attention they could give to Deaf people. Specialist teams within Social Services Departments were also seen to be disappearing.

### **Additional considerations about specialist residential care provision in Wales**

Additionally there were other factors respondents identified would have to be taken into consideration if thinking about a specialist residential care home solution. Despite the fact that a Deaf residential facility would meet need and was requested by members of the Deaf community, stakeholders were only too well aware of the problems that would need to be addressed. One experienced manager cited some of them:

"I think if you were looking at the challenges of setting up a residential care home for older Deaf people, then there are lots of things to think about, ..funding, finding individuals who need the service, needs mapping, but also authorities, I mean do you build one large residential care home? Do you have a small number of care homes? Where would you build that care home?" (SH2)

The issue of strategic responsibility was raised by several stakeholders:

"As X said, which local authority would really take responsibility and where would it be built and who would have access to it?" (SH7)

"You can't build a residential care home for Deaf people in every Authority so there would be issues around, as I've said, where that would be built, and how that would be accessed and how Authorities within Wales would need to really work in partnership with organisations to make that happen. But I think we should do it, absolutely!" (SH2)

These stakeholders were only too well aware of the negotiations that would need to go on between authorities and the systems that would need to be in place to enable service users to access a home located in another authority.

Additionally, respondents immediately recognised the interlinked constraints of geography and the problems inherent in seeking to serve a small, scattered population. This would make it difficult to predict potential numbers of Deaf residents and maintain a financially viable service. Various solutions were suggested. The majority approached the problem by presupposing that there would need to be two Deaf residential homes, one in North Wales and another in South Wales. These two communities were seen as separate and different and that to have only one national facility would thus be inappropriate.

"I suppose if we had an ideal world we might have one in South Wales and one in North Wales, perhaps. Erm, because I think that might meet the cultural needs of Welsh people, as well as the Deaf cultural needs of Welsh people" (SH2)

Indeed from the North Wales perspective, it was suggested that it might make more sense to utilise the Deaf home that already existed in Blackpool rather than invite people to move to South Wales. This had happened previously but service users were reported as not being entirely happy with the distance from friends and family. An alternative suggestion was small units of 4-8 people, either independent or attached to a hearing residential home, possibly in each LA or shared between two neighbouring Authorities.



The small size of the Deaf community, its history and culture also raised potential problems. Within an already small community, the numbers needing or wanting residential care at the same time would be small and, as one respondent reasonably pointed out:

"just because a Deaf person...there are two Deaf people in a home, doesn't mean that they're going to get on does it?" (SH3)

There was also a concern from a Deaf professional that the experience of residential school might deter Deaf people from entering a Deaf residential home. This would be a reason for the small unit approach.

"Scattered all over otherwise they would be reminded of the old days like being in a residential school where they might have had experiences." (SH5)

Yet another aspect of the Deaf community was that news travels quickly. If a Deaf home had a good reputation, it would be popular, but

"if anything goes wrong, word will spread fast and people will be put off immediately." (SH5)

The difficulties of weighing up the relative advantages of being near family and being in a specialist facility for Deaf people that may be at some distance, were also a key consideration mentioned by many stakeholders. Reflecting on the only current option of moving to England if a Deaf older people's environment was wanted, one respondent remarked:

"I know of one home in Blackpool and there were a few people from Wales who used to live there but they weren't happy having to move out of Wales as their families didn't visit them often enough because of the distance. They should be near their families and in a home environment where signing is used." (SH6)

Moving out of Wales to gain an optimum care environment was also not regarded as helpful in terms of meeting an individual's cultural needs in respect of being Welsh, although this was considered more of an issue for those in South Wales than North Wales.

## 5. Conclusions

This research study set out to explore three questions:

- (i) How can the needs of older Deaf people who use BSL be best met in residential care provision?
- (ii) What might constitute good practice for Deaf older people who use BSL and are in residential care/considering residential care?
- (iii) What influences preferences amongst older Deaf people in Wales who use BSL for specialist residential care provision within a signing environment, in contrast to a local residential placement?

Having taken evidence from Deaf people in the community, older Deaf people themselves who are in or who are contemplating residential care and from key stakeholders, it is possible to summarise the following main points. Where relevant these are set against the key priorities and themes of the National Service Framework for Older People in Wales (2006) and the Welsh Assembly Government's Strategy for Older People in Wales (2003).

### **High levels of concern about the current situation**

There was universal concern from all who took part in this study that current residential care provision for signing Deaf people in Wales is:

- inadequate
- fails to meet Deaf older people's needs
- in many cases clearly represents an infringement of individuals' rights
- adversely affects their quality of life
- has the potential to cause significant harm

These concerns arise in the context of there being no specialist provision currently available for Deaf signing older people whether in the form of residential care or supported living environments. An older Deaf person who requires residential care either enters a mainstream service (the usual outcome) or, in rarer cases, is placed outside Wales in one of the few specialist care homes in England.

### **Communication and language as pre-eminent issues**

Central to these conclusions is the issue of language and communication. Currently there is no residential care provision in Wales that can ensure a care home environment where BSL is used as a matter of course. All Deaf older people in Wales are placed in care environments where BSL is not routinely used within the environment by staff (at best a member of staff may have basic sign language or there may be an occasional outreach visit from a signer into

the home). More usually they are the only Deaf resident. This is important because in such a situation a Deaf resident:

- Cannot be assured of being able to communicate their needs in BSL on an everyday basis which has implications for personal safety and quality of care
- Will not be stimulated socially by being able to communicate with others around them in their preferred language, which has implications for personal happiness/contentment as well as having potentially adverse cognitive and mental health effects.

The point was strongly made by members of the Deaf community that not being able to understand or be understood in one's own language was tantamount to communication deprivation. The implications of failing to meet such a basic human need as communication, are far reaching in the context of one of the Welsh Assembly Government's (2003) key aims expressed in the Strategy for Older People in Wales:

"To promote the provision of high quality services and support which enable older people to live as independently as possible in a suitable and safe environment and ensure services are organised around and responsive to their needs". (p.9)

### **Failure to meet cultural needs**

There was also widespread concern that in the current situation of Deaf people being placed in mainstream residential care provision, their cultural needs were also not being met. In this sense it is important to understand that the significance for older Deaf people of regular contact with other Deaf people goes far beyond what might be understood as maintaining a social life. Contact through the Deaf club, Deaf friends and Deaf organisations is a way of maintaining a psychologically healthy Deaf identity through the reinforcement of life long bonds and the sharing and continual re-making of one's cultural heritage. Specific concerns were expressed that:

- Such cultural needs were simply not taken into account when Deaf people were placed in residential care
- Mainstream residential care providers fail to prioritise the meeting of these needs or in many cases fail to appreciate their significance
- The impact on individual Deaf people of being cut off from other Deaf people was personally devastating (and more than once likened to imprisonment)
- Failure to address the maintenance of cultural identity also contributed adversely to mental health outcomes

The failure to address such issues of cultural needs and identity might usefully be considered in light of the National Service Framework for Older People in

Wales' standards of: 'person centred care' and 'promoting health and well being in older age' (pp. 25 - 50) as well as its underpinning theme of 'equity'. Evidence from this study demonstrates how these standards are not being met.

### **The whole older people's care spectrum**

Specialist residential care provision for Deaf older people was not regarded as the only solution (supported housing for example was also discussed). However a specialist residential care facility for older Deaf people was emphasised as needing to exist within a suite of available support options. In this respect, attention was drawn to:

- The great importance of ensuring Deaf people have accessible information and good awareness of the wide range of support that may be available to older people
- Whilst there is a clear need to promote informed choice by older Deaf people about their rights, needs and how these might be met, there was also a concern about the process of involving Deaf people in making choices. In this respect the positive role of Deaf advocacy, where available, was mentioned.
- The need for domiciliary care to be communicatively accessible and culturally appropriate for Deaf people was also considered a priority.

However the extent to which domiciliary care (enabling someone to remain in their own home) is actually consistent with independence for Deaf people was questioned. If staying in one's own home was tantamount to an hour's visit per day from someone who was not Deaf or could not communicate well, would not a Deaf person's independence and well-being be better served by residential provision in a communicating environment with other Deaf people? The same argument might well apply to supported housing also.

This tripartite emphasis on accessible information; services to promote choice; and a culturally nuanced understanding of what might constitute the promotion of independence, should be considered in the context of the NSF (2006) standard of 'challenging dependency'. Indeed based on evidence in this study, there is a strong argument that the placing of Deaf signing people in hearing, non-signing care provision actually achieves the opposite of this standard.

### **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

### **Barriers to specialist residential care provision**

Several potential barriers were clearly identified.

- The low incidence demand set against the geography of Wales. The establishment of one provision in terms of numbers might be justified but distance to travel and reluctance to leave North or South Wales (depending on where it was located) might render it unacceptable.
- The issue of whether Deaf people would want to give up living close to their family set against being in a signing care environment, was not raised as strong an objection as might have been anticipated. It was acknowledged as a factor in decision making but not as an overriding one. Different individuals in different circumstances would come to their own conclusions about priorities. However the need for communication and contact with other Deaf people was an overriding concern of all Deaf people we talked to and therefore would play a highly significant role in any decisions about staying close to family versus being in a Deaf community in older age.
- Service providers were concerned about the logistics of strategic responsibility and funding.
- The Deaf community were concerned about whether those with decision making and funding power would really appreciate the severity of need and Deaf people's perspectives on 'well-being' in older age. They were wary of consultation without action, which many had experienced before, and were concerned that a failure to take the matter seriously would be the most significant barrier.

### **Final comments**

It was not the purpose of this study to make specific recommendations but rather to gather evidence and synthesise it in such a way as to be useful to

those considering the case for specialist residential care for older Deaf people in Wales. However, the conclusions clearly point to the need to do something different from current practice. In making decisions about future provision the research also demonstrate the absolute centrality of meeting Deaf people's linguistic and cultural needs as *the starting point* in those considerations. They are also *the standard* by which the efficacy and appropriateness of any future provision will be judged. There is a clear opportunity to improve the quality of life of older Deaf people in Wales in line with the country's own strategic vision for older people and its National Service Framework. Both the Deaf community in Wales and knowledgeable stakeholders/service providers agree that action is long overdue.

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## APPENDICES

Appendix A	Poster (Open Discussion meeting)
Appendix B	Focus Group Script
Appendix C	Interview Schedule - Individuals
Appendix D	Interview Schedule - Stakeholders
Appendix E	List of thematic categories

## Residential care for older Deaf people – what do Deaf people want?



### Open Discussion



Are you

- Deaf?
- living in Wales?
- over 50 years old

If yes to all, you are welcome to join in

'Open Discussion'

on *date*

at *time*

at *venue*

The Welsh Assembly Government has asked for some research about residential care for older Deaf people. They want to know what the Deaf community wants in the future.

Please come and share your thoughts with researchers from the University of Manchester.

e.g. Do you think a care home just for Deaf people who use BSL is a good idea?

Is it more important to be near your family when you get older?



Refreshments will be provided



For more information, contact Rosie Oram as below;

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## Focus Group Script

The session will begin with a narrative story.

*“Imagine the following situation. There is an older Deaf man called Peter and his wife, Mary who have been married for a long time. Sadly, Mary dies and at first, Peter manages to cope alone. However, one day he has a fall and realises he can’t continue to live alone. What happens next?”*

What do you think are the most important aspects for Peter to think about now?

Are you aware of the choices available? Do you think you have sufficient access to all the necessary information to make an informed choice? Do you worry you may be pressured by other people into making a particular decision?

One possible option is residential care. What do you think day-to-day life in a residential care home is like?

What things do you think would be important for you in this situation?

If you had the chance to talk to a resident of a home you were considering for the future, what questions would you ask them?

When you are older, what do you want? Is control of your own life important? (Interviewer could offer some examples e.g. mealtime routines, plan own day, choose activities, financial independence, etc).

How would you prefer to communicate with staff and residents?

If you moved into residential care and there was something you weren’t satisfied with, do you think you would complain? Who do you think you would tell? Would you know how to make a complaint?

If you moved into residential care, how important would it be to you to be able to keep your links to the local Deaf community?

When choosing a residential home, what equipment specifically for Deaf people would you expect them to have?

From the following options, which are the most important to you? (Choose 3)  
(Have list written on flip-chart)

- quality of food provided
- staff
- cleanliness
- communication
- social activities inside the care home
- social activities outside the care home
- other residents
- privacy/own room
- facilities
- allow pets
- location
- healthcare provision
- other

Why have you picked those options?

If there was a residential care home provided in Wales for Deaf people only, would you be interested in moving there? Yes or No? Why do you feel that way?

Where in Wales do you think it should be? Why that location?

### Group Activity

Please divide yourselves into 3 groups. We have a list of options for you to discuss. Which is most important to you? Please discuss in your groups and try to decide what order they should be? At the end of the session, I will ask you to explain your decision and your reasons. You have XX minutes.

- to live in a residential home near family/friends
- to live in a residential home near local Deaf community
- to live in a residential home with other Deaf people
- to live in a residential home where the staff are Deaf aware, can sign and there are specialised Deaf equipment/facilities available
- to live in a residential home with a high standard of nursing care
- to live in a residential home with cheap fees

### Interview Schedule – Individuals

[Please note: these questions will be translated into British Sign Language (the individuals' main language) and cultural adjustments will be made. The translations and interviews will be undertaken by Rosie Oram who is herself a native signer and a member of the Deaf community.]

Ordinary text = Questions for current residents

*Italics = Questions for individuals considering residential care*

How would you describe your day-to-day life in this residential care home?

*What are your expectations of daily life in a residential home in the future?*

What influenced you to choose your current residential home?

*What factors will influence your decision whether to choose residential care in the future?*

How much control do you feel you have in your daily life? (Interviewer could offer some examples e.g. mealtime routines, plan own day, choose activities, financial independence etc).

*How important will it be for you to have control of your daily life? In what ways?*

If somebody you know was considering moving into your residential home, what would you tell them were the best things about life here?

What about the worst things?

*If you had the chance to talk to a resident of a home you were considering for the future, what questions would you ask them?*

How do you communicate with staff and residents? What is your relationship with them like?

*How would you prefer to communicate with staff and residents?*

If there's something in the home that you are not satisfied with, would you complain about it? Who would you tell? Would you know how to make a complaint?

*If you moved into residential care and there was something you weren't satisfied with, do you think you would complain? Who do you think you would tell? Would you know how to make a complaint?*

Do you visit your local Deaf club/group? Do you visit Deaf friends or do you have Deaf friends who come to visit you?

*If you moved into residential care, how important would it be to you to be able to keep your links to the local Deaf community?*

Does your residential home have any equipment specifically to support Deaf people?

*When choosing a residential home, what equipment specifically for Deaf people would you expect them to have?*

Interviewees will be asked to rate the importance of each of the following on a 1-5 Likert scale. The interviewee will be provided with a laminated copy of the list when considering responses

- quality of food provided
- staff
- Deaf staff
- cleanliness
- communication
- social activities inside the care home
- social activities outside the care home
- social activities with other Deaf people
- being close to my family
- other residents
- other Deaf residents
- privacy/own room
- facilities
- allow pets
- healthcare provision
- feeling safe
- other

Why have you picked those options?

*Same as above*

If there was a residential care home provided in Wales for Deaf people only, would you be interested in moving there? Yes or No? Why do you feel that way?

*If there was a residential care home provided in Wales for Deaf people only, would you be interested in moving there? Yes or No? Why do you feel that way?*

(Below is an optional question which might not be required if the subject of health arises from earlier discussions).

Do you have any specific health issues which affect your day-to-day life? (If yes, did this influence your choice of residential care home?)

*Do you have any specific health issues which you think would affect your day-to-day life in residential care?*

## Interview Schedule – Stakeholders

[In the following interview, the interviewee is reminded they are answering on behalf of their organisation as well as drawing on their own professional experience.]

Please can you tell me your job title and give me an idea what your job entails?

Tell me about what your organisation has to do with services older Deaf people in Wales.

Currently, what works well in residential care for older Deaf people? [Do you have any good practice examples?]

What do you think the key challenges are in planning and delivering residential care services for older Deaf people?

In your experience, do you think older Deaf people are aware of the choices available to them? [+ Do they have access to all the necessary information to make an informed choice? Do you feel they may be pressured by other people into making a particular decision?]

In your experience, how important is it for Deaf people to keep their links to the local Deaf community, after they have moved into residential care? How possible is it?

Do you think it creating a residential care home specifically for Deaf people in Wales is a good idea? [+ Why? Is it realistic? What is the likely demand? What would be advantages and disadvantages?]

Where in Wales do you think it should be? Why that location?

We have a list of options for you to consider. Which do you think is most important to Deaf people, in your experience? Please can you explain why?

- to live in a residential home near family/friends
- to live in a residential home near local Deaf community
- to live in a residential home with other Deaf people
- to live in a residential home where the staff are Deaf aware, can sign and there are specialised Deaf equipment/facilities available
- to live in a residential home with a high standard of care
- to live in a residential home with low fees

Is there any other issue that you feel is important to Deaf people considering residential care that we haven't discussed?



List of thematic categories

Focus Groups

The importance of communication

The importance of social and cultural needs (deaf links)

The fear of isolation and the knock on effects (mental and physical)

Maintaining independence/privacy

Lack of access to information and hence ability to choose

Knowledge of abuse stories (emotional/physical/financial)

Expectations of Social Workers and their role

Problems recognised by everyone, posed by the Welsh geography and the number of Deaf people

Commitment from Welsh Assembly Government being questioned?

Dependency on hearing people (professionals/CODAs)

Conflict between being near family and access to people who could sign

Stakeholders

The importance of communication

The importance of social and cultural needs (deaf links)

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### Individual interviews

The importance of communication

The importance of social and cultural needs (deaf links)

The fear of isolation and the knock on effects (mental and physical)

Maintaining independence/ privacy

Lack of access to information and hence ability to choose

Knowledge of abuse stories (emotional/physical/financial)

Problems recognised by everyone, posed by the Welsh geography and the number of Deaf people

Dependency on hearing people (professionals/CODAs)

Conflict between being near family and access to people who could sign