

**Cambridge** Centre  
for Housing &  
Planning Research

# **Managing hearing loss in vulnerable groups of the Cambridgeshire D/deaf communities**

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# Managing hearing loss in vulnerable groups of the Cambridgeshire D/deaf communities

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# 1) Introduction

This study is the second of two pieces of research aiming to explore the use of different services in Cambridgeshire by people who are D/deaf<sup>1</sup>.

The purpose of the research was to provide a tool for the D/deaf partnership to better understand its constituency, with a particular view to making an input into the revised Joint Strategic Needs Assessment (JSNA). The first piece of research was a scoping study with a view to expanding the research in the future (Burgess and Monk, 2013). It contained the findings from a literature review and drew on interviews with a range of stakeholders and D/deaf individuals in Cambridgeshire to explore the use of services and the best methodologies for conducting research with people with hearing loss.

The first phase of the research identified several gaps in research about particular groups. These were only covered anecdotally or through secondary sources in the first phase. The gaps were:

- Young adults
- Older people in care homes
- School children
- Babies
- Rural isolation

The research found that services for babies, school children and young adults in Cambridgeshire are of a good standard. However, little was known about older people in care homes and those living in rural isolation. Interviews with stakeholders suggested that both groups experience particular problems in managing their lack of hearing, but further research was needed to evidence and understand these problems.

The first phase of the research also identified gaps in services in Cambridgeshire which included:

- Social facilities for young adults
- Hearing care for older people in care homes
- GP services 'a lottery'
- Advocacy services for D/deaf people
- Inequalities in health
- Inequalities in educational achievement

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<sup>1</sup> The group of people encompassed under the term D/deaf are very diverse and this diversity and the ways in which deafness might be physiological condition and/or an identity is often acknowledged through the use of upper case 'D' and lower case 'd'. Lower case 'd' is generally used to refer to the audiological condition of not hearing and is mostly applied to those who use spoken language. Upper case 'D' is used to mark those who use sign languages such as British Sign Language (BSL) and are members of the Deaf community and where 'Deaf' is akin to other markers of cultural-linguistic identity. In this report we will be considering both groups but will use D/deaf throughout for consistency and indicate where we are referring specifically to people who use BSL.

Most of these gaps are also problematic nationally and there is research evidencing them and making recommendations for good practice. However, there was little evidence about advocacy services for D/deaf people in the county. It is possible that there is a gap in services with the loss of the Our Voice advocacy service.

The second phase of the research therefore concentrated on these three issues:

1. Rural isolation amongst people with hearing loss
2. Older people in care homes
3. Advocacy services

This second report presents the findings of research into how these three groups are supported to manage their hearing loss in Cambridgeshire.

### **1.1 Aims and objectives**

The aims and objectives of the scoping study were to identify the issues faced by each of these three groups in managing their hearing loss and to explore the best ways to support them.

The key research questions were:

#### **1) Rural isolation amongst people with hearing loss**

- Do people in isolated rural areas face particular difficulties in managing their deafness?
- Do people in isolated rural areas face particular problems as a result?
- What is the best way to support people in rural areas to manage their hearing loss?

#### **2) Older people in care homes**

- How are older people in care homes supported, or not, to manage their hearing loss?
- What else could be done to provide support?

#### **3) Advocacy services for D/deaf people**

- Do people with hearing loss have particular problems in accessing advocacy services?
- What measures are in place to assist them?
- What further support could be provided?

## 1.2 Methods

Interviews were conducted with a range of relevant stakeholders. Twenty seven in depth interviews were conducted in total. This included:

- People who work with older people in rural areas e.g. mobile wardens, CAMTAD volunteers, organisers of older people's groups, or who have hearing loss and live in isolated areas.
- People who are involved with older people with hearing loss in care homes such as care home managers, carers, people with family in a care home, nurses, an audiologist and volunteers.
- To explore advocacy services people were interviewed who work for support services such as the Cambridgeshire Deaf Association, Age UK, and Voiceability.

Interviews were conducted by telephone as far as possible. People who live in rural areas with hearing loss were interviewed. However, people who have hearing loss in care homes were not interviewed directly. As a vulnerable group it was not felt appropriate to interview people who were likely to be very frail, although spouses of residents were interviewed. People who are D/deaf who have used an advocacy service were also not directly interviewed. There was not scope within the research to include a large enough sample to be representative of the views of this group. Key stakeholders working in the provision of advocacy to D/deaf people were interviewed.

The research was commissioned by the Cambridgeshire Deaf Partnership. The Cambridgeshire Deaf Partnership is an informal group of charities and public sector representatives in Cambridgeshire that meets regularly to discuss issues of interest to the D/deaf communities and people with hearing loss. The core members are Cambridgeshire Deaf Association, Cambridge CAMTAD (Campaign for Tackling Acquired Deafness) Cambridgeshire County Council and Addenbrookes Hospital. Other organisations attend from time to time.

CAMTAD acted as liaison for the research and provided contacts and introductions. CAMTAD is a charity for people with hearing loss. Their mission is to reduce the impact of hearing loss on daily lives. CAMTAD volunteers provide drop-in hearing help sessions where NHS hearing aid users can get free batteries and hearing aid care and home visits to those who cannot get to the sessions. They also provide free advice about hearing loss and offer talks and training to groups or businesses that need to be deaf aware.

## 2) Literature review

This section recaps on the literature review from the first study in relation to hearing loss and ageing and managing hearing loss in care home settings (Burgess and Monk, 2013). It also reviews literature around advocacy services.

### 2.1 Ageing

Diagnosis of hearing loss in adults is opportunistic and ad hoc – on average, there is a 10-year delay in people seeking help and evidence suggests that GPs fail to refer 45% of people reporting hearing problems for any intervention, such as a referral for a hearing test or hearing aids (Action on Hearing Loss, 2011).

The majority of people with hearing loss are older and the prevalence increases with age (Davis, 1995). The UK's population is getting older; life expectancy is rising and by 2027 the number of people aged over 65 is estimated to increase by 60% (ONS, 2009). The prevalence of hearing loss is set to grow - the Medical Research Council estimate it will increase by around 14% every 10 years and by 2031 there will be approximately 14.5 million people with hearing loss in the UK (Action on Hearing Loss, 2011).

Gradual deterioration of the ear means that for most people, deafness is an unwelcome feature of later life (Deafnessresearch.org, 2012). Although the degree of disability varies greatly, and some people adjust quite well to the slow decline in their hearing, for many this form of hearing loss, known as presbycusis, causes frustration, loneliness and depression. Presbycusis can occur in both ears and affects over half of all people over 60 years old, making it the second most common cause of disability in older people. Hearing loss may also be accompanied by other health problems associated with ageing, leading to reduced mobility and wellbeing. Older D/deaf people may become isolated, either in their own home, or in a residential or nursing home.

There are particular concerns for older D/deaf people who use BSL. Although the D/deaf community can be a support system for D/deaf people throughout their lives, it is a small community and one which requires participation (Pullen and Kyle, 1997). As people become older and less mobile, it becomes much more difficult to reach the deaf club on a regular basis and there may be no organised transport which can be used (ibid).

D/deaf people with dementia find it difficult to obtain adequate referrals, information, support and services that are suited to their needs. They need all of these things provided in a way that reflects their own use of language - British Sign Language (BSL) - and deaf culture (Alzheimer's Society's, 2012).

There are advantages to ageing in rural areas; for example, they tend to perform well on economic indicators and there are proportionally fewer instances of cancer, stroke and coronary heart disease compared to urban areas (Age UK, 2013). However, the characteristics of rural areas, with low population densities and distance between residential and commercial centres, can bring additional challenges for older people, such as higher living costs, housing that is hard to heat and maintain, poor transport links and more limited

social networks (ibid). The over 85 age group is estimated to increase by 186% by 2028 in rural areas compared to 149% in England as a whole (ibid). A recent Age UK report makes recommendations as to how challenges can be overcome, drawing on efforts that rural communities are making to find solutions. It calls for action from the government to:

- consider the interests of rural people in policies and services
- take the 'rural premium' (the extra cost of delivering services to people living in a rural area) and social value into account
- support community participation, and target social isolation (Age UK, 2013).

## **2.2 Residential and care homes**

Four hundred thousand older people live in the UK's care homes, and that number is set to grow year on year. Care home residents are disproportionately affected by hearing loss (Echalier, 2012). It is estimated that around three-quarters of older people who live in these settings have a hearing loss and, as the number of people in care homes increases, more and more residents will be affected by hearing loss. Research 'A World of Silence: The case for tackling hearing loss in care homes' found that if care home residents' hearing loss is managed effectively, there is a real chance of improving their quality of life (ibid). But it also identified a trend in hearing loss not being diagnosed and managed properly.

In research in care homes there were high levels of hearing loss but the overwhelming majority of people were unwilling to take any further action, mainly because of many residents' acceptance that hearing loss is just something that comes with old age (Echalier, 2012). Although there were many cases of undiagnosed hearing loss, on the whole, staff had a good understanding of how to communicate effectively with residents with hearing loss. There were a range of problems experienced by residents who wore hearing aids, including flat batteries and whistling, people's hearing aids falling out, aids getting lost, and residents waiting a long time to get them repaired. The staff who provided care on a daily basis for residents with hearing loss had only a very limited understanding of the special products available, such as amplified or hearing aid compatible telephones.

There is a need for earlier intervention in hearing loss. As soon as someone moves into a care home, it becomes more difficult to diagnose and manage this hearing loss, as they may have another long-term condition such as dementia.

There is a small but significant number of older profoundly D/deaf people (BSL users) who will require residential care provision (Hunt et al, 2010). There is often no other option than for them to be accommodated within mainstream services where they are likely to be the only D/deaf person. Older D/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. For optimum health and well being older D/deaf people need to be in a signing environment. Specialist providers also argue for the significance of meeting D/deaf people's cultural needs - to be with others like themselves, with shared values, experiences and histories. Without specialist provision older

D/deaf people's independence is likely to be eroded. There are concerns that in a mainstream residential care environment, the specialist needs of D/deaf sign language users are being overlooked because they are presumed to be the same as those with acquired hearing loss (ibid).

Research in Cambridgeshire raised concerns that staff are not trained to manage hearing aids and there are often ambiguous situations where there is no clarity as to who should take responsibility, staff or the residents and their family (Cambridgeshire Deaf Partnership, 2012). CAMTAD delivers basic information and training to carers and care staff, but are unable to provide this on a large scale throughout the county.

### **2.3 Advocacy**

The group of people encompassed under the term D/deaf is very diverse and their support needs vary widely. But there are issues associated with deafness that can make D/deaf people more vulnerable and in need of advocacy support, particularly profoundly deaf BSL users.

The review of existing literature about D/deaf people's access to and use of health care services suggests that there are health inequalities as compared to the hearing population. D/deaf people do not experience the same health as the hearing population and do not have the same access to health services. They are more likely to experience mental health problems. Deafness also has serious consequences for literacy, educational achievement, socio-emotional development, and ultimately employment (Mason et al, 2010). Research into the employment experiences of severely and profoundly deaf people found that at a time of near full employment, D/deaf people were four times more likely to be unemployed than the general population. The main barrier to getting a job is seen as negative attitudes from employers (RNID, Opportunity Blocked, 2007). Barriers to communication caused by hearing loss can have far-reaching consequences and lead to isolation and exclusion (Action on Hearing Loss, 2011). Recent research found that people with hearing loss are likely to withdraw from social activities involving large groups of people and, where they do take part, communication difficulties can result in feelings of loneliness (RNID, Hidden Crisis, 2009).

These additional vulnerabilities as a result of being D/deaf can mean that some people with hearing loss need the support of an advocate in certain circumstances e.g. going to court, appealing against benefit decisions, in meetings with social care, or even in attending hospital appointments.

In particular, those who are profoundly deaf and use BSL may require support. BSL is structured in a different way to English and like any language it has its own grammar. BSL users can struggle to understand English as it is their second language meaning there are barriers to accessing services, including banks, welfare benefits, health appointments and retailers. As a result BSL users may need both interpreters and advocates to support them in accessing services.

For most people, making their own decisions and choices is a matter of some considerable importance (Elite Cic<sup>2</sup>). Being part of decision making processes is not only a route where self identity is expressed but it is also an important aspect of personal freedom. However, a number of barriers can prevent people from actively taking part in decisions which affect their lives and can affect an individual's ability to speak up for themselves. Advocacy reaches out to some of the most marginalised and disadvantaged sections of the community, people that formal services and systems can overlook. An advocate is an independent agent and not connected to the carers or to the services which are involved in supporting the person.

The National Lead for Advocacy, Valuing People Team, 2009 defines advocacy as 'taking action to help people say what they want, secure their rights, represent their interests and obtain services they need. Advocates and advocacy schemes work in partnership with the people they support and take their side. Advocacy promotes social inclusion, equality and social justice'.

Advocates should ensure advocacy support is appropriate to the service users' needs and/or expressed wishes. Advocates should take instruction from service users wherever possible and base their actions on mutually agreed plans and preferred outcomes and work in partnership with service users to achieve this.

Our Voice was an independent advocacy service for people who are D/deaf, hard of hearing and Deafblind, working in Cambridgeshire and Peterborough. Our Voice advocates were all trained in British Sign Language (BSL) to Level 3 and above, but were also skilled in a wide range of communication techniques encompassing BSL, Sign Supported English (SSE), "Total communication" techniques, speech, lipreading and written communication, utilising English, pictures, symbols and many other methods. They also had a background in working with D/deaf people in a range of roles, including as befrienders, interpreters and support workers. The organisation is no longer in operation after funding was discontinued, but carried out research to establish what clients and professionals identified as the unique benefits of a D/deaf specific advocacy service. The conclusion of the report was that this specific advocacy service can provide unique benefits to clients because:

- The communication skills and experience of specialist advocates for D/deaf people enable them to build relationships of trust and confidence with clients and bring specialist knowledge to bear on their problems.
- Advocates for D/deaf people can reduce clients' isolation by enabling them to access both specialist and mainstream services through support and referral.
- Advocates for D/deaf people provide a crucial link between vulnerable hard-to-reach deaf clients (including those with mental health problems) and the numerous professionals that surround them.
- The advocacy relationship empowers clients, raises their confidence and improves their sense of well being.
- Advocates for D/deaf people can fulfil a unique awareness raising role amongst other professionals working with D/deaf clients.

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<sup>2</sup> Elite Cic aims to promote Independent Living and Social Inclusion within the community for disabled and non disabled people and their carers.

One issue that the report raised was that the role of interpreter and advocate sometimes get confused in the minds of the professionals. The key difference is that an interpreter is independent of both parties and only there to translate from English to BSL and vice versa. In contrast the advocate is there to support the client and ensure that the client fully understands and is completely understood. The report argues that it is vital for advocates to be able to communicate with their clients directly in BSL as it enables them to build up a relationship of trust and allows direct communication with the client without relying on an interpreter as intermediary. But the report also argues that it is vital that the client still has access to a professional interpreter in formal meetings such as medical appointments, legal proceedings and others.

### 3) Research findings

#### 3.1 Older people in rural isolated areas

The interviews exploring the ability of older people in rural areas to manage their hearing loss consistently raised the same issues. In this section interviewees are predominantly referring to people who have lost their hearing as they have aged/through health reasons.

One issue that is not unique to people in rural areas is that people are not always aware that they have hearing loss, particularly in its early stages, as the change in their hearing can be over a long time period. But once people are aware that their hearing is deteriorating then they need to acknowledge it and seek help. People can be deterred from seeking support as there is a certain stigma attached to deafness.

“The ladies who are housebound are of that age where they do not like to ask for help. It is difficult to get past that. They say they don’t want to cause any problems. People need to be aware there is help. But even so there will be some who will not take it up”. (Volunteer at coffee morning in rural area)

People need to recognise that their hearing loss is a valid issue on which to seek medical help and their first point of contact should be their GP.

“For me it has made quite a difference. I can hear my husband, the children, the TV and the ladies at the coffee morning. It has made a difference to my husband who now hears music very differently..... It cuts you out and makes you more isolated. If you can hear it opens so many things for you”. (Volunteer at coffee morning)

Many people do not seek help with their hearing loss. For example, one interviewee described how older farmers can suffer from hearing loss because of the nature of their work but will rarely seek help:

“I have noticed members of the farming fraternity have hearing problems and they won’t admit to it. They all work with noisy machinery and shoot. It is ok if you have head protection but lots of farmers are my age in their 70s and didn’t have ear protection. They won’t acknowledge it. Some get help. But most don’t though and they just shout at one another”. (CAMTAD volunteer 2)

But deafness in later life can itself be isolating as it makes interacting with other people and engaging in everyday activities more difficult. However, this isolation can be compounded if an older person with hearing loss also lives in a rural area. Living in rural areas can be more challenging as public transport is often relatively poor which makes accessing health services for hearing loss, everyday facilities and social activities more difficult.

“Lots of people in isolated areas have fewer options to access integrated services. The market says it is not worth providing in these areas so there are only statutory services which mean less choice and fewer options”. (Local organisation 1)

The most isolated older people are those who are housebound in rural areas which are far from local services. But without support to manage their hearing loss, older people can become even more isolated which reduces their quality of life.

“People would just manage without their aids until someone helped them. If people cannot hear it is worse. We had a gentleman with hearing aids who liked to read so we arranged for the doorstep library to visit him but he couldn’t hear the doorbell. Without it he would just sit and do nothing as he likes to read and not watch TV. So we arranged for the library to visit when we were there. People who have no one to intervene just get more isolated”. (Mobile warden)

Interviewees raised the problem of lack of awareness about deafness and what can be done to manage hearing loss. Some interviewees suggested that GPs do not always see dealing with hearing loss of older people as a priority health issue and do not always ask patients about it or suggest appropriate responses or services. GPs need to be aware of the importance of dealing with hearing loss, make appropriate responses and be aware of services they can point people to. Interviewees said that whilst there are support services for people in rural areas with hearing loss, such as CAMTAD drop in sessions, people often do not know what help is out there and need to be aware of services in order to access them.

There are services to support older people in rural areas such as mobile wardens, coffee mornings and befriending schemes. The people who provide these ought to be aware of the problems of hearing loss and what can be done to support it. This would mean that those working with older people in rural areas would be able to give advice on how to seek help for hearing loss and how to access services such as CAMTAD. It would also be helpful if they had better knowledge of how to change batteries and fit hearing aids so that those in regular contact with older people could provide basic advice and support to people who wear hearing aids.

If older people are in contact with one service, such as a warden scheme, it is this connection which can help them to support their hearing loss. For example, if they are housebound the warden can collect their hearing aid batteries or put them in contact with other services like CAMTAD. So it is important that all those involved in providing support to older people know about the need to deal with hearing loss and the help that is available.

“Without the warden they probably wouldn’t know about CAMTAD or be able to use it. People would just be stuck, for example, with no one to collect their batteries. We often think about the mobile warden scheme, what on earth would people do without it? Most people have family but not locally. They would probably just manage until family came to visit them. We have had cases in the village where carers contacted us because people needed a new battery and the carers won’t change them”. (Mobile warden)

If people have no one to support them, or have carers and family who are not willing or able to help maintain their hearing aids, then keeping aids in good working order is very difficult.

It depends on if they have carers who come in to help, or family, or a spouse, then it is not as difficult to manage their hearing loss. But if they are on their own it is

tricky.....And it may not be the same carer which is the biggest problem. If they have family who help then it is generally ok but not all family are willing or able to do the hearing aids and to clean and maintain them. They have to make sure the aid is working, that the batteries are in properly and that it is in the ear properly. But some family members are not willing or able. Carers often come in to do personal care but they don't have enough time. They might have 30 minutes to wash, take them to the toilet, prepare a meal and maybe feed them so there is no time. Or they put the aid in but do not realise how it works. If it is not the same person each time it is a problem. And things go missing all the time, they get lost, or thrown away in tissues or bedding....It is hard to look after your aid if you are not able. (Former audiologist)

Interviewees said that a face to face hearing support service is best as even when people are in touch with services and get their hearing aids checked regularly there can be other problems that they do not seek help with but which they mention once they get talking. This can reveal further hearing related problems and service providers can point them to solutions and information to support them.

“Some is awareness about what is on offer. A few people have difficulties with things in their home such as the hearing TV. If they make us aware we can point them to the sensory loss team. But they have to tell you. The big value is that during the course of the clinic we talk to them all the time to bring these things out”. (CAMTAD volunteer 1)

### **3.2 Older people in care homes**

The findings about how hearing loss is managed in care homes were mixed. The results suggest that people have very different experiences of hearing loss support in care homes which depend on a number of factors. In this section interviewees are predominantly referring to people who have lost their hearing as they have aged/through health reasons.

Hearing loss in a care home setting that is not managed well was felt to be isolating and detrimental to resident's quality of life.

“If they can't hear then people can't join in with activities e.g. bingo and making things. Not being able to join in is very isolating, for example if they can't join in at lunch. Then they might just sit in their room with the TV turned up which then upsets their neighbours. If hearing aids are not working it can cause lots of problems. And if people just shout it is not nice..... It is very sad if you go into a home and someone is just sitting there and all they need is a battery in their aid and when you put one in their face lights up”. (Former audiologist)

“It makes a difference not being able to hear, you get more isolated. It is very hard to talk to someone who can't hear, so people end up not bothering and people are lonely and cut off”. (CAMTAD volunteer and former community nurse)

The transition from independent living to a care home is an important time for people with hearing loss as if they wear hearing aids then the care home needs be aware. In

circumstances where people cannot communicate about their hearing loss e.g. through loss of speech or dementia then they are unlikely to have help and may become more isolated.

The level of dependence of people in care homes varies, so some people are more able to manage their hearing loss than others. Hearing loss can be managed by an older person in a care home if they are still able to manage daily tasks such as fitting a hearing aid themselves, although they are still likely to need assistance in changing batteries and maintaining the aids. For people who are more dependent, if there are staff who know the people who have hearing loss and can fit, turn on and manage aids then hearing loss can be well managed. This may also be the case if there are regular visits from a CAMTAD volunteer who checks and helps to maintain hearing aids and to train staff.

“The volunteer role is very important....But there is a high turnover of staff so it is difficult to cover them all the time as the staff do change so we have to keep awareness going. It is important that the volunteers get to know the staff so the staff know they can ask for help from the volunteers”. (CAMTAD volunteer and former nurse)

Residents who have regular visits from family who are used to helping with hearing aids can also be important.

“They moved him to [local care home] and it didn't help him all that moving about and he lost some things when they moved him. I think that was when he lost one of his hearing aids. They didn't always make sure he wore them. I would go to visit him and look and only be able to find one but with one in his good ear he was ok”. (Spouse of care home resident 2)

Training is important on how to use and look after aids, but it is not provided by standard care/health training. It can be provided by specialist CAMTAD volunteers. But the onus is on the care homes to request training for their staff and one issue highlighted was that staff turnover is very high and so they will only know about how to use and manage hearing aids if training is regular, but this is not always the case.

“The homes start with good intentions and training. But there is high staff turnover. You do not have continuity of care. Then staff are not trained and their priority is to feed people and keep them clean. Hearing is not always a priority”. (Former audiologist)

One interviewee said that they had known a care home to have one member of staff who took responsibility for managing resident's hearing aids, changing batteries and cleaning aids. Aids can vary and it is hard for all staff to keep up to date, but the interviewee felt that having one staff member with good knowledge and clearly defined responsibility had worked well.

“In care homes ideally at least one member understands how aids work. Ideally all have disability and deaf awareness training and have this refreshed once a year. Some have nominated carers in the home for each client. Some homes have one person dedicated to looking after all the aids and this can work well. In one home,

one lady who did the activities checked all the aids and kept all the record books. But it would be best for all staff to have basic training in how to put a battery in, how to turn it on and off, put it in the ear the right way". (Former audiologist)

Other suggestions of good practice were the recording of serial numbers on hearing aids to make it easier to replace them if they were lost or to identify which resident they belonged to if lost and found. Keeping the 'brown books' issued with hearing aids by the audiology department in a safe place, either with aids or centrally, was also suggested as good practice. Regular hearing checks where possible, good maintenance of aids, staff training and/or use of services such as CAMTAD were all highlighted as important.

"Someone needs to take responsibility for looking after people's hearing loss in care homes. They need to be aware of services like CAMTAD. And they have to keep in touch with audiology as people's hearing changes over the years and they need regular checks". (CAMTAD volunteer)

It can be difficult for staff to keep up with managing hearing aids for residents as it does take time and effort and requires training.

"It is an issue if aids need cleaning. We have asked for training for the carers. Carers either don't want to or don't know how to clean and look after and use the aids. And there are lots of different aids. And we don't have cleaning tools. With batteries we do get them. We try to give people independence so we let those who are able manage their own aids. But this can mean that they leave them on and the batteries run out. We have to post them in a SAE to audiology for new batteries for the NHS ones which are registered here or relatives bring them for the private ones. But this means there is a delay". (Care home manager)

In care homes where staff have little or no training about hearing loss and hearing aids then aids are less likely to be worn and in good working order. Where people living in care homes cannot hear, they are more likely to become isolated with diminished quality of life. So care home staff need to see managing hearing loss as important, but they face many time pressures and it is not always a priority.

"Staff in care homes vary tremendously. I know of two homes where the staff are awful. They don't know when the batteries need changing. They are badly trained or have no training. I visited one man who had Alzheimer's which made him fidget so the staff had taped his hearing aid up. This meant it was permanently switched on and so the batteries quickly went flat. In one home they had put the battery in upside down and I couldn't get it out so I had to send it to hospital. They vary, some are good, some are bad". (CAMTAD volunteer)

It is also more difficult for staff to manage hearing loss if hearing aids are regularly lost but can only be replaced with difficulty, for example when residents come from out of the area or use privately bought aids so there is no easy access to their hearing aid record, and/or if the brown books supplied with hearing aids are not brought to the care home.

“We do shout to try and get them to hear. Some had aids but they tend to lose them so we tend not to utilise them. It doesn’t make any difference. They say they can’t hear. Some make more effort than others to understand us.....They lose them. We have lots of batteries but no aids. If we got them a new one they would lose it so it feels like a lost journey. We do our best to communicate with them. Two people did get new aids but they lost them straight away. No one has aids now”. (Care home staff member)

It can be difficult for staff to ensure that hearing loss is managed when residents have a degree of independence and fit and use their aids themselves but regularly lose their hearing aids, don’t wear them correctly or use them properly. Yet to intervene would disempower residents and be seen as an encroachment on their independence.

“It is difficult when you have a lot of beds to know who has aids. We try to give them control of their aids. But they get lost. And some private ones are very expensive. But we can’t take away their independence so we have to let them manage their aids”. (Care home manager)

Everyone has different experiences and some people never liked their wearing their aids before going into a care home and preferred to manage without them, so continuing to manage without hearing aids is not a change and may even be a personal choice.

“He didn’t take his aids in with him. We have asked him if he wanted them. But it has been a long time since he last had a hearing test so he would need another test. But we didn’t do anything about it. He developed a very negative view of hearing aids. So if the staff tried he would probably resist. And the staff are very sensitive to what people want.....I imagine if all was going smoothly the aids might help if he would accept them and try but he didn’t like them. He would be resistant”. (Spouse of care home resident 1)

There were mixed views on the need to manage hearing loss for people with dementia. Some felt that for some people with dementia and/or nearing the end of their life, it does not always make a difference if they can hear or not so wearing hearing aids is not as important as other forms of care and support. However, several interviewees felt that the isolation brought about by dementia and frailty are further compounded by deafness.

“Using their aids makes a great difference to people, especially people with Alzheimer’s. If their aids are not maintained then they lose contact. It is important that the staff know they must wear their aids. Without them it makes dementia etc much worse as it cuts people off..... Sometimes they don’t see it as important when people are old and frail but it helps people to keep in contact. You don’t realise how much you lose when you have hearing loss”. (CAMTAD volunteer)

### 3.3 Advocacy services

The interviews with stakeholders consistently raised similar findings about problems faced by D/deaf people in accessing advocacy services. In this section, interviewees are predominantly referring to profoundly deaf BSL users.

A number of barriers to accessing advocacy support were identified. A key issue raised during the interviews was the need for interpreters, in addition to advocates, but there is a problem over who takes responsibility for paying for an interpreter. Interviewees said that service providers often do not want to pay for interpreters. Interpreters are expensive and there are no clear rules on who has responsibility for payment of interpreters when needed by a D/deaf person to access services.

Age UK Cambridgeshire provides advocacy and support to older people on a range of issues. They have around 110 open cases county wide at any one time in addition to a waiting list. The older people can have some degree of hearing loss. The budget is limited and it is not clear who has responsibility for paying for an interpreter, for example, to support an older D/deaf person in discussing a care plan or appealing against an Attendance Allowance decision.

“Understanding the money is key – who, why, and in what circumstances is interpretation paid for? For example, if Attendance Allowance has been refused and there is an appeal, who bears the cost for the facilities to make sure the older person can take part? If your first language was not English then you would need that assistance and it would be provided under the Racial Equality Act, but under the Disability Equality Act it is vague as to who is entitled to what support and who pays. But you still need to be heard. And deafness is a hidden disability.....If people are having a care plan put together there is a baseline for the cost, but if you need an interpreter it is not clear if the cost is included in the basic benchmark of the care plan or if the person is expected to fund the interpreter out of their own purse. But if you have hearing loss and are having a long conversation about a care plan then an interpreter is key”. (Local organisation 1)

The issue of who should bear the cost of an interpreter was raised by other interviewees.

“Who pays? Normally if [local organisation] needs an interpreter they pay, if a person goes to court the court pays, if the job centre needs an interpreter then they pay. Normally it is paid for by whoever is engaging with the deaf person. CAB won't provide an interpreter and won't pay for one. I don't think a deaf person would go to CAB. I took someone once and it was hard to explain what was going on or to get advice”. (Local organisation 2)

Service providers can be resistant to arranging and paying for an interpreter.

“Another issue is who pays for an interpreter? At [local organisation] we believe that a BSL interpreter or a hearing loop/adaptation should be provided by services deaf people are trying to access. A bank would provide a ramp for a person in a wheelchair. But interpreters are expensive and organisations do not want to pay for

them so deaf people can access their services. Even other disability organisations do not want to pay for deaf people to access services. For example a sight loss organisation argued they should not have to pay for an interpreter..... It is incumbent on the service provider to enable a deaf person to access their services but they always argue.” (Local organisation 3)

Even if a D/deaf person has an interpreter, interviewees said they may also need an advocate. An interpreter can translate word for word what is being said in a meeting, but they cannot speak on behalf of the D/deaf person, discuss their options or check that they have understood what has been said.

“Deaf people might need an advocate for hospital appointments, education or social care meetings. They can book an interpreter who will translate word for word but they cannot go off the subject. But some deaf people find it hard to ask questions or to explain how they feel. An advocate would meet with them beforehand to talk about their options, agree what they want to say and in the meeting may speak on their behalf. An interpreter might not be involved e.g. if it is an appeal on benefits it might take place at their home and the advocate will help explain their options. They have more clout than a support worker or interpreter. An advocate may interrupt and explain if they think the deaf person has not understood”. (Local organisation 2)

“Legal situations are difficult. They are not dealt with by [local organisation] but they would refer them to a solicitor and tell them to get an interpreter. But I disagree with this. People have a right to a non legal advocate”. (Local organisation 3)

The closure of the Our Voice organisation was felt to have left a gap in services for BSL users. Our Voice provided advocacy specifically to this group. But they also provided more general support on a range of issues and it was felt that this lack of support to help D/deaf people to access hearing services had left a gap in provision.

“It was a very blurred line between advocacy and what used to be called old fashioned social work. Like a social support network. For example literacy is very poor amongst profoundly deaf BSL users and advocates would turn up to deal with an advocacy issue and find unopened bills and important correspondence because English is their second language. So Our Voice operated a very open ended service and they would turn up for one problem and see lots of other problems.....Deaf people have poor health as they do not go to the doctors. Our Voice would go to appointments with people but [local organisation] will not. Our Voice was more than advocacy but was about allowing deaf people to access hearing services. And as the state has withdrawn other social support, there is no one to make that bridge for people”. (Local organisation 3)

One of the reasons that Our Voice did not have its funding continued was because the unit costs of the service were considered to be relatively high. The unit costs for general advocacy are around £30-35 an hour, but Our Voice’s unit costs were about £60-70 an hour. The higher cost was partly because Our Voice advocates spent more time with each client, but also because the advocates were paid more than general advocates as they were qualified to BSL interpreter level and were acting as both advocate and interpreter. A

conventional general advocacy service would have to pay the additional hourly cost for an interpreter to enable a D/deaf person to use the service.

D/deaf people may now seek advocacy support from a general advocacy service but be referred to other professionals, e.g. a solicitor, for certain issues. But interviewees argued that this is problematic for D/deaf people as they may be too daunted to make an appointment with a solicitor, will need to organise an interpreter, and may also benefit from a non-legal advocate, but there is no longer a service that can provide this support.

“There is a policing of what is advocacy and what is not. Our Voice was very open. We would go to court and do DLA appeals. Voiceability will not. They will say that there are professionals who are skilled in dealing with these things and refer deaf people to them and tell them to get an interpreter. But this is a barrier for deaf people. And who will provide the interpreter? This is even if as a deaf person you have the courage to go to a solicitor”. (Local organisation 3)

Existing organisations such as CDA, which provides support to D/deaf people mainly on housing issues, refer people they would have previously referred to Our Voice to Voiceability. Voiceability is a service which provides advocacy across Cambridgeshire. However, some interviewees said that D/deaf people did not feel happy being referred to a service that was not part of D/deaf culture e.g. staff members do not sign. It was felt that there is now no advocacy service to refer D/deaf people to which understands D/deaf culture.

“If there is a need for advocacy then we refer to somewhere where they can get professional help. But there is a lack of advocates for the deaf and we are struggling.....Those we would have referred to Our Voice we now refer to Voiceability. But most clients say they don't want to go there as they can't do the job Our Voice used to.....Sometimes I deal with it myself rather than refer as it is easier even though I shouldn't. I had a lady who needed to go to a tribunal but she wanted me to go with her instead of someone from Voiceability as she felt they don't understand deaf people's needs. She felt more confident with me. They don't know the culture. Our Voice could sign one to one. If a BSL user goes to Voiceability then they have to get an interpreter which makes it more difficult.....We need someone like Our Voice which deals with people with hearing loss specifically, uses BSL and does the type of work they used to do. No one fills this gap”. (Local organisation 2)

“But also the deaf community has barriers internally with engaging with external organisations and Our Voice was considered an internal organisation with deaf staff and part of the community. But Voiceability is not”. (Local organisation 3)

Interviewees felt that there was a need for awareness raising and campaigning around the need to enable access for D/deaf people to hearing services:

“There are campaigning issues to raise awareness both in and outside the deaf community. You need champions to argue about access and interpreters. Really you need funding for an advocacy service for BSL users but there isn't any. It is not an

issue of not enough interpreters but it is the cost that is the barrier". (Local organisation 3)

There is the possibility of development of a new local cross-county advocacy service for the D/deaf and visually impaired.

"It is difficult. It works better in other counties. For example Suffolk has a private organisation which provides advocates for deaf people. For children it is paid by children's services but for adults out of personal budgets. Advocacy is quite new. Cambridge is heading there but it will take time. Other professionals see how it works in other counties. An advocate needs knowledge of the deaf community. They can't be a general advocate. It is a completely different community. There is a gap for specific deaf advocates. We have just started enabled support services across Suffolk, Cambridgeshire and Norfolk to develop advocacy services for the deaf and visually impaired. So hopefully things will change. We can prove it gets amazing outcomes with an advocate on board. It enables independence. But we need to get people familiar with how the new funding works. Things have changed. It used to be provided by a charity but now it is not. But we are hoping to develop a new style of service across Cambridgeshire". (Local organisation 2)

There may also be change and improvement over time as the younger generation of D/deaf people have more independence and are more used to accessing hearing services.

"There have been shifts in the BSL community with the younger generation. The BSL community will always be there. But the ways in which hearing loss is dealt with have changed. Our client base was over 40. Younger people have access to cochlear implants so there is a change in complexion and some will find it easier to access classic advocacy and hearing services. There is this one tranche that were neglected from birth and discriminated against. But I hope that the younger generation will be different and will engage more with services". (Local organisation 3)

## **4) Conclusions and recommendations**

### **4.1 Older people in rural isolated areas**

If it is not diagnosed and well managed, hearing loss in older age can cause social isolation and deterioration in quality of life. But older people living in rural areas are more likely to suffer from social isolation where they cannot drive, have few family/friends locally to provide transport and where public transport is poor. Being housebound further worsens isolation. Access to important services can be limited as a result, such as health services, but simply not seeing many people for social interaction can be detrimental to quality of life. This can compound the problems of isolation associated with hearing loss.

The first step is encouraging older people to seek help to manage hearing loss. Health professionals must recognise it as an issue that needs addressing. Services need to know about the people who need help, this can be difficult if they are isolated so there needs to be a system of referrals to appropriate help and support services. Both professionals working with older people and older people themselves need knowledge about available services so that they know where to go for help e.g. to know about CAMTAD and local hearing support groups.

There are a lot of organisations that engage with older people in rural areas e.g. mobile wardens, volunteers running coffee mornings. There is a need for these people who go out to rural communities to be aware of hearing loss, of what can be done to manage it, and what help is out there. Older people in rural areas need as many contact points as possible and all those working with older people should have a basic understanding of hearing aids and batteries, or where to get help with these issues. CAMTAD clearly plays an important role in raising awareness of hearing loss and how to manage it and could focus on the organisations that work with older people in rural areas.

### **4.2 Older people in care homes**

The experience of hearing loss management in care homes is a mixed picture. There are homes where staff are trained and/or have support from CAMTAD volunteers. But care homes, particularly given high staff turnover, can struggle to maintain staff training. Care home staff work in a pressurised environment and have to manage priorities. People have mixed views on the need to manage hearing loss for people who have dementia or who have previously managed without hearing aids.

A national report<sup>3</sup> (Echalier, 2012) argued that if care home residents' hearing loss is managed effectively, there is a real chance of improving their quality of life. The report made a series of recommendations on what care homes should do to support residents with hearing loss and are campaigning for the Care Quality Commission to introduce these standards into the care home environment (Echalier, 2012). These echo the research

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<sup>3</sup> <http://www.actiononhearingloss.org.uk/supporting-you/policy-research-and-influencing/research/a-world-of-silence.aspx>

findings from this project on what would best support people with hearing loss in care homes. They are presented below:

### *Diagnosis of hearing loss*

Staff should:

- Know how to recognise signs that someone has a hearing loss.
- Understand what they should do if person's behaviour suggests that they may have a hearing loss.
- Recognise that hearing loss can be a gradual process and be prepared to engage with people who use services over a long period of time.

### *Recording and communicating hearing loss*

Care homes should ensure that:

- There are clear procedures around assessment and recording of hearing loss, and staff follow these.
- Hearing loss is clearly documented, for instance, within the care record.

### *Hearing aids and wax management*

Staff should:

- Check and record every day that hearing aids are working and that people are wearing them correctly.
- Know how to use the t-switch and controls on hearing aids, how to change batteries and how to clean hearing aids.
- Ensure there are adequate arrangements for hearing aid re-tubing, repairs and battery replacement.
- Ensure there are arrangements in place to minimise the number of lost hearing aids, and to ensure that lost hearing aids are replaced as quickly as possible.
- Understand that other long term conditions may have an impact on hearing aid use, for instance, people with dementia may forget that they have hearing aids.
- Know who to consult (for example a GP or nurse) to examine ears for wax and to arrange ear syringing, where appropriate.

### *Buildings*

Care homes should ensure that:

- Induction loop systems are installed in the TV rooms, in communal rooms and in reception areas.
- Telephones used are fitted with induction loops or are specially designed for people with hearing loss.
- Clear procedures are in place to ensure that all induction loops are checked and maintained on a regular basis.

- There is good lighting in all areas.
- There are reserved quiet areas, without televisions, where residents can go to hold conversations.
- Procedures are in place to minimise the amount of background noise, for instance, table cloths are used to dampen the sound of cutlery at mealtimes.

### *Communication*

Care homes should ensure that:

- Staff are aware of communication techniques for people with hearing loss and use these.
- Staff have attended deaf awareness training.
- Staff and managers take steps to stimulate conversation among people who live in the care home.
- Communication support, such as a sign language interpreter, is available to people who would benefit from this.
- Staff understand how people can use assistive technology, such as TV listeners, in order to manage their hearing loss.

### *Information*

Care homes should ensure that:

- Care home staff should ensure that people are able to access audiology departments, when appropriate.
- Care homes should be aware of services that are available and facilitate people's use of these services, where appropriate.
- Care homes should access and make available external sources of information to people who live in the care home and their families.

## **4.3 Advocacy services**

A key issue raised during the interviews was the need for interpreters, but who takes responsibility for paying for an interpreter is a problem. Interviewees said that service providers often do not want to pay for interpreters. There needs to be recognition that some D/deaf people in certain circumstances may need both an interpreter and an advocate. In some cases they may need two interpreters, for example, in very long social services meetings or court cases, as interpreters can only work continuously for so long before another interpreter would need to take over.

The loss of Our Voice has left a gap in local service provision for BSL users. This organisation provided general support in addition to advocacy and was considered to be knowledgeable of, even part of, D/deaf culture in a way other generic advocacy organisations are not. There is no evidence about the number of D/deaf people in need of advocacy support so the scale of the possible support need is difficult to define.

In an ideal world there would be a dedicated organisation for people who are D/deaf, particularly BSL users, providing advocacy and more general support. There would be clear guidelines on who has responsibility for the provision of interpreters and their payment. However, the possibility of the development of a new local advocacy service for the D/deaf and visually impaired based on best practice in other counties is a promising development.

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