

**Cambridge** Centre  
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**Scoping study on service use by  
the Cambridgeshire D/deaf  
communities**

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# Scoping study on service use by the Cambridgeshire D/deaf communities

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# 1) Introduction

This study aimed to begin to explore the use of different services in Cambridgeshire by people who are D/deaf.

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). It was a scoping study with a view to expanding the research in the future.

The report has two main sections. The first contains the findings from a literature review which then informed the scoping research. The second section draws 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.

## 1.1 Aims and objectives

The aims and objectives of the scoping study were to:

- Review literature and existing evidence on D/deaf user experience of using services in Cambridgeshire.
- Through primary research to understand current D/deaf user experience of existing services in Cambridgeshire.
- Through primary research to understand service provider awareness of the needs and experiences of D/deaf people.
- Explore perceptions of what further services could be useful or could be accessed to support different parts of the D/deaf communities and to understand barriers to access in Cambridgeshire.
- Test out methodological approaches to research the above questions on a larger scale.

## 1.2 Methods

The study began with a review of existing literature to see what research had already been conducted about service use amongst people with hearing loss, with a particular focus on Cambridgeshire. The findings from the literature informed the scoping exercises for the qualitative research i.e. who to speak to, what questions to ask and how best to contact/communicate with them.

Interviews were conducted with service providers e.g. GP, hospital audiologist, and people with hearing loss. Some interviews were individual face to face whilst others took place within a group setting e.g. at a CAMTAD drop in centre and a deaf club. This enabled the testing of different methods to explore the views of service users. Contacts and introductions were provided through the Cambridgeshire Deaf Partnership.

## 2) Findings from the literature review

### 2.1 Defining the D/deaf community

The group of people encompassed under the term D/deaf are very diverse, their experiences of the world and their identities are very different and each has a different relationship with 'not hearing' and a different understanding of what it is to 'be deaf' (Young and Hunt, 2011).

The experience of deafness will be very different for an older person who experiences hearing loss in later life, for a Deaf person who grows up in a Deaf household and communicates from a young age in sign language, and someone who uses the spoken language supported by hearing aids and lip reading. Some people may identify as Deaf and pride themselves on their Deaf heritage and value the culture into which they were born (Padden and Humphries 1988). Others will not consider themselves to have an identity or culture based around deafness.

The Deaf Community are a self-defining group. There may be many ways to become identified as a member but signing as the main language is the most significant one. Other groups with hearing loss are much more fluid as self-defining is less clear. Some people with hearing loss get a hearing aid, but there are many deaf people who never get hearing aids. There are lots of people with hearing aids who might call themselves 'hearing impaired' but who don't identify with others in the same position and hide their aids to avoid being identified. Then groups that form for limited periods or purposes such as lip-reading classes, CAMTAD volunteers, or the Cambridge Hard of Hearing club. The lack of groups and group identity may disadvantage people such as deaf/hearing impaired people who would like to join a social group aimed at people with hearing loss e.g. to attend films with subtitles, but who can't find companions because they are reluctant to be identified as deaf. But for many people with hearing loss it is not a defining part of their self or group identity.

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' (Young and Hunt, 2011). 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 (ibid).

The Department of Health uses the term 'hearing loss' to cover the whole spectrum of Deaf/deaf hearing impaired people in its proposed Long Term Conditions strategy. There are some objections to this because the Deaf Community have not 'lost' hearing, but for practical purposes the use of one term has been decided upon for use by the Department.

Deafness in any degree is not a medical condition or disability but the consequence of a physical or medical condition. The categories from mild to profound loss are used for the purposes of 'medical' interventions (including audiology) but people do not view themselves as disabled in relation to the severity of their hearing loss. For example, someone may have moderate to severe loss (40%) but they may be less disabled than many because their hearing aids work well and they are not disabled in any other way. This is because the disability is not deafness but barriers to communication.

There is an interesting literature about how the hearing community should treat deafness. Research in linguistics and social anthropology likens users of sign language to hearing people for whom English is not a first language (Ladd, 2003). In the light of this literature,

which is also a literature of protest and political activism, there is an argument for differentiating between people experiencing hearing loss in old age and those either born without hearing or losing their hearing when young.

There are therefore different ways of understanding and conceptualising deafness, which are over-lapping and contested, such as the medical, cultural and social models of deafness. The medical model focuses on deafness as impairment and a deviation from normal functioning where deafness is something to be remedied; the goal being to restore hearing in such a way as to enable the individual to function in as unimpaired manner as possible (Young and Hunt, 2011). In the cultural model deafness is not perceived as a loss, but a distinct identity, with specific (sign) languages and cultural ways of being that accompany it; for example, norms of behaviour, cultural perspectives, conventions and shared histories (ibid). In the social model of deafness, attention turns to the ways in which society disables those who are deaf, where the roots of disability do not lie in impairment per se, but/and in the ways in which the social context fails to adapt to enable the participation of its citizens (ibid).

## 2.2 Scale of hearing loss

The scale of hearing loss currently contains various estimates which are not very satisfactory.

It is difficult to produce an accurate estimate of the size and scale of deaf communities in either the UK or Cambridgeshire. This is because while statistically we know that a certain proportion of people will develop hearing loss as they get older, in practice many people do not register as deaf with social services (which is the only form of registration available) because there are no particular advantages in doing so – most benefits are available without registering. Also people have difficulty defining themselves as being in need of services. Getting a hearing aid is a defining moment for most people with acquired hearing loss. Nevertheless people consistently underestimate the degree of disability that hearing loss can impose on them.

The table below has been compiled by the Department of Health Audiology Advisory Committee from a range of different sources.

**Table 1: Estimated population with hearing loss in England**

	<b>Mild</b>	<b>Moderate</b>	<b>Severe</b>	<b>Profound</b>	<b>Total</b>	<b>Data quality</b>
Adults <sup>a,b</sup>	5,804,578	2,735,013	1,847,909	388,082	10,775,582	High
Children (0-19) <sup>c</sup>	n/a	11,160	4,216	4,712	20,088	Moderate
Of which: Children (0-5) <sup>d</sup>	n/a	1,599	888	1,066	3,553	High

Sources:

a: Davis et al (2007)

b: Davis (1995)

c: BMJ (2001)

d: Newborn Hearing Screening Programme website (3/10/2011)

On the basis of the totals in Table 1, the proportion of adults in England who have hearing loss or no hearing is around 27% and the proportion of children aged 0-5 with hearing loss or no hearing is just under 1%. The proportion of those aged 0-19 is less than 2% but this is the least robust figure. These estimates are based on the 2011 Census table PO2 usual resident population by single year of age and sex. If these proportions are considered at least indicative, this means that in Cambridgeshire the numbers of people with hearing loss can be estimated as follows:

**Table 2: Estimated population with hearing loss in Cambridgeshire**

Group affected by hearing loss	Numbers
Adults 25+	113,825
Children 0-24	285
Children 0-4	33

Source: Table 1 and 2011 Census of Population

The Cambridgeshire Joint Strategic Needs Assessment has produced estimates of the number of adults with hearing loss in the county, now and also in the future using POPPI data. Table 3 shows the results, by age group.

**Table 3: Predicted numbers with a moderate or severe hearing impairment by age group (18+ years), Cambridgeshire 2012-2030**

Year	Age group (years)								Total
	18-24	25-34	35-44	45-54	55-64	65-74	75-84	85+	
2012	86	335	1,240	4,927	8,227	11,151	21,325	12,479	59,770
2013	86	341	1,215	5,003	8,196	11,636	21,819	12,988	61,283
2014	85	346	1,196	5,082	8,233	12,086	22,439	13,498	62,946
2015	84	348	1,188	5,143	8,318	12,397	22,935	13,922	64,335
2016	83	352	1,170	5,186	8,478	12,736	23,307	14,602	65,915
2020	80	359	1,166	5,080	9,355	13,145	27,217	16,895	73,297
2025	79	351	1,264	4,753	10,304	13,245	33,731	20,971	84,698
2030	88	340	1,316	4,802	10,179	14,999	35,976	26,830	94,530

Sources: Projecting Adults Needs and Service Information (PANSI), Projecting Older People Population Information (POPPI), Institute of Public Care  
Based on national prevalence estimates applied to mid-2010 based ONS population projections  
Replicates Table 5.14 in Cambridgeshire Joint Strategic Needs Assessment 2012.

Regarding the number of children known to sensory impairment services in Cambridgeshire, 138 have been identified in schools across the county; 16 with visual impairment as well. This totals 154, which is only 0.1% of the population aged 19 and under (JSNA 2013).

The estimated number of adults with hearing impairment was 61,283 in 2011 which is almost 10% of the adult population (JSNA 2013). This seems low compared with national estimates. For example, Action on Hearing Loss gives an estimate of all adults in the UK with hearing loss as 10,111,500 which is 16% of the adult population (Action on Hearing Loss website accessed 18/10/2012).

Action on Hearing Loss (formerly the Royal National Institute for the Deaf) provides a factsheet on statistics dated July 2011 which is slightly more up to date. Yet the headline

figure remains 'more than 10 million people in the UK have some form of hearing loss', or one in six people.

**Table 4: Adult population with hearing loss in the UK and England**

	<b>Working age</b>	<b>Retirement age</b>	<b>Total</b>
UK			
All hearing loss	3,721,00	6,390,500	10,111,500
Severe/profound	135,500	685,000	820,500
England			
All	3,106,000	5,344,500	8,450,500
Severe	122,000	575,500	697,500

Source: Action on Hearing Loss, website accessed 18/10/2012

However, the population is ageing (i.e. living longer) so that it is estimated that 14.5 million people will have hearing loss by 2031.

In terms of childhood deafness, Action on Hearing Loss estimates that there are more than 45,000 deaf children in the UK, plus more suffering from temporary deafness from conditions such as glue ear. About half of all deaf children are born deaf while the rest acquire deafness during childhood (ibid). Since the MMR vaccine was introduced, fewer babies are born deaf from German measles (rubella) during pregnancy but this fall has been offset by more babies born deaf from other causes such as premature birth and lack of oxygen during birth. More babies now survive with multiple disabilities (ibid).

The Department of Health defines people as 'deafblind' if their 'combined sight and hearing impairment causes difficulties with communication, access to information and mobility.' It is estimated that 356,000 people have combined visual and hearing loss in the UK (Sense). Nearly two thirds are aged 70 or over. By 2030 the number of deafblind people is expected to increase by 60%, with the largest increase among older age groups (Robertson and Emerson, 2010).

### **2.3 Health and social care**

There have been several national, regional and local surveys exploring deaf people's experience of basic health services, such as making appointments with a GP or hospital, understanding diagnoses and treatment, and generally being treated with respect. The review of existing literature about deaf people's access to and use of health care services suggest that there are health inequalities as compared to the hearing population. Deaf people do not experience the same health as the hearing population and do not have the same access to health services.

In 2003 the University of Manchester carried out a project on 'Access to health services for deaf people' in which they interviewed 98 profoundly Deaf people across North West England. Half were men, half women, and their ages ranged from 18 and 76. All had no effective hearing and relied mainly on sign language for communication. They were interviewed in sign language by a researcher who is Deaf.

The findings indicate problems in accessing and using health services. 40% had difficulty making appointments with their GP and most had to go in person or ask someone to

telephone on their behalf. Three people accessed their surgery using a textphone<sup>1</sup>. Four other practices had a textphone but it was seldom switched on. Fourteen people made contact using TypeTalk<sup>2</sup>. Nearly two thirds said it was very important for them to have someone to help them communicate with their GP, yet more than half were alone at their last appointment. Just 17 had a professional sign interpreter.

Three receptionists could communicate in sign language. 20% had problems knowing when it was their turn to see the GP, usually because they missed their name being called out. Only 20% of surgeries had a visual patient call system (e.g. electronic name display). One GP had a qualification in BSL and communicated in sign language. The presence of professional communication support made a big difference to the success of the consultation. Nearly 90% of those with sign interpreters asked all the questions they wanted, gained a better understanding of their illness and fully understood the treatment prescribed. In contrast, more than half those who saw their GP alone felt unable to ask all the questions they wanted, 20% gained no greater understanding of their illness, and left without knowing fully what to do next. The experience of those attending with a family member was only slightly better, because family members are often selective about what information they pass on.

Around a third felt that the GP had not tried their best to communicate. In addition, lone Deaf people were twice as likely to get less than five minutes with their GP and twice as likely to say they hadn't enough time (as Deaf people with family or interpreter). Most GPs did make an effort to communicate and Deaf people praised doctors who followed basic precepts of Deaf Awareness. In addition, 40% complained or had felt like complaining about something that happened during a visit to the GP in the last year. This is four times higher than the general population (National Survey of NHS Patients, General Practice 1998). Most of the complaints were about poor communication or staff attitudes. A quarter of all Deaf people had worried about a medicine prescribed for them. Many thought they had been given the wrong medicine or were worried about side effects. Two people had been seriously ill after drinking an external medicine.

In over 80% of communications with lone Deaf people GPs used writing to communicate. Yet many patients still did not understand their GP. Either they could not decipher the handwriting, or the medical terms used were unfamiliar to them. GPs may not realise that due to a lack of exposure, many Deaf people have difficulty reading and a limited vocabulary of medical terms.

As part of the study, practice managers at 31 practices in the North West were interviewed about their provision for Deaf patients. Four practices had evaluated their services for Deaf patients. Only one had a textphone, but this was not always switched on. All had a fax machine, which was made available to patients in 81% of practices. About a quarter had a visual patient call system. Five claimed to allow more time for consultations with Deaf patients. Three (10%) said they could arrange interpreters, but only one had ever done so. The other two had not told Deaf patients about the service and could not say who was responsible for paying for it. Four practices had staff with a BSL qualification. Staff at seven practices had Deaf Awareness training, but doctors and nurses took part at only two. One had introduced annual training in basic signing for all staff.

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<sup>1</sup> A textphone, sometimes called a minicom, plugs into a standard telephone socket and has a keyboard and a display that allows the user to type and read conversations.

<sup>2</sup> The relay service initially delivered by the RNID (now Action for Hearing Loss), TypeTalk, is now run by BT and was renamed Text Relay in 2009. It uses a third party operator to relay voice and text communication.



The study produced an estimate of the costs of improving access to GPs for Deaf patients. This showed that to implement the package – combined text and phone, visual patient call system, Deaf Awareness Training for staff and hire of sign interpreters – would cost £73,000 in the first year and £46,000 in subsequent years for a medium-sized PCT of 30 practices.

There is an excellent archived blog site, Deaf Health Talk, dated 2009, where deaf people have been describing their experiences with the Health Services. Some are good, some are bad and some are very bad. <http://www.deafhealthtalk.org.uk/>. Overall, they suggest that nothing much had changed in 2009 since the Manchester study in 2003.

Sign Health, the healthcare charity for deaf people, produced a report in 2009 following the publication of the GP Patient Survey 2009 *Why Are You Still Missing Me?* On the basis of analysis of the survey, they conclude that deaf people experience huge health inequalities. Deaf people do not experience the same health as the hearing population, do not live the same lifestyles and do not have the same access to health services. It is now well known that occupation is linked to health. Among Deaf respondents, only 30% were in paid employment, compared to 50% of the general population. 20% of Deaf respondents were 'sick or disabled' compared to 6% of the general population. The findings confirm the results of the 2008 GP Patient Survey and show no improvement in Deaf people's life chances. Sign Health argues that Deaf people are dying earlier than they should, from preventable conditions.

In late 2011 the Cambridgeshire Deaf Partnership was established to give local D/deaf service providers a forum for discussing their work and exploring the potential for closer partnership working. The group in 2011 comprised of Cambridgeshire Deaf Association (CDA), Cambridge Campaign for Tackling Acquired Deafness (CAMTAD), Cam Sight (comprising the Supporting Deaf People Project (SDPP)), Our Voice (OV) and representatives from Cambridgeshire County Council (CCC). The first piece of work that the group commissioned was a mapping exercise of all services provided to D/deaf people in Cambridgeshire. The aim of this exercise was to produce a snapshot of the services available to D/deaf people across all age ranges, from all providers and demonstrating the range of funding available.

The research found that audiology services are comprehensively covered across all age ranges by both Addenbrookes and Hinchingbrooke Hospitals (Cambridgeshire Deaf Partnership, 2012). CAMTAD's "Hearing Help" sessions and home visits provide support with hearing aid maintenance to around 2500-3500 individuals per year, predominantly in the 50+ age range. Specsavers, with these NHS hospital audiology services and CAMTAD, have formed a partnership called the Cambridgeshire Adult Hearing Service which has brought together public, private and voluntary sector organisations to allow easy access to services across a wide geographical area, aimed at people aged 50 and above who have non-complex hearing impairments. The Emmeline Centre is a nationwide centre of excellence in hearing implants, and Cambridge has one of four nationwide outreach teams for NDCAMHS based here. The Hearing Support team also plays a key role in the monitoring of speech and language development in young children. During the course of the interviews for this project no participants expressed any concern about gaps in the services aimed at addressing the medical/audiology provision for D/deafness and hearing loss (ibid).

However, there were concerns about whether there is enough capacity within D/deaf specific mental health services in the area to cope with the demand for provision of various therapies, especially counselling and psychotherapy (Cambridgeshire Deaf Partnership, 2012). In addition concerns were raised about the general lack of deaf awareness of GPs and their resultant inexperience with diagnosis of mental health problems in D/deaf people; this is problematic because GPs now hold the purse strings for the funding of any necessary interventions. Several people mentioned the need for more support for adults who are newly

diagnosed, helping them and their families to adjust to their hearing loss, to using hearing aids and supporting them with the emotional issues that they and their families may experience (Cambridgeshire Deaf Partnership, 2012). A gap was identified in support services for D/deaf people who are leaving inpatient care for mental health problems and in obtaining safety equipment for hearing households where an older D/deaf child lives.

## 2.4 Education services

Every year approximately 840 children in the UK are born with moderate to profound deafness ([www.rnid.org.uk](http://www.rnid.org.uk)). Deafness has serious consequences for literacy, educational achievement, socio-emotional development, and ultimately employment (Mason et al, 2010). School provision in the UK depends on the local authority and appears to vary enormously (ibid).

Evidence shows that a lack of support for deaf children has an effect on their educational attainment (Action on Hearing Loss, 2011). In 2009 in England, 71% of deaf children failed to achieve the government benchmark of five GCSEs at grades A\* to C, including English and Maths (ibid). They were 43% less likely to achieve this mark compared to all children.

Over 90% of deaf children are born to hearing parents with no experience of sign language, so they cannot provide input to their babies in terms of communication. Despite this, most deaf children go on to become fluent sign language users. However, for some deaf children, their first contact with sign language will be when they go to school aged 4, so that their language development is already delayed. Teachers therefore spend resources in bringing these children up to the level they should have been when starting school, but they therefore miss out on the rest of the curriculum and so it is difficult to catch up (Mason et al, 2010).

There is a large literature on measuring the educational attainments of deaf children. Much of the evidence suggests that deaf children of deaf parents, who learn sign language from native users, do better in cognitive and literacy tests than those born of hearing parents (see for example Braden, 1995). However, Gregory (1996) argues that the issue is more complex than it first appears. Is this because the deafness had been genetic rather than from other causes such as meningitis which are likely to be associated with other disabilities? Are deaf parents better at establishing pre-linguistic skills that are essential for later language development? More research is needed to explore these issues.

One reason why it may be more difficult for sign language users to learn English could be that sign language users think differently. An Open University study in 1995 found that while their sample achieved good communication skills in sign language, they were not all developing the complex linguistic structures necessary for higher levels of education. In the past, it was assumed that exposure to sign language was sufficient, and the fact that pupils picked it up so quickly endorsed this view. But in order to develop signing to a higher level, so that pupils have access to complex ideas within the school curriculum, specific methods for teaching sign language may be needed.

*'It is salutary to compare the attention paid to teaching BSL to deaf pupils with the attention paid to teaching English to hearing pupils'* (Gregory, 1996).

Gregory (1996) explains that during the late 1970s, at the same time that sign languages were being recognised nationally and internationally as true languages, dissatisfaction with oralism was growing. Conrad (1979) found deaf pupils left school with median reading ages of 9, poor speech intelligibility and lip reading skills no better than the hearing community despite specific training. These results were confirmed by studies in other countries. The idea that English needed to be taught as soon as possible to (hearing) immigrant children

was also being challenged by research showing that, for children using English and French in Canada, bilingualism was an advantage. Language development was not inhibited (Cummins, 1978). Bilingual education became more mainstream and applied to deaf children as well as those for whom English was a second language.

Bishop et al (1995) found that 38% of their interviewees used BSL as their preferred or only language, so it played a very significant role in their lives. This had implications for the education of deaf pupils. Increasingly, it is recognised as important that deaf children should be taught in BSL, ideally by native signers, but if by skilled non-native signers then native signers should be available to deaf children as part of their learning environment. One study (Young, 1995) looked at introducing deaf adults to families with deaf children but hearing parents in order to facilitate the development of signing. This showed that it is not BSL skills alone that were seen as critical by these deaf tutors, but the overall attitude to deafness and modes of communication (Gregory, 1996).

The Open University study mentioned above (Gregory et al, 1995) found that when teaching deaf signing pupils to develop literacy skills it was easier to focus on writing rather than reading in the first instance. This was because for a deaf child whose first language is BSL, writing allows them to think in their first language and control their use of the second as they choose what to write down. Reading means having to work from the second language, where they have no control over the material and they have to translate back into their first language in order to understand it. Many approaches to reading do recognise this and ensure that a child's first readings are materials they have prepared themselves, through signing and writing.

Nationally there is poor provision of teaching lip reading. For example:

'From surveys of lipreading tutors, desk-based research and Freedom of Information Act requests, we found that in June 2010, there were just 451 classes running in England and Wales with an estimated 4,739 people learning to lipread. Given there are millions of people who could benefit from a lipreading class, this shows that current provision of lipreading classes is extremely poor and too many people are being denied the opportunity to maximise their communication with others.' Source: Paying Lip Service: The State of Lipreading Classes in England and Wales, Action on Hearing Loss  
<http://www.actiononhearingloss.org.uk/search.aspx?qcs=lip%2breading>

The report recommends specifically that lip reading classes should not be classed as a leisure activity but as an 'essential skill' so that there is more funding available for learning providers to run classes at little or no cost to the learner. Lip reading classes are important because they also improve general communication skills, interpreting the context etc. Also some hearing may still be available and lip reading can help.

There is some research that suggests sign language users think differently from those brought up in an oral and written tradition. The Open University study followed a sample of children for one year. Analysis of their written work found that many of the errors related to the structure of BSL, suggesting that this influences writing skills. However, the authors suggested that this could be used positively – the first language, BSL, could be used to discuss and develop the second, English (Gregory, Wells and Smith, 1995).

Department for Education data (2011) show that while some progress has been made, too many deaf children are failing to achieve their potential throughout the educational system. At Key Stage 2 only 45% of children with hearing loss reach the expected level compared to 87% of those with no special educational needs. The difference at Key Stage 4 is 40% compared to 70%. Cuts to specialist educational services for Deaf children across the UK

will threaten this attainment gap further. Because of this gap, historically, many more adults with hearing loss have lower educational achievements and fewer qualifications than the hearing population. This in turn makes it more difficult for them to access the written word (which might be thought to be a substitute for speech communication). It also means that Deaf adults are likely to need support and help to access services that are taken for granted by the hearing population.

## **2.5 Employment**

D/deaf people are employed in a wide variety of jobs in a range of employment sectors. There is evidence of problems in accessing employment. Research conducted in 2007 into the employment experiences of severely and profoundly deaf people, found that at a time of near full employment, deaf people were four times more likely to be unemployed than the general population, with negative attitudes from employers seen as the main barrier to getting a job (RNID, Opportunity Blocked, 2007).

A survey found that 60% of respondents were employed when they lost or began to lose their hearing (Action on Hearing Loss, 2011). Just under half (45%) told their colleagues about their hearing loss, and even fewer (37%) chose to tell their employer. The research also found that 40% found their hearing loss made them less confident in their abilities.

The government's Access to Work programme is designed to assist disabled people to overcome barriers they face in the workplace. It pays all or some of the costs of special aids, adaptations to premises, equipment, and support workers, including communication support. However, the programme is under-funded and poorly publicised and neither employees nor employers are well informed about the scheme (RNID, Opportunity Blocked, 2007).

In the research in it was felt that newly diagnosed adults who are still in the workplace may need particular support at work to help both them and their employers to adjust. Concern was expressed about 18-34 year old Deaf people who rarely access any of the existing services, but who may be experiencing difficulty as they transition into either University, further education or the workplace. Some people expressed the need for advocacy for older young people to help them understand their options for the future and increase their confidence with making their own decisions (Cambridgeshire Deaf Partnership, 2012).

## **2.6 Leisure**

Hearing loss has significant personal and social impacts. 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).

However, there is little specific evidence of D/deaf people's participation in leisure activities or problems in accessing leisure opportunities. A study in Scotland found that there were gaps in the provision of accessible leisure activities for young deaf people within their local communities (NDCS, 2007). Young deaf people are no different from their peers in having a wide range of leisure interests and skills in which to participate in sports and other activities. The report argued that more must be done in terms of improving deaf awareness, and the ability to communicate more effectively with young deaf people in their chosen form of communication, including knowing how to adapt things using equipment and different approaches in activities so that young deaf people can participate fully. For example, one

could use hand signals instead of whistles, and the use of communication gestures during sports.

There are a number of national and local voluntary sector organisations delivering services and support to people with hearing loss (Action on Hearing Loss, 2011). Types of support include information and resources, self-help and support groups, lipreading classes, training in communication strategies, sign language classes and counselling, but some may also provide social and leisure opportunities.

The 2003 Communications Act saw a significant increase in subtitling requirements – both the BBC and Channel 4 subtitle 100% of their content, and many major TV channels subtitle 80% of their output (Action on Hearing Loss, 2011). Access to the cinema has improved since 2004, with the advent of systems that synchronise the projection of subtitles with the corresponding film print (ibid). However, in the UK only around two thirds (65%) of cinemas currently have subtitling equipment and only around 550 screenings of subtitled films are shown each week nationwide (ibid). Increasing the provision of subtitled films and TV would enable a lot more young deaf people to take part in youth culture - seeing films their hearing peers see, watching popular TV programmes, and further enable them to have a common ground with other young people and increase their participating in this area of leisure activities (NDCS, 2007). This is a particular issue with cinemas where there is a very limited choice of films that are subtitled and often much later after the film has already been released. Many theatres have loop and infrared systems installed and some show performances with subtitles and/or BSL interpretation. However, they are limited in number, so there is a restricted choice of performance time (Action on Hearing Loss, 2011).

In Cambridgeshire CDA provides various social activities for the BSL community, the Hard of Hearing Club provides talks and social opportunities for people with acquired deafness (most of its members are older people). There is another similar club in the county. For the very young, Hearing Support has a preschool group for families with small children but it was felt that it is the 18-34 age range that struggle to access opportunities to socialise and meet people who have similar experiences to themselves (Cambridgeshire Deaf Partnership, 2012).

## **2.7 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 elderly Deaf people. Although the Deaf Community can be a support system for 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).

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).

## **2.8 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. 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 Deaf people 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 Deaf person. 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. For optimum health and well being older Deaf people need to be in a signing environment. 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. Without specialist provision older Deaf people's independence is likely to be eroded. There are concerns that in a mainstream residential care environment, the specialist needs of Deaf sign language users are being overlooked in being presumed to be synonymous with 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.

### **3) Conclusions from the literature review**

The scoping review found very little literature or research evidencing problems for people with hearing loss specifically in Cambridgeshire.

The scoping of the literature shows that people who are D/deaf are very diverse, their identities are very different and each has a different understanding of what it is to 'be deaf'. This means that any research into service use amongst D/deaf people will need to be sensitive to these differences. The scoping study research had to consider a wide range of people and interviewed people with hearing loss and those who are Deaf and stakeholders who engage with all types of deafness.

There are no accurate data on the scale of hearing loss in Cambridgeshire, or even nationally. This is because while statistically we know that a certain proportion of people will develop hearing loss as they get older, in practice many people do not seek help and therefore their hearing impairment is not recorded. This raises the issue that when researching D/deaf people's experience of using services we do not know precisely how many people will have similar experiences. This meant that the scoping research was able to get a broad overview of experiences in Cambridgeshire, but unable to attach numbers to the different service users and their experiences.

Although there is no specific evidence for Cambridgeshire, there is evidence nationally that deaf people experience health inequalities. Deaf people experience poorer health as the hearing population, do not live the same lifestyles and do not have the same access to health services. There is evidence of variations in health care provision for D/deaf people. The scoping study aimed to explore access to health and social care in the county.

Some deaf children are failing to achieve their potential throughout the educational system and historically many adults with hearing loss have lower educational achievements and fewer qualifications than the hearing population. Lack of support for deaf children has an effect on their educational attainment and the nature of specific provision for D/deaf children varies. The scoping study used interviews with D/deaf people and stakeholders e.g. service providers to explore this in the county.

D/deaf people are employed in a wide variety of jobs in a range of employment sectors but there is national evidence of problems in accessing employment. Severely and profoundly deaf people are more likely to be unemployed than the general population, with negative attitudes from employers seen as the main barrier to getting a job. Hearing loss has significant personal and social impacts. Barriers to communication caused by hearing loss can lead to isolation and exclusion. 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. However, there is little specific evidence of D/deaf people's participation in leisure activities or problems in accessing leisure opportunities. The majority of people with hearing loss are older and the prevalence increases with age. It can cause frustration, loneliness and depression. Hearing loss may also be accompanied by other health problems associated with ageing, leading to reduced mobility and wellbeing and increased isolation. If care home residents' hearing loss is managed effectively, there is a real chance of improving their quality of life, but this requires their hearing loss to be diagnosed and managed properly. There was no specific evidence about problems accessing employment or leisure opportunities in Cambridgeshire,

or of particular problems facing older people, so this was discussed during interviews in the scoping research.

The next section draws on primary research to discuss evidence from interviews in Cambridgeshire about D/deaf people's use of services.

## **4) Findings from the scoping research**

This section discusses the findings about D/deaf people's service use in Cambridgeshire based on qualitative interviews and written evidence.

The interview participants included:

1. D/deaf people having hearing aid adjustments at a local CAMTAD drop in centre
2. Interview with Cambridgeshire audiologist
3. Interview with Cambridgeshire GP
4. Interview with Cambridgeshire Teens audiologist
5. Interview with local Deaf lady
6. Interviews with members of a Cambridgeshire Deaf club
7. Interviews with people at a Hearing Support Centre

The research also drew on written material provided by the Cambridge D/deaf partnership, discussions with a contact at CAMTAD and a report from CAMTAD volunteers about problems experienced by people with hearing loss in Cambridgeshire care homes.

The findings in this section reflect the views of the interviewees and are based on their personal experience. Further research would be needed to explore the extent to which these experiences are shared by other similar groups. Interviewees were not always clear about whether they were referring to only BSL users or others and the discussion reflects this.

### **4.1 Defining the D/deaf community**

During the interviews participants reiterated the findings from the literature review that there are two main categories of deaf people, those who identify with the hearing community and those who do not. The latter are culturally deaf and use sign language. Their choice of communication is visual. Written English is learned as a second language.

Those who identify with the hearing community mostly suffer from late onset deafness, which is usually a gradual process. Deafened people are those who had a sudden onset of severe or profound deafness. They identify with the hearing community because they learned to communicate through spoken language. They rarely use sign language and may not lip read. Some may learn BSL as a second language.

There is also a third group, infants and babies who are born deaf or become deaf prior to language development. This group is increasing and CMV – Cytomegalovirus – is an emerging cause of infant deafness.

Interviewees felt that the needs of the different communities are completely different.



## 4.2 Scale of hearing loss

According to the audiology department at Addenbrooke's, currently one in six adults are affected by hearing loss, but this varies from slight hearing loss to complete deafness.

## 4.3 Health and social care

The interviews suggested that the health service needs of those who identify with the hearing community are different from those of the BSL community.

### *Hearing community*

In Cambridgeshire, the voluntary service CAMTAD provides drop in centres for people with hearing loss to have their hearing aids checked and adjusted. Those interviewed at the CAMTAD drop in centre were all older people with acquired deafness who were able to rely on a relative for their service use. Because they had experienced gradual hearing loss associated with old age, the digital hearing aids make a huge difference and they said that they can function pretty much as people with good hearing. The oldest clients tended to have other health problems such as sight and mobility.

No-one in this group of interviewees could think of any real problems with getting what they wanted or needed, although the service provided by CAMTAD volunteers where, for example, volunteers clean and service hearing aids, was greatly appreciated as it was so convenient. They said that going to Addenbrooke's every time the aids needed servicing would be much less convenient for them. They had heard about the service either because this was their local GP surgery or through the information provided when they were first fitted with a hearing aid.

Equipment problems were identified during the interviews. Although people interviewed felt that Cambridgeshire is better than in neighbouring counties, they raised concerns about getting the right system installed. Where people get their system installed by the sensory team from the county council, it usually works very well. However, even though sensory services will repair and replace systems, the interviewees felt that in their experience, there is no support when things go wrong. The interviewees said that that for all assistive devices, an expert is needed to help the deaf person get started (rather like learning to use IT) and to trouble shoot later when anything goes wrong.

One interviewee pointed out that one of the biggest problems in ensuring that deaf people can access health services as easily as hearing people is denial. The interviewee said that many people simply avoid difficult situations where they cannot hear and just withdraw. They become very quiet and dislike noise. So getting those with hearing loss back into the 'old' situation can be very hard. Often other people notice someone's deafness because they don't realise themselves – they don't hear the phone so they are not aware or they think something is wrong with the phone.

Interviewees described how accepting a hearing loss, even mild, is like going through the five stages of grief that people have to go through – denial, anger, bargaining, depression and finally acceptance. People can remain at one stage for a long time before moving on. So it can take five or even ten years from the initial loss of hearing to taking action to address it.

## *BSL community*

Much of the scoping evidence on the BSL community supported the findings from the literature review on access to health services. For example, it was stated that 'GPs are a lottery' because while in the experience of interviewees some GPs are very good and appointments can be booked on-line, others are less so. One interviewee explained that GPs should be using a sign-screen but they do not. She said that she hates making an appointment and if she was really ill, she would not be seen as she cannot use a phone and her surgery makes people come first thing in the morning to make appointments in person, there is a queue outside the surgery, so if you are seriously ill you simply cannot go. She thinks that a lot of deaf people die young because they put off seeing a doctor because it is so difficult.

The same interviewee reported that there are also problems once you have an appointment. For example, you constantly need to watch to see when the receptionist bangs on her window to tell you it is your turn. Apparently there is a deaf comedian who goes through these deaf experiences in a very funny way.

A GP interviewed for this scoping exercise drew on experience at two Cambridge practices, one quite small, the other much larger and better resourced. She pointed out that the workload of GP practices has increased enormously in recent years. However, in her experience the surgery often knows the patient so the receptionist will write Hard of Hearing next to the appointment so that the GP will see it. The GP in turn will usually make sure that the patient understands everything in writing. The interviewee said that some patients are so good at lip reading that you would not know they were deaf. A GP will also print out information, as a national database is linked to the practice computer system so the GP can find it and print it out. Even older people generally have some access to a computer, if only via their children or grandchildren. However, only about 20% of people use the web to make appointments. Most practices do not have a visual display, but it is common practice for the GP to come into the waiting room to find the next patient. Patients have a right to an interpreter and GP practices should be able to arrange one, but the GP interviewed had not experienced this.

## *Teenagers*

One issue that has been recognised in the literature and existing research as critical for deaf people is the transition into adulthood. This involves moving from children's services, where the health service is responsible for the patient's care, making appointments and so on, to adult services where the patient takes over all responsibility. Interviewees said that this can be a difficult time for young deaf people. It was reported that the main aim of the transition team is to ensure that people take responsibility for their hearing. The transition clinic covers all teenagers from about 15 to prepare for adult services and it was felt to be beneficial that that both children's and adult services are under the same roof.

People's needs change as they get older, for example when they leave home for university or college or get a job. Interviewees said that the clinic makes them fully aware of all the support services that are available. Transition does not mean that once teenagers reach a certain age, they are unable to access support – it was reported that the team likes to support each individual until they are ready. If they are going to university, they like to complete the transition before they go, whereas if they are looking for a job the clinic will see them into that job first before moving to adult services.

Interviews suggested that this transition from children's services to adult services is taken very seriously in Cambridgeshire and a Hearing Impaired Teenagers Working Group has

been set up. It is made up of professionals from the health sector, local sixth form colleges, charities and local authorities including social services. It runs an annual event, Moving On, for teenagers across the county. Around 50 teenagers attended the last one, but the transition team felt that there is a gap in terms of social facilities for those first entering adult services. This event enables them to meet others of their own age in similar circumstances which hopefully will be supportive in the future.

#### **4.4 Education services**

The Hearing Support Centre is a specialist resource base providing support for deaf children from across South Cambridgeshire. It is based at Mayfield School in Cambridge where there is a qualified Teacher of the Deaf and a team of specialist Hearing Support teaching assistance. The team aims to ensure that all deaf children develop an effective communication system so that they can access information and express their thoughts and feelings. A major focus is on supporting class teachers and specialist teaching assistants so advice is provided on inclusive teaching strategies and resources that enable deaf children to achieve similar levels of educational attainment to their hearing peers. In doing so, they hope to help with the learning needs of hearing children, as innovative teaching strategies such as Visual Phonics by Hand have proved helpful to hearing children as well.

Interviewees reported that deaf children are included in mainstream classes as much as possible. Where their needs are better met outside the classroom, the Hearing Support Centre provides a quiet environment and a base for resources where deaf children can learn and consolidate their progress both individually and as part of a small group. One parent reported that the presence of hearing impaired children enriches the school because from Reception every child learns some sign language and accepts it as a normal part of life. At assemblies and other school events, sign language is used by everyone and all are included.

Nevertheless, despite these aims, interviewees said that it remains the case that deaf children can lack confidence especially in the presence of hearing people. Interviewees did say that things are changing for deaf children. One interviewee said that ten years ago there were lots of signing children but today many of them get cochlear implants and use BSL less and less. The aim is for them to gain speech and function in the hearing world. But research shows that they perform better if they learn BSL first and then learn English as a second language.

One interviewee said that people who are born deaf into a hearing culture tend to lack confidence. One research participant said she had been very shy as a child, until she learned BSL and gained confidence. She also said that those born into a deaf culture don't need to use specialist services because they are confident in their own culture and also when they use an interpreter they are confident in the hearing culture and will be prepared to complain when things go wrong, but without an interpreter they can lack confidence.

The interviews suggested that there are issues with the provision of teaching lip reading in Cambridgeshire. It was reported that there is a bottleneck caused by a lack of teachers and that classes in Cambridgeshire are very oversubscribed. It was also felt that there needs to be better access to classes for young people – classes are mostly held during the day.

It was reported during interviews that BSL classes are being squeezed and only one parent is funded to learn BSL. But one interviewee felt that the whole family needs to learn from professional, skilled signers, not from another learner. The National Deaf Children's Society is campaigning on this issue. Research shows that deaf children born to deaf parents learn BSL much earlier and become more skilled than deaf children born to hearing parents, and

as a result the communication sections of their brains are more highly developed. This not only makes them more confident socially, but provides a better base from which to learn English as a second language. To enable deaf children born to hearing parents to 'catch up' in terms of confidence and socialisation, the whole family needs to learn BSL from a skilled and experienced teacher.

Interviewees felt that the problems associated with service cuts may not be known yet and it is important to take a long term view. For example, there has been research that supports the benefits of music to develop auditory processing. So children who learn to play an instrument not only benefit at the time, but if they develop hearing loss later in life they will be more equipped to cope because they are better at picking out what they need to hear from a range of other sounds. Special needs children benefit too. But there were concerns amongst some interviewees that music is likely to be removed from the school curriculum as it becomes more focused on academic subjects and that music therapy will also be cut. Concerns were raised that the long term impacts of education cuts on deaf people are not yet known but could be far reaching.

#### **4.5 Employment**

The transition team can direct teenagers about to leave school to Access to Work. When they start a job, the communications support that they need should be available and in place if they need it to do the work. The people who run Access to Work do not know what is needed, so the audiologist writes a letter explaining what, why and how, and the teenager then takes the letter to use in an Access to Work application.

Each teenager has an interview with the audiologist where they discuss what type of job they are looking for, what difficulties might be associated with their hearing loss, what kind of equipment could help and the Access to Work scheme and how to apply. It provides evidence of initiative to a prospective employer if the teenager can show that they know what is needed and have already taken steps to arrange it.

Interviewees reported that younger adults tend to have a limited knowledge of the support that is available to them. The Hearing Impaired Teenagers Working Group wants to address this, but said that age group were poor attendees, so the Moving On conference is a way of disseminating knowledge and information. Research participants also said that a lot of young people can be misinformed, partly through pre-conceived ideas among family and friends about what they will and won't be able to do. It was felt important that they understand the law and what they are entitled to. One interviewee said that often the less confident teenagers are surprised to be told that they can achieve whatever they want.

It was reported that call centres and companies that conduct business on the phone, such as insurance companies etc, tend not to be enabling environments for deaf people. There are technologies such as TypeTalk but interviewees said that people find them very difficult to use. They may also find using a third party, as with TypeTalk, problematic, for example when talking to your bank about your finances. The charity Our Voice supported deaf people and picked up some of the advice and support with technology or battling with organisations to help deaf people get what they needed. But this has closed in Cambridge and it is not clear where else to refer people. Addenbrooke's can only direct people to other sources of help such as Citizen's Advice, they cannot help directly, so the loss of Our Voice in Cambridge was felt to be quite serious.

Access to Work was reported to be problematic for some people. One interviewee said that they often have to be persuaded to use the services available, but deaf people are often fearful about finding work and there are barriers to getting the right equipment needed in

order to do the job. Addenbrooke's has some equipment that they can lend it to people on a trial basis, but this is governed by the individual. It was also said that Addenbrooke's can tell the individual what the hospital thinks their needs are in a letter to take to Access to Work, but problems can arise if the Access to Work people persuade them that they need something totally different – and then when the equipment arrives it is in a big box and the individual often has no idea where to start.

Interviewees said that the technology is getting better as it becomes more mainstream. But problems arise with the loop technology, for example because it is not maintained. Places of Worship were mentioned in particular as having loop systems that are not working – interviewees felt that the people running it think it just has to be installed and that is the end of it, but they know nothing about checking it, maintenance etc. High street banks were also reported to be problematic – they say the loop is available at the counter but often it is switched off. So two key areas to improve are:

- Deaf Awareness for the general public, service providers and employers
- Basic communication skills

That is, best practice for both the deaf and the hearing person.

#### **4.6 Leisure**

As noted above, the deaf community in Cambridgeshire falls into two main parts – sign language users and hearing aid users. For BSL speakers, the Cambridgeshire Deaf Association supports active Deaf Clubs in Cambridge, March and Peterborough which hold regular meetings. In addition regular drop-in sessions are held monthly in Cambridge, March and Huntingdon and fortnightly in Peterborough. Those who use hearing aids are far more likely to identify with the hearing community and as a result there is less obvious social activity across the county.

Interviewees who use hearing aids reported considerable success in enjoying concerts, theatre and films provided the loop systems are working properly. One said 'that made a hell of a difference' and also reported that having a hearing aid meant he could hear everyone down at the pub – there had been some embarrassing moments in the past when he had answered the wrong question. Another agreed but pointed out that it just amplifies, it doesn't make it clearer, so it is best in a quiet environment.

There was a clear gap in the scoping exercise's ability to contact young adults with hearing loss. This is likely to mean BSL users or lip-readers, again two potentially different groups with different needs. Both the Deaf Club organiser and the audiologists acknowledged that it is difficult to contact this age group and this is something that is worthy of further investigation.

#### **4.7 Ageing**

Gradual hearing loss as people age is common. Those interviewed agreed that they had been in denial, and only went to their GP when a relative (usually wife) insisted. One said that having a hearing aid had made a big difference immediately as his tinnitus ceased and has never returned. This man had his first hearing aid 10 years ago and got one of the first digital aids because he was part of a research project at the university. The aid was adjusted two years ago as he had lost more hearing.

Another said that it is the high frequency sounds that are lost first, which meant that he genuinely could not hear his wife.

Several of those interviewed were elderly and frail. They had been brought to the CAMTAD drop in session in wheelchairs by members of the family or friends. Nevertheless, one who is also partially sighted said she goes to several clubs: Elderly Action Group, Blind Club and Contact, all of which she enjoys. She relies heavily on talking books which arrive by post.

Those attending the Deaf Club were BSL users. They were mostly retired and drove to the club themselves, often from some distance away. The interpreter explained that many of them had been at boarding school together as children so their friendships go back a long way. This gave them a shared experience and they clearly enjoyed the session, joking and laughing (out loud) a lot.

#### **4.8 Residential and care homes**

CAMTAD volunteers visited a nursing home and a residential home in Cambridge for the third time recently. They reported that they previously had very few customers but there was an increase this time.

At the nursing home the majority of hearing aid users were in convalescence or respite care. The long term residents mostly suffered from some degree of dementia. The volunteers were concerned that although they possessed hearing aids, almost all had difficulties with them and they had to refer several of them back to Addenbrooke's for reassessment, new moulds or replacement hearing aids. There did not seem to be any role for nursing home staff in this respect.

At the residential home, the volunteers reported that it was mostly the case that these rather more alert people either had difficulties with their hearing aids, did not wear them, or seemed to need encouragement to do so. The home also has people coming in for convalescence or respite care and the staff noted that CAMTAD volunteers can help those temporary residents too.

The volunteers felt that there is clearly a service deficiency where there were no check-ups for health issues other than the condition that caused them to be in the home. This suggests that the GP, in-patient hospital staff, or OPD staff do not explore further than the presenting health problem. Communication and treatment could be so much easier if hearing aids were found to be worn, repaired or cleared if blocked. But if the patient does not know about CAMTAD, the research participants felt that there seems to be no-one who will sort things out. The volunteers reported that 'it seems a pity to accept that a percentage of hearing aids are simply not being used to good effect – if they are used at all. Many longer-lived people might find their lives greatly enhanced if they could hear properly and the distress of dementia and confusion could possibly be ameliorated.'

### **5) Conclusions from the scoping research**

The age group that seems least engaged with services is 18-34. However, given the improvements in services for teens and transition from children's to adult services, this may improve in the future.

Older people in care homes are the other group identified as having problems with service provision. There appears to be no line of responsibility for ensuring that hearing aids are

used, never mind in good working order. Often they sit in a drawer unused. This isolates the older person and contributes to a poor quality of life.

GP services are described as 'a post code lottery' in that some GPs seem much more aware of deafness than others. Interviewees suggested that some do not refer people early enough even when they present to their GP, some still make it very difficult for deaf people to make appointments (for example, when they are too ill to come to the surgery) although others have on-line bookings and are able to hire an interpreter for signers or use technology to show whose turn it is to see the doctor. Research is lacking here to find out which practices are 'good' and which are less so.

The drop in services run by CAMTAD are well used and much appreciated. If they were not available, people would have to go to the audiology service and this would increase the unit's case load. People find it more convenient to attend the drop in service. Even so, they often leave it a long time before coming, with wax build up, running out of batteries etc (even though these are available by post).

The views of the research participants suggest that the signing community appears to be in good shape. Drop in clubs are well attended, although there are always more people out there who don't attend – the organisers know this because every month someone new turns up. However, the clubs tend to cater for an older age group – those who are mobile (some attend from out of county) and more gregarious. This may make it harder for new comers to attend and to integrate.

Other facilities, like GP surgeries, can vary. The use of hearing loops was described as wonderful when it works, but often the loops are not switched on, or not well maintained so that when they break down no-one takes the responsibility to replace them.

Adults who suffer hearing loss as they age often take a long time to accept that they need a hearing aid. During this time they can become quite introverted and isolated. Once diagnosed and treated, it takes a few months to adjust. But then normal activities like going to the pub with one's friends become possible again.

Interviews suggest that the transition to adult services is well provisioned at the Addenbrooke's unit. Teenagers remain with children's services until they go to university or get a job. The unit prefers them to have transitioned before they go to university, while those wanting a job are helped through the application process including Access to Work. An annual conference for deaf teenagers is held where they can meet others in a similar position and learn more about the transition and what the future may hold.

In addition to the gaps identified through interviews and discussions, the literature review identified further gaps that are likely to be reflected across Cambridgeshire as well as other parts of England or the UK as a whole. These included inequalities in health, with statistics showing that deaf people die earlier than they should, from preventable conditions.

## 6) Stage 2 of the research

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

- 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 is 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 deaf people
- Inequalities in health
- Inequalities in educational achievement

Most of these gaps are also problematic nationally and there is research evidencing them and recommendations for good practice. However, there was little evidence about advocacy services for 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 will therefore concentrate on these three issues:

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

### 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?

It is likely that these problems will be experienced in particular by older people living in rural areas. CAMTAD is extending their work into rural Fenland. A greater understanding of the problems faced by people in managing their hearing loss and how services can best be provided will be useful to the service.



The research will aim to include interviews with:

- CDA in their role of delivering Supporting People funded services to people with high levels of need across the county
- Volunteers from CAMTAD living in rural areas
- Discussion with two older people's groups in rural areas
- Scheme Manager(s) of sheltered housing scheme/warden(s) in villages covering people living outside sheltered communities
- District nurse working in rural area
- Manager(s) of older people's groups
- COPRG

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

Interviews with stakeholders during the first phase of the research identified older people in care homes as a group having problems with service provision. There appears to be no line of responsibility for ensuring that hearing aids are used or in good working order. Often they sit in a drawer unused. This isolates the older person and contributes to a poor quality of life.

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

The research will aim to include interviews with:

- Volunteers who have been into care homes
- The Hope and/or other care home manager(s)
- Manager(s) of older people's groups
- Carer(s)/relative(s) of people living in care homes

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

In the first phase of the research it was suggested that deaf people may have particular problems in accessing advocacy services and that this may be compounded by the loss of the Our Voice service. The research will explore:

- 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?

The research will aim to include interviews with:

- CDA in their role of delivering Supporting People funded services to people with high levels of need across the county
- CAB
- Age UK
- Voiceability
- People with hearing loss

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