

JOINING

UP

Why people with hearing loss
or deafness would benefit
from an integrated response
to long-term conditions



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Photographs are for illustrative purposes only. The people featured may not have hearing loss or any of the conditions mentioned in this report.

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Executive Summary

Joining up, an Action on Hearing Loss and Deafness Cognition and Language (DCAL) Research Centre report, looks at the issues around providing health and social care services to people who have hearing loss or who are deaf and also have other long-term conditions. There are an estimated 15 million people in the UK with long-term conditions (Department of Health, 2013) – conditions that can be managed but not cured, such as hearing loss, diabetes, asthma, sight loss, cardiovascular disease and dementia.

In the first part of *Joining up* we outline the relationship between long-term conditions, hearing loss and deafness, in particular, the strong link between hearing loss and dementia. We describe what can be done to ensure health and social care services respond effectively to people who have long-term conditions, who also have hearing loss or deafness. We illustrate this in the second part of the report, with an example showing that savings of over £28 million could be achieved by taking account of hearing loss in the care for people with dementia.

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Hearing loss and deafness

Hearing loss is a major public health issue affecting over 10 million people in the UK (Action on Hearing Loss, 2011). There are a number of reasons why people experience hearing loss; however, as we age, hearing loss becomes increasingly common.

By 2031 the number of people experiencing hearing loss or deafness is set to grow to 14.5 million (Action on Hearing Loss, 2011). This includes those who are born deaf or become deaf at an early age. People in this group often use British Sign Language (BSL) and identify themselves as part of a linguistic and cultural minority group known as the Deaf community.

Estimates vary for the number of deaf people who use BSL as their preferred language. According to figures from the 2011 census, sign language is the main language for 22,000 people in England and Wales (ONS, 2011). The IPSOS Mori *GP Patient Survey 2009/10* data gives an estimate of approximately 125,000 people in England who use BSL (NHS England, 2009/10).

Effective communication between a patient and healthcare professional is necessary for the assessment, diagnosis and management of all long-term conditions. People have different degrees of hearing loss and their ability to communicate can fluctuate from day to day and in different situations. Hearing loss or deafness can cause difficulties accessing health services, and can lead to anxiety, stress, depression and isolation.

Dementia

There is strong evidence of a link between hearing loss and dementia. People with mild hearing loss have nearly twice the chance of going on to develop dementia as people without any hearing loss. The risk increases to threefold for those with moderate hearing loss and fivefold for those with severe hearing loss (Lin, FR et al., 2011).

If dementia services were made responsive to the needs of people with hearing loss and deaf people it would enable earlier diagnosis, delay entry into care homes and prevent acute admissions. This is because effective communication and appropriate assessment is required to achieve a timely diagnosis and to keep someone with dementia in the community.

Signers who also have dementia need specialist provision for effective diagnosis and ongoing care. Not providing this can have a terrible impact at an individual level, and it also forces deaf people with dementia into more costly models of care.

At least £28 million per year could be saved in England by properly managing hearing loss in people with dementia

Health services should take a joined-up approach to the assessment, diagnosis and management of dementia for people with hearing loss and deaf people who use BSL. We estimate that at least £28 million per year could be saved in England by properly managing hearing loss in people with dementia, and thus delaying their admission to residential care. This is calculated by offsetting the cost of community-based provision for people with severe dementia against the cost of residential care, which would be avoided.

Other long-term conditions

In many cases long-term conditions are linked to the ageing process. This means that a large proportion of people will have hearing loss, along with one or more other long-term conditions. It is important that services setting out to prevent and manage other long-term conditions are designed with people who have hearing loss, and sign language users, in mind.

There is a need for specialist diagnostic tools, interventions and novel approaches to the delivery of services. In particular, the communication needs of people with hearing loss or deafness will need addressing to ensure that they receive effective care, especially where they also have other conditions that affect communication, such as dementia or impairments following a stroke. In conditions such as diabetes and hypertension, where patients can play a large role in self-managing their conditions, facilitating effective communication with health professionals is particularly important.



Government policy

Health departments across England, Scotland, Wales and Northern Ireland have all introduced plans to improve the management of long-term conditions (Department of Health, 2012, *NHS Outcomes*; Department of Health, 2012, *The mandate*; NHS Scotland, 2009; DHSSPSNI, 2009; Welsh Assembly, 2007). These plans tend to consider long-term conditions in isolation and do not adequately take account of issues relating to hearing loss and deafness. For example, the National Dementia Strategy for England (Department of Health, 2009) does not acknowledge the need to manage hearing loss in people with dementia.

Government plans tend to consider long-term conditions in isolation and do not take account of hearing loss or deafness

Recommendations

We call on health departments, commissioners and providers of health services throughout the UK to recognise hearing loss and deafness in assessing, diagnosing and managing people with other long-term conditions:

Earlier intervention and prevention

- Introduce an adult hearing screening programme for 65 year olds and integrate opportunistic and targeted hearing checks into other services and settings, such as in pharmacies, care homes, during consultations for other conditions, and alongside other health checks at GPs.
- Ensure that information and health promotion campaigns are accessible to people with hearing loss and deaf people who sign.

Managing other long-term conditions in people with hearing loss

- Services for people with dementia, cardiovascular disease, diabetes and sight loss must take into account the needs of people with hearing loss and deaf people.
- Fund research to develop better diagnostic tools, specialist services and guidance to support people with hearing loss and deaf people who also have other long-term conditions; and make sure these are used.

Making cost savings

- Ensure that resources are allocated in a cost-effective way by properly managing hearing loss in people with other long-term conditions. For example, the lack of resource allocated to hearing loss within the National Dementia Strategy for England should be reviewed.

Introduction

Within the fields of health and social care there has been a growing focus on long-term conditions, both their impact on people's quality of life and the challenges to effective management of these conditions. However, there has been a tendency to consider long-term conditions separately, and to overlook the importance of managing hearing loss in people with other long-term conditions.

Long-term conditions are not experienced in isolation. Most long-term conditions, such as diabetes, hearing loss, sight loss, cardiovascular disease and dementia are concentrated in older groups. This means that a large proportion of this population will have a hearing loss and at least one other long-term condition. Of this group, many will not have recognised or addressed their hearing loss, which can make it much more difficult to manage other long-term conditions.

A large proportion of older people will have a hearing loss and at least one other long-term condition

In England, enhancing quality of life for people with long-term conditions is one of the main focuses of the *NHS Outcomes Framework* for 2013/14 (Department of Health, 2012, *NHS Outcomes*) and the *NHS Mandate* for 2013-2015 (Department of Health, 2012, *The mandate*). The Scottish, Welsh and Northern Ireland governments have also all introduced plans to improve the management of long-term conditions (NHS Scotland, 2009; Department of Health, 2012, *The mandate*; Welsh Assembly, 2007). All of these plans emphasise the need for early intervention and diagnosis, a focus on the health and wellbeing of the individual patient, and the need for better integration between services.

Improving earlier intervention and better management are particularly important in respect of hearing loss, which can increase the risk and impact of other long-term conditions. Governments are recognising the importance of hearing loss – the Department of Health is developing a cross-governmental strategy to address issues around hearing loss. However, the need to ensure earlier diagnosis of hearing loss and integrated management of the condition, as well as to take account of hearing loss and deafness when diagnosing and managing other long-term conditions, have not been recognised. For example, the *National Dementia Strategy for England* (Department of Health, 2011) does not acknowledge the need to manage hearing loss in people with dementia.

Although newborn hearing screening and numerous other health checks are on offer across the UK, there is no programme of hearing screening for older people. Such a programme would deliver large benefits in terms of earlier diagnosis and intervention for the millions of people who develop age-related hearing loss. It would allow people to adjust to and manage their hearing loss earlier and more effectively, reducing the risk and impact of other long-term conditions.

Earlier diagnosis and better-integrated management of hearing loss and deafness, alongside other long-term conditions, could improve the quality of life of many people and it could also lead to significant cost savings.



This report from Action on Hearing Loss and the Deafness Cognition and Language (DCAL) Research Centre sets out:

- The evidence of overlap and association between hearing loss and deafness and other long-term conditions.
- How earlier diagnosis and better management of hearing loss, along with greater recognition of hearing loss and deafness in the management of other long-term conditions, would secure improvements in quality of life.
- The cost savings to be gained from properly managing hearing loss in people with other long-term conditions, using dementia as an illustrative example.

Action on Hearing Loss (formerly RNID) is the charity working to create a world where hearing loss doesn't limit or label people, where tinnitus is silenced and where people value their hearing enough to look after it.

DCAL is a research centre based at University College London and funded by the Economic and Social Research Council (ESRC), which brings together leading deaf and hearing researchers in the fields of linguistics, psychology, and neuroscience to study the impact of deafness on cognition and language.

Hearing loss and other long-term conditions

A long-term condition can be managed but not cured. This definition includes conditions such as diabetes, asthma, hearing loss, sight loss, cardiovascular disease and dementia. The Department of Health estimates that there are 15 million people in the UK with long-term conditions (Department of Health, 2013). In many cases these are linked to the ageing process. For example, cardiovascular disease is the most common disease among men aged 65 and over (The Information Centre, 2005), affecting 37% of this group. One in 14 people aged 65 and over has some form of dementia (Alzheimers Society, 2012), and at least one in eight has diabetes (Diabetes UK, 2012). However, these conditions can also affect younger people, particularly where they have not had access to health promotion/prevention messages or resources.

Because of the high prevalence of many long-term conditions in older people, the conditions are often not experienced in isolation. For example, moderate to severe hearing loss will be experienced by almost half (44%) of all people aged 70 or over, many of whom will have one or more other long-term conditions. It is essential that this is taken into account as it has implications for the diagnosis, progression and management of long-term conditions.

This section looks at the research around the prevalence and management of hearing loss and some of the issues around access to health services for people with hearing loss and deaf people who use sign language. It then goes on to review the research into the relationships between hearing loss and a range of other long-term conditions, and considers practical issues around the management of hearing loss alongside other long-term conditions.

Hearing loss

Hearing loss is widespread; it affects 10 million people in the UK while six million people have or could benefit from hearing aids. As our society ages this number is set to grow and, by 2031, there will be more than 14.5 million people with hearing loss in the UK (Action on Hearing Loss, 2011). However, an estimated four million people have unaddressed hearing loss. It takes 10 years on average for people with hearing loss to seek help, and even when they do, 45% of general practitioners (GPs) fail to refer them on (Action on Hearing Loss, 2011).

Age-related damage is the single biggest cause of hearing loss, which means that older people are very likely to experience hearing loss alongside other long-term conditions. Other causes include exposure to loud sounds, drugs that are harmful to the cochlea and/or hearing nerve, some infectious diseases and genetic predisposition (Action on Hearing Loss, 2011).

There are various options for the management of hearing loss. Digital hearing aids are the equipment most commonly and effectively used. These work by amplifying noise and delivering this to the ear canal. Other equipment or interventions include cochlear implants, suitable for people with severe or profound deafness who cannot use hearing aids, and active middle ear implants, which are suited to people who find it difficult to manipulate hearing aids (Sinha et al., 1996). Assistive technology such as FM or infrared

listening equipment is also available – again, this works by amplifying and transmitting sounds. Other assistive devices for daily living include vibrating alarm clocks, flashing doorbells and flashing smoke alarms.



The Deaf community

Those people who identify themselves as part of a linguistic and cultural minority group whose first or preferred language is British Sign Language (BSL) are also known as the Deaf community.

BSL is the ‘mother tongue’ of both deaf and hearing children of BSL-using Deaf parents. It is also used by deaf children and their hearing parents throughout the UK. Estimates for the number of deaf people who use BSL vary, and some will see BSL as their main language while others may use BSL alongside English. According to figures from the 2011 census, sign language is the main language for 22,000 people in England and Wales (Office of National Statistics, 2011). The IPSOS Mori GP Patient Survey 2009/10 data gives an estimate of approximately 125,000 people in England who use BSL (NHS England, 2009/10).

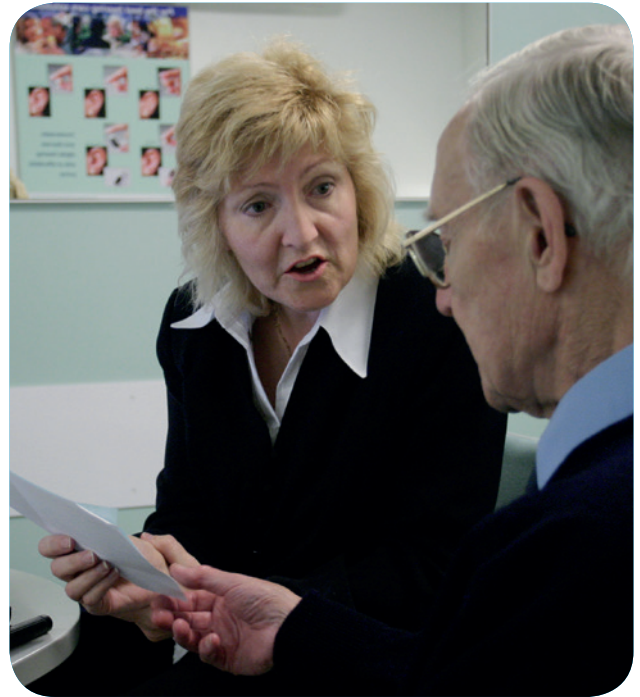
People in the Deaf community use BSL as their preferred language and have different degrees of ability in English. This can create significant barriers when they have to communicate with health and social care professionals who are not BSL users. It also creates issues around the assessment of conditions such as dementia and impairments following stroke. Specialist assessments have been developed by [DCAL](#) for use with these groups.

Research

Where research has focused on one particular group this has tended to be people who use BSL. The remaining research either specifically considers people with age-related hearing loss, or it groups together people with different types of hearing loss. There is a lack of literature that focuses on people who have developed hearing loss in childhood or early adulthood and the issues that they experience. These people are not severely or profoundly deaf at birth, so they are less likely to use sign language, but their hearing loss is not age-related, so they must manage their hearing loss while they are younger and may still be working. The specific issues that this group face should be further recognised and researched.

Access to health services

People with hearing loss and deaf people who use BSL experience greater difficulties in accessing health services and receive a lower standard of healthcare across the board, when compared to the general population. For example, there is evidence that people with hearing loss or who are deaf may avoid going to see their GP because of communication problems. They are more likely to report that they have been left unclear about their condition because of communication problems with a GP or nurse (RNID, 2006; Action on Hearing Loss, 2013). A survey of BSL users also found that 68% had not been provided with a sign language interpreter when they have asked for one, and that 41% have left a health appointment feeling confused about their medical condition because they could not understand (Action on Hearing Loss, 2013).



Research from the United States found that doctors asked fewer questions of deaf than hearing patients (Ralston, Zazove, Gorenflo, 1996). A further study of American Sign Language users found that the use of preventative services, such as receiving a flu vaccination, was higher when patients were provided information in sign language (McKee et al., 2011, *Impact of communication*). These are also likely to be issues in the UK, which may result in BSL users having worse health outcomes because they are not provided with an interpreter. It is vital that services are accessible to signers and people with hearing loss.

Even where patients are able to access health services, hearing loss has a negative impact overall on self-management of long-term conditions. A 13-item patient activation measure, including areas such as a patient's knowledge, skills and confidence to self-manage, was used to assess the factors that influence levels of patient activation. The study found that higher levels of hearing loss were linked to lower levels of patient activation (Gerber et al., 2011).

Better communication and improved access to health services are needed to reduce inequalities in health outcomes and improve the diagnosis and management of long-term conditions for people with hearing loss and deaf people who sign. Novel approaches to delivery of services, such as telemedicine and other service developments, could enable significant cost savings. For example, if improved services resulted in earlier diagnosis or better management, this could lower the rate of hospital admissions and delay entry into residential care.

Dementia

Dementia is caused by structural and chemical changes in the brain that affect cognitive function. Its symptoms include a decline in memory, reasoning and communication skills, as well as a loss of skills needed to carry out activities of daily living. It is widespread, affecting one in 14 people aged over 65 (Knapp et al., 2007).

Given the age profile of people with dementia and people with hearing loss we would expect these conditions to co-occur. However, there are stronger associations between them. There is evidence to show that hearing loss is associated with a decline in cognitive function (Boxtel van et al., 2000; Gates et al., 2002; Lin, 2011). People with mild hearing loss have nearly twice the chance of going on to develop dementia as people with normal hearing, and the risk increases to threefold for those with moderate hearing loss, and fivefold for those with severe hearing loss (Lin et al., 2011). Moreover, it has been reported that the degree of severity of hearing loss and the degree and rate of increase in cognitive dysfunction are related (Lin et al., 2011; Lindenberger and Ghisletta, 2009; Lin et al., 2013). This suggests that age-related hearing loss may be an early marker for the development of dementia (Gates et al., 2011).

There is no consensus as to the nature of the mechanism that links hearing loss and dementia. However, the following have been suggested and, to a limited extent, tested:

1. **Common cause:** a shared pathology whereby both hearing loss and dementia result from age-based changes to the central nervous system (Baltes and Lindenberger, 1997; Lin, 2011)
2. **Additional effort** used to manage everyday interactions in the face of hearing loss depletes cognitive resources (Boxtel van et al., 2000; Boyle et al., 2008; Lin, 2011; Peelle et al., 2011)
3. **Social isolation:** it has been shown that a rich social environment and social connectedness reduce the risk of developing dementia (Fratiglioni, 2000; Lin, 2011; Verghese et al., 2003). One study found a 60% higher risk of developing dementia among people with a limited social network (Fratiglioni et al., 2000). Hearing loss and resulting communication problems may deprive people of stimulation, leading to social isolation which may itself lead to dementia.

Arguments given against the 'common cause' and 'additional effort' theories include the fact that most hearing loss does not appear to be directly related to cognitive function. Pure tone audiometry is considered to be a measure of auditory peripheral function and does not require higher levels of auditory cortical processing (Lin et al., 2011; Sinha, 1996). Pure tone audiometry does not detect problems that affect central auditory function, such as difficulties hearing conversations in noisy environments. In contrast, it is central auditory dysfunction that is thought to be related to dementia (Gates et al., 2008; 2011; Gates et al., 1996; Gates et al., 2010).

There are good theoretical reasons to support the ‘social isolation’ theory. The risk of dementia associated with hearing loss appears to increase only at thresholds greater than 25 decibels (dB), the threshold at which hearing loss begins to impact on verbal communication (Lin et al., 2011). Similarly, it has been noted that those people who wear hearing aids do not demonstrate the same level of decline in cognitive function as those who do not (Lin, 2011). Both of these suggest that it is the impact of hearing loss on communication, rather than a biological process, that leads to increased rates of dementia.

The impact of hearing loss on communication may lead to increased rates of dementia

Further research could provide an essential insight into the links between hearing loss and dementia, something that could improve our understanding of the social and biological mechanisms around both hearing loss and dementia. Nonetheless, the fact that hearing loss can precede the onset of dementia indicates that early intervention (screening and aural rehabilitation) may be extremely important in terms of minimising the risk and impact of dementia. Currently, hearing loss is frequently underdiagnosed (Burkhalter et al., 2009).

Hearing aids can improve quality of life for people with hearing loss, for example, by improving social relationships (Appollonio et al., 1996). They may improve cognitive function (Lin, 2011; Mulrow et al., 1990) or slow down the deterioration in cognitive function (Allen et al., 2003). However, any impact of hearing aids on dementia may be long term and mediated via other factors such as social isolation. Moreover, any measure of the impact of hearing aids would need to take into account the effectiveness of aural rehabilitation (Lin et al., 2011).

Managing hearing loss and dementia

Not only is hearing loss often undiagnosed (Burkhalter et al., 2009), but there is a risk that hearing loss is misdiagnosed as dementia (Boxtel van et al., 2000) or that dementia is underdiagnosed because of hearing loss or deafness. Where both conditions are present, their impact, diagnosis and management can be made worse. For example, where hearing loss or deafness cause communication problems in people with dementia, this can lead to behavioural and psychological problems that could have been avoided. Both hearing loss and dementia need to be addressed early (Alzheimers Disease International website, 2013) and when they are diagnosed and treated they should take into account each other’s challenges. For example, one study found that only 5% of care home residents, many of whom had dementia, were able to complete a full hearing assessment (Burkhalter et al., 2009). Particular approaches to audiological assessments for people with dementia have been outlined, for example, by simplifying instructions and using short sentences (Lemke, 2011). Some audiology departments in the UK have adapted their testing procedures so that they meet the needs of people with dementia.

For deaf people who use BSL, work has focused on the provision of cognitively, linguistically and culturally appropriate services. For this group, communication must be available in BSL. Qualified sign language interpreters must be provided to ensure a proper communication environment. This may be a challenge in some settings, such as care homes. For assessments of language and communication, mediation via an interpreter is not always sufficient. The Alzheimer's Society is currently funding research to design appropriate cognitive assessment tools to diagnose dementia in Deaf people and to build culturally relevant information and support (Atkinson et al., 2011).

In practice, hearing loss, deafness and dementia are often addressed separately. There should be an approach to hearing assessment, systematically taken, that allows for the high levels of co-occurrence of hearing loss and dementia and takes into account the challenges around this. Similarly, it is essential that services address the underdiagnosis of dementia in the presence of hearing loss and deafness. People with hearing loss and deaf signers should be able to access those services that diagnose and help people to manage their dementia as effectively as possible.

Hearing aids
may improve
cognitive function

Later in *Joining up* we set out how, as well as reducing the risk and impact of dementia, the proper diagnosis and management of hearing loss among people with dementia can save money over the long term by delaying the need for admission to residential care and other expensive interventions.

Cardiovascular disease

The term cardiovascular disease refers to heart and circulatory disease, including conditions such as coronary heart disease and stroke (British Heart Foundation, 2013).

Diabetes is a risk factor for cardiovascular disease and obesity is a risk factor for both diabetes and cardiovascular disease. It is difficult to unravel these relationships and any links with hearing loss. Again, as these conditions are associated with the ageing process we would expect them to occur more in people with age-related hearing loss. Research is needed to ascertain whether they run in parallel or there is a causal relationship.

While there is disagreement around the relationship between hearing loss and cardiovascular disease, many studies conclude that an association does exist (Rosenhall and Sundh, 2006). Some propose a strong link between cardiovascular disease and hearing impairment; for example, Torre et al reported that women with a self-reported history of myocardial infarction were twice as likely to have cochlear impairment as women without this history (Torre et al., 2005). It has been suggested that this may be caused by a relationship between hearing loss and the risk factors for cardiovascular disease.

There may be a link between smoking and hearing loss (Agrawal, Platz and Niparko, 2009; Fransen et al., 2008; Helzner et al., 2011; Shargorodsky et al., 2010), perhaps mediated through the socioeconomic or educational factors that make people more likely to become smokers (Fransen et al., 2008). There have been indications of a relationship between obesity and hearing loss; for example, correlations between hearing loss and a high Body Mass Index (BMI) (Fransen et al., 2008; Helzner et al., 2011) or a high waist circumference (Hwan et al., 2009). The relationships between different risk factors and any underlying mechanisms are not clear.

While some studies identify an association between hearing loss and hypertension (Pirodda et al., 1999; Rosenhall and Sundh, 2006) others find no association (Shargorodsky et al., 2010). It may be that the impact of particular factors on hearing loss, such as high blood pressure, is compounded by exposure to noise (Rosenhall and Sundh, 2006).

While these findings are ambiguous they suggest a need to tackle risk factors including smoking, obesity and high blood pressure in people with hearing loss and the signing community. One reason for these associations might be that public health information and programmes do not reach these groups.



There is evidence that people who are deaf – sign language users in particular – are not included in prevention services. Studies of specific areas have found that deaf people are at greater risk and have lower levels of health knowledge than others. For example, a recent survey in Rochester, New York, indicated a greater cardiovascular risk among Deaf participants (McKee et al., 2011, *Impact of communication*). Similarly, US research suggested that knowledge about cardiovascular disease among patients who are Deaf was considerably lower than that of the general population: in a survey, 40% of American Sign Language users could not list any symptoms of heart attack; 60% couldn't list any symptoms of stroke (Margellos-Anast, Estarziau and Kaufman, 2006).

Barriers identified include a lack of healthcare information, lack of access due to language and communication challenges, financial constraints and stress (McKee et al., 2011, *Perceptions of cardiovascular health*). It is important that prevention services are designed with people with hearing loss and deaf users of BSL in mind.

Stroke

A stroke occurs when there is a blood clot or a blood vessel breaks in any of the four parts of the brain: the right hemisphere, the left hemisphere, the cerebellum or the brain stem.

The right hemisphere controls movement of the left side of the body and analytical and perceptual tasks.

The left hemisphere controls movement of the right side of the body and speech and language abilities for most people. (National Stroke Association website, 2013)

There has been UK research into the impact of a stroke on BSL users, in particular, the relative impact of right and left hemisphere damage.

Like spoken language, sign language is left-lateralised, and a left-hemisphere stroke has comparable impacts on sign language production and comprehension as on spoken language. Some impairments in spatial elements of sign language arising from right-hemisphere strokes have also been reported (Atkinson et al., 2005). Particular symptoms of strokes, such as limb apraxia (difficulty in planning movement) or paralysis make it more difficult for sign language users to communicate. Similarly, visual difficulties that may follow a stroke make comprehension more challenging (Atkinson et al., 2002). While this particular research has focused on the impact of strokes on BSL users, visual difficulties cause problems for anyone with hearing loss who relies on lipreading to communicate better.

In this way, strokes can present specific challenges to deaf people who use sign language. Despite this, there is a lack of equality in terms of service provision. A study that measured referral for stroke services found that BSL users were around five times less likely to be referred to a Speech and Language Therapist than members of the population overall. They also face difficulties in accessing physiotherapy and occupational therapy due to poor awareness and language barriers (Atkinson et al., 2002).

A relationship between hearing loss and risk of stroke is usually accepted (Formby, Phillips and Thomas, 1987). The association appears to be with sudden hearing loss rather than more gradual age-related hearing loss. For example, Lin found that patients with a sudden hearing loss had an elevated chance (around one and a half times) of having a stroke during the next five years (Lee, 2008).

BSL users who'd had a stroke were around five times less likely to be referred to a Speech and Language Therapist

Hearing loss is one of the communication-related impairments that can be caused by a stroke. Some types of stroke have been isolated as a cause of damage to the inner ear and sudden deafness (Lee, 2008). Strokes can, in particular, affect central auditory function in older adults (Hariri et al., 1994), for example, sound localisation or auditory discrimination.

Another communication impairment caused by strokes is aphasia (language disorder). It is recognised that environmental factors can influence communication for people who've had a stroke in both healthcare and other settings; it is essential that barriers are removed and communication is facilitated (O'Halloran, Worrall and Hickson, 2011). Such measures should also take into account the elevated risk of hearing loss for this group.

Diabetes

Type 1 diabetes is an autoimmune disease where the pancreas stops producing insulin. Where someone has type 2 diabetes, their pancreas produces insulin but their body cannot use the insulin effectively. Around 90% of people with diabetes have type 2, and this is often associated with ageing and obesity, and with long-term complications, including heart and blood-vessel disease, and strokes. (National Diabetes Information Clearinghouse, 2013)

While there is some evidence that diabetes may increase the risk of developing hearing loss, there is no consensus around any association (Maia and Campos, 2005). Higher rates of hearing loss have been identified in people with diabetes than in those without diabetes (Agrawal, Platz and Niparko, 2009; Chasens, Enock and DiNardo, 2010; Mitchell et al., 2009). There are thought to be links to angiopathy and/or neuropathy (blood vessel disease and damage to nerves, respectively) related to diabetes, which may cause hearing loss. Another possible explanation is that both diabetes and hearing loss are not dependent on one another but are both components of a genetic syndrome (Maia and Campos, 2005).

Chasens identifies the need for diabetes services to learn how to communicate better with patients with hearing loss and deaf patients who use sign language; and to identify people who should be referred for a hearing test (Chasens, Enock and DiNardo, 2010).

Parkinson's

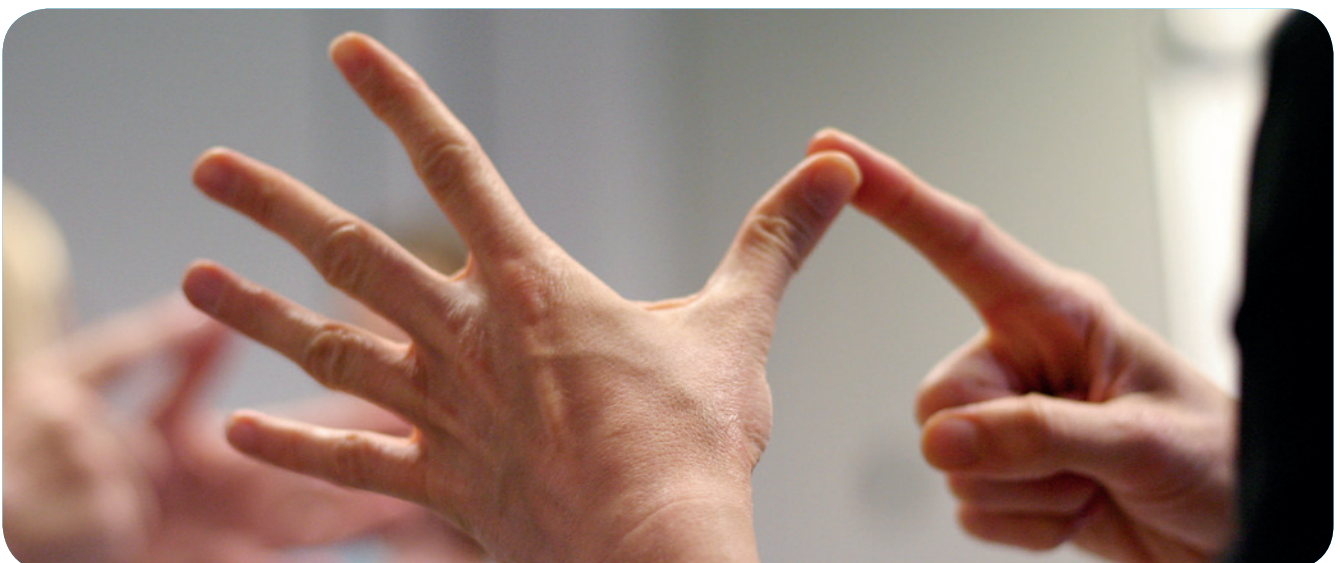
Parkinson's is a progressive neurological condition that affects around 127,000 people in the UK. It is caused by a lack of the chemical dopamine in the brain, and it causes symptoms such as tremor, rigidity and slowness of movement (Parkinson's UK website, 2013).

The experiences of sign language users with Parkinson's have been of particular interest because of the insights that these can offer into the neural mechanisms of language and, specifically, the brain's control of language and movement (Brentari, Poizner and Kegl, 1995; Poizner and Kegl, 1992). Much of the literature has focused on a small number of individuals and more research would be required to capture a better range of experiences.

Unsurprisingly, deaf people with Parkinson's demonstrate changes in how they sign. These include:

- Reduced amplitude of movement (Brentari, Poizner and Kegl, 1995)
- Substituting 'easier' signs; for example, someone with Parkinson's might adapt a sign so that it originates from their wrist rather than their elbow (Brentari, Poizner and Kegl, 1995; Brentari and Poizner, 1994)
- Less clear handshapes (Brentari and Poizner, 1994; Tyrone and Woll, 2008)
- Changes in timings, for example, longer pauses (Brentari, Poizner and Kegl, 1995)
- Loss of facial expression.

It is agreed that such changes make it more difficult to understand a sign language user with Parkinson's (Brentari and Poizner, 1994); and their signing is perceived as more monotone (Brentari, Poizner and Kegl, 1995; Brentari and Poizner, 1994). However, in the cases studied the sign language was still judged to be intelligible.



Sight loss

Any combination of significant vision and hearing impairment is known as dual sensory loss (Brennan, Su and Horowitz, 2006). It is estimated that there are currently 356,000 deafblind people (people with little or no useful hearing or sight) in the UK (Sense website, 2013).

There is some suggestion of an association between hearing loss and visual impairment in older people, some studies finding that older people with visual impairment are also more likely to have hearing loss (Chia et al., 2006; Schneck et al., 2011). However, this finding has not been replicated across all such studies (Bergman and Rosenhall, 2001). It is suggested that hearing and sight loss could share risk factors or ageing markers, but there is no consensus as to the nature of the relationship (Chia et al., 2006).

Dual sensory loss limits the information a person receives about the environment, communication, and their ability to carry out day-to-day activities (Brennan and Bally, 2007). Specific conditions that cause dual sensory loss include Usher Syndrome, where people are born deaf or hard of hearing and gradually lose their sight in their teens and early adulthood (Sense website, 2013).

Dual sensory loss has been identified as having wide-ranging, negative impacts, including on mental wellbeing (Brentari and Poizner, 1994; Capella-McDonnall, 2005; Crews and Campbell, 2004), social functioning (Brennan and Bally, 2007; Crews and Campbell, 2004; Fischer et al., 2009; Schneider et al., 2011), general quality of life (Schneider et al., 2011), cognition (Brennan and Bally, 2007; Schneider et al., 2011) and mobility (Crews and Campbell, 2004). It has even been identified as an independent predictor of a heightened rate of mortality (Crews and Campbell, 2004). There may be various reasons for this, and the evidence is inconclusive. For example, evidence suggests that older people with dual sensory loss are three times more likely than people with no sensory loss to experience symptoms of depression (Capella-McDonnall, 2005). However, another study found that this association did not persist once health indicators were controlled for (Chou, 2008).

Older people with dual sensory impairment are also more likely to have falls than people with visual impairment only; one study found that dual sensory loss increased this risk around three-fold (Crews and Campbell, 2004). This is likely to be related to the fact that hearing loss prevents the reception of other information about the environment that can compensate for visual impairment (Crews and Campbell, 2004; Kulmala et al., 2009).

People with dual sensory loss have needs that are different from those with hearing loss only, and specialist interventions are required (Brabyn et al., 2007). Conventional interventions often rely on the other sense, for example, people with visual impairment learn orientation skills that rely on their hearing. Approaches to managing hearing loss often rely on vision (Brabyn et al., 2007), meaning that the efficacy of particular devices, such as subtitles, is limited for people with dual sensory loss.



For deaf people who use sign language, even mild visual impairment may interfere with perception of sign language (Naeye, Siegel and Clay, 1992). Brabyn et al recommend that signers maximise contrast, for example by standing against a plain and contrasting background (Brabyn et al., 2007).

In terms of diagnosis, it is important that audiologists and opticians make enquiries about the other sense (Schneck et al., 2011). Similarly, they should acquire an understanding of the other discipline and co-operate closely in the assessment process (Brabyn et al., 2007).

Cost savings

The impact of hearing loss on the management of long-term conditions means that effective management of hearing loss could make an important difference in terms of the quality of life of people with long-term conditions. This is particularly important given the size of the population affected by both hearing loss or deafness and other long-term conditions and, in particular, the strong link between hearing loss and dementia.

The high costs of managing long-term conditions and the interaction of hearing loss, deafness and other conditions mean that significant savings could accrue from a joined-up approach. This section considers the potential cost savings that could accrue from the effective management of hearing loss and dementia. Many of the findings are also relevant for hearing loss and other long-term conditions.

Hearing loss and dementia

We know that, in the UK, 44% of over-70 year olds have moderate to severe hearing loss and there are around 720,000 people aged over 70 in the UK with dementia. This means that, within this age group, there are at least 316,000 people with a hearing loss and dementia. In reality, since people with hearing loss are more likely to go on to develop dementia, this figure is likely to be much higher. Nonetheless, we know that there is a large group of older people who have both hearing loss and dementia.

Dementia and hearing loss or deafness can make communication more difficult, but the diagnosis and management of both conditions rely on effective communication. In particular:

- It can be more difficult to diagnose either hearing loss or dementia where the other condition is present
- If people with dementia are unable to communicate effectively this can cause behavioural and psychological problems
- Ineffective management of hearing loss can make symptoms of dementia worse and/or appear worse.

The extent of the group of people with hearing loss or deafness and dementia, as well as the complications caused by co-occurrence of these conditions, mean that health services should take a joined-up approach to their management. This is currently not happening.

Cost of unmanaged hearing loss in people with dementia

It is clear that important improvements in quality of life – and cost savings – can be achieved if hearing loss and dementia are managed more effectively. Although many of the cost savings are likely to be diffuse and indirect, we can illustrate their extent by focusing on estimated savings that could be made in social care and support costs.

In the UK at least 316,000 people aged over 70 have hearing loss and dementia

The Department of Health in England has described how people with dementia find themselves on a conveyor belt that takes them into residential care because professionals are not aware of the alternatives (Department of Health, 2008). Over a third of people with dementia who go into hospital after living in their own homes are then discharged to a care home setting. This risk is higher for people with unmanaged hearing loss. Two factors, in particular, compound this:

1. Inability to communicate, often experienced by people with hearing loss, can cause behavioural and psychological problems. This means that unmanaged hearing loss can make the symptoms of dementia worse, and its management more difficult.
2. If the assessment process for dementia does not take into account the effects of hearing loss, the assessors could conclude that the patient’s symptoms of dementia are more advanced than they actually are.

Both of the above mean that someone with unmanaged hearing loss and dementia is more likely to be referred straight to a higher-cost intervention than would be the case if their hearing loss was taken into account. Cost savings could be made, therefore, through better management of hearing loss, providing services that are accessible to people with hearing loss or deafness, and ensuring that the diagnosis and management of dementia takes a person’s hearing loss or deafness into account. The cost to the NHS of hearing loss management is relatively low, for example, assessing someone, fitting two hearing aids, and providing follow-up care costs around £300 to £400. For this small sum, people could avoid or delay higher-cost interventions such as being admitted to a residential care home.

An economic model used by the Department of Health (Department of Health, 2008) in England provides us with useful estimates of potential savings from delaying admissions to care homes. The model estimated that a programme of carer support and counselling would reduce care home placement by 28%, with a median delay to placement of 557 days.

85,000 people with dementia enter care homes in England every year – of these, at least 37,400 will have a hearing loss. If services responsive to the needs of people with hearing loss were able to bring about the same reduction in placement in residential care as the programme described above, this would result in savings of at least £28 million per year in terms of residential care. The way this is calculated is shown in the boxes below.

Total annual cost per person with dementia	
Type of support	Cost (£)
Community-based provision for people with mild dementia	14,500
Community-based provision for people with moderate dementia	20,300
Community-based provision for people with severe dementia	28,500
Residential care	31,300

Calculating estimated cost savings from better management of hearing loss in people with severe dementia in England

Cost savings are calculated by offsetting the cost of community-based provision for people with severe dementia against the cost of residential care.

In England **37,400** people with hearing loss and dementia go into a care home every year. A reduction of 28% means that **10,500** people would receive care in the community instead of residential care.

For 10,500 people, residential care would cost **£329 million** per year (10,500 people at £31,300 per year).

For 10,500 people with severe dementia, community-based provision would cost **£299 million** per year (10,500 people at £28,500 per year). Provision of two hearing aids and follow-up care for this group would cost around £1.4 million per year (10,500 at £130 per year). Therefore, the total cost for this group would be **£301 million** per year.

This represents a potential saving of around £28 million per year.

Assumptions:

1. This is based on the assumption that introducing services that are responsive to the needs of people with hearing loss can achieve the same level of reduction in care home placement as a programme of counselling and care support.
2. The cost of care is based on the [Alzheimer's Society Dementia UK report \(2007\)](#)
3. It has been assumed that hearing loss can be managed with the use of hearing aids and 'relevant support to use these appropriately.

It is important to note that the £28 million is a conservative estimate. As well as reducing costs by working to mitigate the factors described above in points 1 and 2, if services are more responsive to deaf people and people with acquired hearing loss, people with dementia and hearing loss or deafness would benefit far more from interventions which rely on effective communication, such as counselling.

Effective management of hearing loss would also mean savings in terms of reduced hospital admissions and specialist care. People with dementia who are over 65 are using up to one quarter of hospital beds at any one time. This suggests that there is scope for significant savings.

Two more detailed case studies enable us to identify wider and more significant savings, in particular, in the take up of mental health services for the elderly; and the length of hospital stays.

Case study 1

John T currently lives in his own home. He moved there following the death of his wife, to be closer to his granddaughter.

He has recently been diagnosed with Korsakoff's syndrome, a form of dementia; this makes him difficult to deal with and forgetful.

His preferred language is British Sign Language and, therefore, he needs the right communication support. Ideally, he would be supported by qualified interpreters, receive language and culture-appropriate assessments, be helped by a care assistant with appropriate communication skills, and access to a care setting providing communication and the opportunity to interact with others.

With this support John's needs would be assessed accurately – and he'd receive the services to meet them. In turn, his needs would be less likely to escalate, delaying the time when he needs more acute services, such as elderly mental illness care. In practice this would mean that he could live at home for longer.

If good language support were provided, John's care would cost £122,500 over five years. In contrast, if he receives poor language support, John's care would cost £268,200 over five years.

This means that savings of around £145,700 could accrue over a five-year period. While the communication support has a cost, this will be much lower than the potential savings.

Read a more detailed comparison of the cost of John's care in Appendix 1.

Case study 2

Anne D lives in sheltered accommodation. She has two sons who live over 100 miles away but she regularly visits them and other friends. In the last few months she has found some daily activities more challenging and was recently found outside the housing complex, without a coat, in cold weather. She was admitted to hospital after feeling unwell; although a urinary tract infection was diagnosed, a gerontologist indicated that she might have early-stage dementia.

Anne has significant age-related hearing loss and uses a hearing aid, but she often communicates through lipreading.

Anne's experience of care, and the costs of care, would depend on whether hearing loss is taken into account. Effective management of her hearing loss would include maintenance of her hearing aids, appropriate equipment and diagnostic tests that take into account her hearing loss; and the support of deaf-aware care staff.

This would ensure that Anne receives an accurate assessment, and access to the services she needs, avoiding costs associated with delayed or incorrect diagnosis. It would also mean that re-ablement (where Anne would be supported to re-learn the skills of daily living) would be more likely to be successful. This would delay the time when she needs more acute services, such as home care and nursing care.

If health and social services take into account her hearing loss, Anne's care would cost £57,400 over five years. In contrast, if poor language support were provided, Anne's care would cost £138,000 over five years.

This means that savings of around £80,600 could accrue over a five-year period.

Read a more detailed comparison of the cost of Anne's care in Appendix 2.

Both of these case studies account for benefits in terms of cost savings. However, there would also be other less easily quantifiable but very important benefits, such as improvements to John and Anne's quality of life. In a more detailed analysis, tools such as Social Return on Investment (SROI) could be used to quantify these extra savings.

This issue is particularly pressing because the number of people with dementia and entering care homes is set to grow by **1.5%** every year.

Dementia costs **£8.2 billion** a year in England in direct health and social care costs. Of this, at least **£3.6bn** will be spent on dementia care for people who have moderate to severe hearing loss. Moreover, the Department of Health in England has made available £150 million of additional funding to support the implementation of the National Dementia Strategy.

Dementia costs £8.2 billion a year in England in direct health and social care costs

Given the crossover between these two conditions some of the funding should have been used more effectively by better managing hearing loss and co-ordinating management of both conditions. We believe that it is essential that this happens in the future. It is also likely that these cost savings could be replicated across services managing other long-term conditions such as diabetes, sight loss and cardiovascular disease.

Conclusions and recommendations

We've discussed the clear associations between hearing loss, deafness and other long-term conditions, in particular the strong link between hearing loss and dementia. While there is much research into this link, further biomedical research is needed to build a consensus as to the mechanisms involved in this relationship. Longitudinal research that measures the effectiveness and impact of aural rehabilitation, such as hearing aid provision in the ageing population, in either preventing or delaying cognitive deterioration, is needed.

The evidence linking hearing loss and other conditions such as cardiovascular disease, diabetes and sight loss is more mixed. Hearing loss and deafness may affect communication, thus interfering with diagnosis, and limit access to health information and access to health services, which may make people more likely to develop these other conditions, or there may be other mediating or common factors. At the very least, the fact that these long-term conditions and hearing loss are concentrated within older groups means that a large proportion of people will have hearing loss and at least one other long-term condition.

People with hearing loss, especially deaf people who use BSL, may not be reached by public health information and programmes. This may lead to increased rates of smoking, obesity or high blood pressure, resulting in a higher risk of developing some long-term conditions, particularly cardiovascular disease and diabetes. It is important that prevention services are designed with people with hearing loss and deafness, including sign language users, in mind.

Addressing communication needs is often essential to managing hearing loss alongside other long-term conditions. Unmet communication needs can lead to social isolation and limited access to healthcare services which, in turn, has a negative impact on diagnosis and intervention. Some long-term conditions, such as dementia and impairment by a stroke, themselves affect communication. This can compound communication issues caused by hearing loss and deafness and cause difficulties in reaching diagnoses and offering effective treatments. In conditions such as diabetes and hypertension, where patients can play a large role in self-managing their conditions, facilitating effective communication with health professionals is particularly important.

Long-term conditions are often considered in isolation, but it is particularly important that hearing loss is better managed in people with other long-term conditions. Currently, only one in three people with hearing loss have accessed hearing aids; diagnosis of hearing loss is ad hoc, taking, on average, 10 years; and GPs fail to refer up to 45% of people reporting hearing loss. Early diagnosis and proper management of hearing loss could reduce social isolation and remove barriers to accessing health services, leading to a reduction in the risk and impact of other long-term conditions, improvements in quality of life and cost savings.

We've illustrated this with an example of how cost savings of at least £28 million could be gained by taking account of hearing loss in the care for people with dementia in England. This issue is particularly pressing because the number of people with dementia and entering care homes is set to grow by 1.5% every year, and a large amount of money is already spent on managing dementia.

Recommendations

We call on health departments, commissioners and providers of health services throughout the UK to recognise hearing loss and deafness in assessing, diagnosing and managing people with other long-term conditions:

Earlier intervention and prevention

- Introduce an adult hearing screening programme for 65 year olds and integrate opportunistic and targeted hearing checks into other services and settings, such as in pharmacies, care homes, during consultations for other conditions, and alongside other health checks at GPs.
- Ensure that information and health promotion campaigns are accessible to people with hearing loss and deaf people who sign.

Managing other long-term conditions in people with hearing loss

- Services for people with dementia, cardiovascular disease, diabetes and sight loss must take into account the needs of people with hearing loss and deaf people.
- Fund research to develop better diagnostic tools, specialist services and guidance to support people with hearing loss and deaf people who also have other long-term conditions; and make sure these are used.

Making cost savings

- Ensure that resources are allocated in a cost-effective way by properly managing hearing loss in people with other long-term conditions. For example, the lack of resource allocated to hearing loss within the National Dementia Strategy for England should be reviewed.

Appendix 1

Case study 1

John T's illustrative health and social care costs

	Good language support		Poor language support	
	Type of care	Cost for the year	Type of care	Cost for the year
Year 1	Home care (52 weeks) One week of hospital care (mental health)	£8,200	Home care (52 weeks) Three weeks of hospital care (mental health)	£14,200
Year 2	Home care (52 weeks) One week of hospital care (urine infection)	£7,400	Elderly Mentally Ill (EMI) residential care (52 weeks) Three weeks of hospital care (urine infection)	£39,000
Year 3	Residential care (52 weeks)	£31,300	Elderly Mentally Ill (EMI) residential care (26 weeks) Older people mental health unit (26 weeks)	£68,000
Year 4	Elderly Mentally Ill (EMI) residential care (52 weeks) One week of hospital care (minor stroke)	£41,800	Elderly Mentally Ill (EMI) residential care (26 weeks) Older people mental health unit (26 weeks) Hospital admission that has been extended by an additional two weeks (minor stroke)	£79,000
Year 5	Elderly Mentally Ill (EMI) residential care (52 weeks)	£33,800	Elderly Mentally Ill (EMI) residential care (26 weeks) Older people mental health unit (26 weeks)	£68,000
	Total	£122,500	Total	£268,200

Appendix 2

Case study 2

Anne D's illustrative health and social care costs

	Services that take into account hearing loss		Services that do not take into account hearing loss	
	Type of care	Cost for the year	Type of care	Cost for the year
Year 1	Community-based support (no care cost) Hearing aids and equipment	£200	Home care (52 weeks)	£5,000
Year 2	Community-based support (no care costs) Hospital admission of expected length (hip replacement) Hearing aids and equipment	£9,000	Home care - higher level of support (52 weeks) Hospital admission that has been extended by an additional two weeks (hip replacement)	£21,200
Year 3	Home care (52 weeks) Hearing aids and equipment	£7,200	Elderly Mentally Ill (EMI) residential care (52 weeks) Hospital admission that has been extended by an additional two weeks (urine infection)	£39,000
Year 4	Home care (52 weeks) Hospital admission expected length (urine infection) Hearing aids and equipment	£7,200	Elderly Mentally Ill (EMI) residential care (52 weeks) Hospital admission that has been extended by an additional two weeks (urine infection)	£39,000
Year 5	Elderly Mentally Ill (EMI) residential care (52 weeks) Hearing aids and equipment	£33,800	Elderly Mentally Ill (EMI) residential care (52 weeks)	£33,800
		£57,400		£138,000

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DCAL is a research centre based at University College London and funded by the ESRC, which brings together leading deaf and hearing researchers to study the impact of deafness on cognition and language.

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