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Working with deaf people

Older Deaf People and Social Care: A Review



Older Deaf People and Social Care: A Review

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Author and Acknowledgements

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Foreword

The Royal Association for Deaf People and [sonus] are committed to delivering services that Deaf people want and need. For some time now we have been concerned about the lack of provision of care and support services delivered in British Sign Language (BSL).

Having access to communication is important for us all. For people who are Deaf being in the company of people with whom they can communicate is vital to their health and well being. It reduces feelings of isolation and incidence of depression. Being able to communicate with care workers about their care needs without the need to use interpreters is important; it helps to build relationships and ensure that older Deaf people's needs are fully understood and that they receive the best possible care and support.

Many older Deaf people are increasingly faced with the dilemma of moving into residential care services which do not use BSL, near their families or moving some distance away to live with other BSL users in a residential care service. We believe this is not a choice Deaf people should be forced to make.

This report is a first step to making sure that the needs of older Deaf people are understood by decision makers and commissioners. It also demonstrates our intention to address the challenges that older Deaf people face and our commitment to ensuring that care and support services are developed to meet the needs of older Deaf people.

Roger Beeson
Chair
Royal Association for Deaf People and [sonus]

Liz Jones
Chief Executive
[sonus]

Dr Jan Sheldon
Chief Executive
Royal Association for Deaf People

Key contributions of this report

This is the first report of its kind to review specifically social care and older Deaf people based on available evidence. It applies mainstream social care frameworks to understand service need and planning of social care provision to the highly specific context of Deaf BSL users, over the age of 65. Its main contributions of knowledge and service development can be summarised as:

1. This report collates for the first time available statistical evidence on the numbers and population characteristics of Deaf sign language users aged 65 and over and demonstrates the extent to which the population estimates are not reliable.

2. It provides projections of population growth based on an analysis that combines ONS estimates in growth of numbers of older people with parameters of potential Deaf BSL user population estimates.

- i.** By 2035, the population of over 65s who are Deaf BSL users in the UK is estimated to be between 11,500 and 26,680 using the most conservative and the largest estimates respectively.
- ii.** By 2035 the number of over 85 year old Deaf BSL users in the UK is estimated to be between 2,500 and 5,800, based on minimum and maximum population estimates.

3. It draws attention to the culturally, socially and generation-specific data of the older populations of Deaf BSL users today as the basis for current and future service development providing specific examples.

4. Using a framework based on the domains of social care activity, the report identifies two key questions currently not addressed by the Care Quality Commission (CQC):

- i.** In what ways do the characteristics of the population of older Deaf people obscure need, hide strengths and hinder effective service provision within these domains of activity?
- ii.** To what extent do the characteristics of health and social care provision in the mainstream facilitate or deny equitable access to effective social care services for older Deaf people?

5. It applies for the first time, an outcomes framework for defining social care provision used in mainstream services and concludes that there are two fundamental questions to be addressed for which there is currently no data:

- i.** Do we know from older Deaf people themselves, their definitions of desired outcomes which support their aspirations, goals and priorities?
- ii.** What might facilitate or hinder the achievement of outcomes which are valued by older Deaf people?

6. Using a framework based on the 5 key principles in the delivery of social care, it concludes there are two unaddressed questions with this population:

- i.** How does the minority cultural-linguistic status of Deaf people impact on the execution of core principles within the provision of their social care?
- ii.** On an individual basis, how should Deaf people's language, culture and values shape the services to which they are entitled?

7. A review of the small body of literature available on older Deaf sign language users identified 3 key issues for which there was specific evidence:

- i.** The maintenance of cultural and social networks is regarded by Deaf people as a priority and there is evidence of its efficacy as a primary preventative measure in supporting older Deaf people's health and well-being;
- ii.** Being Deaf is associated with much poorer health and mental health outcomes on a life-long basis which means older Deaf people are likely to be more vulnerable to the challenges of older age;
- iii.** Poor communication access and lack of cultural competence in service provision will adversely affect the kind and quality of assessment and service provision available to Deaf older people.

8. The report provides an in depth analysis of the specific features of social care practice associated with inadequacies in linguistic access and cultural competence.

9. It proposes a new model for understanding, predicting and responding to factors which influence the quality of social care provision for older Deaf people. This has not previously been conceptualised.

10. It highlights key areas of evidence in this field that are currently lacking.

Introduction

This review was commissioned by RAD (Royal Association for Deaf People) and [sonus] to inform the organisations' strategic planning for meeting the social care needs of older Deaf people. It responds to the need for greater clarity about this population, including size, current needs and projected service use. In line with trends in the wider population, Deaf people are living longer and the proportion of the Deaf community consisting of people over the age of 65 is increasing. The review addresses the strength of available evidence and identifies where gaps in knowledge exist which are relevant to meeting the social care needs of this population. It also provides a bibliography of resources for future use.

The focus of the report is Deaf people who are British Sign Language (BSL) users (signers) as distinct from the larger population of older people who might become deaf, or deaf people who have been spoken language users throughout their life and have no Deaf community or Deaf cultural affiliations. Although this definition includes Deafblind people who are signers and older Deaf people

with learning difficulties, these specialist groups are not its main focus. The definition of social care encompasses but is not confined to domiciliary and residential care services. It also incorporates features of culturally and linguistically appropriate provision in meeting older Deaf people's everyday needs including those arising from faith/worship and sustained contact with Deaf community/heritage. No strict boundary is drawn between health and social care needs in order to adequately address those issues encompassed by both such as end of life care.

The review is divided into three sections:

- What do we know about the size and characteristics of this population?
- Framing social care activity with older people
- How does being Deaf interact with the domains, outcomes and principles underpinning social care activity with older people?



1. What do we know about the size and characteristics of this population?

How many Deaf people are there over the age of 65?

Estimating the number of Deaf people over 65 is not straightforward, firstly because the means of collecting official population data on Deaf people in general (regardless of age) uses varying and unhelpful definitions.

The 1948 National Assistance Act started the use of a categorisation “deaf with speech or deaf without speech” on the assumption that the latter implies sign language user. However, means of communication is not the same as language. Many older Deaf people who use BSL today were educated using the oral method; being able to speak does not define their linguistic or cultural affiliation. Section 29 of the Act required Local Authorities to keep a register of deaf and hard of hearing people in their area, although registration has not been compulsory. The last report from the NHS Information Centre for Health and Social Care reporting for England defines ‘deaf’ as “Those who (even with a hearing aid) have little or no useful hearing” which is an audiological-based definition that says nothing about language use. It defines ‘hard of hearing’ as “Those who (with or without a hearing aid) have some useful hearing and whose normal method of communication is by speech, listening and lip reading.”

This is a definition associated with language and communication. Yet someone defined as ‘deaf’ in this categorisation might or might not be a BSL user. Also someone who is ‘hard of hearing’ as defined may be a BSL user if they are a sign bilingual for example. Although the report breaks down those registered by age its findings are not reliable for any service planning because registration is not compulsory and definitions are so unreliable. Indeed, statistics on deaf and hard of hearing

people who register with their local authority are no longer collected and reported centrally nor used as the basis for resource allocation.

Extrapolation of data about Deaf people from national population data sets in the UK is also extremely difficult and often highly unreliable because of the definitions used within the primary data collection, e.g. the Office of National Statistics Harmonisation Group has been carrying out a piece of work specifically associated with disability data collection within UK surveys. One of their concluding recommendations is: “revise the response categories to better represent service needs and policy requirements, that is; split blindness, deafness and communication into separate categories, using the terms vision, speech and communication impairment, with illustrative categories such as blind or partial sight, deaf or partial hearing.” How would a Deaf BSL user, who audiologically is not profoundly deaf and who has good written English but poor speech fit into that categorisation?

The 2011 national census in England and Wales allowed for the first time the possibility of choosing to state that ‘Sign Language’ was an individual's main language. This was only possible if the person filling in the form said that English (or Welsh) was not their main language but an ‘other’ language was, then Sign Language could be written into the box. This format of final question meant that it was not possible to record how many users of Sign Language there actually were, if it was not regarded as the ‘main’ language. ONS acknowledged the loss of data by the choice of the final wording of the question. Originally BSL was a stated option in the languages section of the census with the possibility of indicating degree of fluency receptively (understanding) and expressively (communicating). But this format was dropped after extensive testing and therefore the original aim to audit the number of BSL users in England and Wales was not fulfilled.

The actual number of BSL users has attracted widely differing estimates. Action on Hearing Loss suggest it is 50,000 in the UK, the British Deaf Association that it is 70,000 in the UK, Sign Health that it is 100,000 in England only, and the ONS data release (January 2013) on languages records 22,000 sign language users in England and Wales of whom 15,000 said specifically it was BSL. The Welsh Assembly Government estimate that BSL is the first or preferred language of 3,000 people in Wales and the Scottish Executive that it is the first or preferred language of 8,000 people in Scotland. The Department of Culture, Arts and Leisure in Northern Ireland suggest that there are 5,000 sign language users of whom 2,500 use BSL and 1,500 use ISL (Irish Sign Language).

There is no obvious relationship between the incidence of deafness at birth or during childhood and later BSL use/Deaf cultural affiliation. We know with some certainty that the incidence of congenital deafness is between 1.3 and 1.6 per 1000 live births (where deaf refers to permanent bilateral hearing loss of 40 dB or greater). It has also been demonstrated that for every 10 children with a permanent bilateral hearing impairment >40 dB which is detected at birth, “another five to nine children would likely manifest a hearing impairment by the age of 9 years.” The increase is a result of childhood illnesses and accidents as well as progressive hearing losses not apparent in infancy and therefore not identified through universal newborn hearing screening. However, these population level data tell us virtually nothing about an individual’s language choices in adulthood. They cannot form the basis of any data projections about the numbers of Deaf people over 65.

Furthermore, the number of children born deaf has not been constant through history. The current population of 65- 80 year olds were born between 1933 and 1948. This was a period when there were no vaccines against conditions causing deafness such as rubella or childhood illnesses which could result in deafness such as measles and scarlet fever. It was also a time of war (1939-45) and pre-universal health services (NHS founded in 1948). It is therefore reasonable to assume, although there is little hard evidence, that the incidence of congenital

and childhood deafness was higher than is the case today and therefore the potential current population of older Deaf people larger than a simple extrapolation from population figures might suggest.

Searching the historical record to estimate current populations of older Deaf people through controlling for average survival rates over time is also not possible. The 1931 census did record under ‘infirmity’ whether a child was ‘deaf’ but the records were largely destroyed during World War II and those which survived are embargoed until 2032. Records for the 1921 census will not be released until 2022. The 1939 national identity card registration records, which later formed the basis of the first NHS GP registration records, is also currently not available for public scrutiny apart from requests linked to individual persons or addresses.

In summary:

- Data on the current numbers of Deaf BSL users in the UK is highly problematic. Therefore without a reliable baseline it is questionable whether using general population age trends to estimate numbers of BSL users over 65 would be accurate enough
- The historical population data on Deaf people which might be useful in estimating current populations of over 65s (allowing for survival rates) is largely destroyed
- Extrapolating from the incidence of ‘deafness’ tells us virtually nothing about later language use and cultural affiliation
- National level general population data do not use definitions and categories which enable reliable extraction of age-related data concerning Deaf BSL users

However, it is possible to model some likely parameters using general population age trends and projections and upper and lower estimates of the Deaf BSL population in the UK.

In the UK population, the percentage of people aged 65 and over in 2010 was 17%. By 2035, it is projected that this will increase to 23% of the total population.

Assuming a UK population of 50,000 BSL users implies the numbers of over 65s will increase from 8,500 to 11,500 by 2035.

Assuming a UK population 116,000 BSL users (100,000 in England, 3,000 in Wales, 5,000 in NI and 8,000 in Scotland), this implies the numbers of over 65s will increase from 19,720 to 26,680 by 2035.

By 2035, the number of people aged 85 and over in the UK will be 2.5 times larger than in 2010 and account for 5% of the total population.

Assuming a UK population of 50,000 BSL users, this means 2,500 will be 85 years and over by 2035.

Assuming a UK population of 116,000 BSL users (100,000 in England, 3,000 in Wales, 5,000 in NI and 8,000 in Scotland), this means 5,800 will be 85 years and over by 2035.

With regard to older Deafblind people, a recent prevalence study has demonstrated that there are approximately 250,000 Deafblind people in the UK of whom 222,000 are over the age of 70. However the methodology used to derive this population estimate and to predict future trends does not enable the extraction of the numbers of those over 70 who are sign language users.

Generation effects – who are older Deaf people?

All individuals are to some extent a product of their time – the era in which they were born and grew up. However, in relation to Deaf people historical location is very highly influential because of the pace and extent of change experienced by Deaf people in the 20th century. The century saw significant differences in educational approach/philosophy, hearing technologies and social attitudes toward Deaf people which radically affected early life experiences and later life chances. A Deaf person born in 1930 or 1960 or 1990 will have experienced very different lives. Therefore in understanding the characteristics of older Deaf people today, it is important to historically locate their early life experiences and how those might affect their needs and strengths today.

Taking the year **2013** as our reference point:

65 to 80 year olds	Born between 1933 and 1948
Over 80 year olds	Born before 1933

For example, a 5 year old in 1921 would be 97 today. The 1921 census for England and Wales recorded that there were 14,700 institutions of which 35 were for the ‘deaf and dumb’. They catered for all ages from the under 5s to the over 65s. At the time, 226 out of every 10,000 people in the general population lived in an institution and 0.8 out of every 10,000 people in the general population were deaf and dumb and living in an institution. Using this figure and extrapolating from the 1921 general population statistics, there were 4,736 ‘deaf and dumb’ children and adults living in institutions with the vast majority recorded as aged 5 to 15 years.

By contrast a 5 year old in 1950 would be 68 today. By 1950 the NHS was established meaning hearing aids were more available to a wider population and schools had been established employing the new methods of

deaf education pioneered by leaders of the day such as the Ewings. Research in the US focussing on the baby boomer generation, defined as those born between 1946 and 1964, points out that “The deaf individuals encompassed in the baby boom generation are in a unique position because they are truly the largest generation of deaf individuals to be widely accepted into general society and not turned away and institutionalized.”

However, for the generations of Deaf people currently over 65 and over 85, social conditions of the time could commonly create disabling conditions with longer term effects on development. For example, in the early decades of the 20th Century being deaf and being learning disabled were hardly differentiated. Being a deaf child during a time of war would inevitably lead to greater risk of accidents and physical harm. In later decades, transgressions of social rules led easily to assumptions of mental illness and incarceration for many years in asylums.

Research by the Canadian Association of the Deaf in 2001 emphasised the significance of the life experiences of older Deaf people for subsequent generations, pointing to these as a source of fundamental respect which should be shown in how we treat older Deaf people today. They write:

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

Latest research and practice concerning older people in general, and those with dementia in particular, emphasises the importance of understanding the early life experiences and social contexts of those who use services today. For example, ensuring care environments resonate with the familiar, promoting reminiscence therapies which acknowledge history as it was for the individual and appreciating values that are of importance to the older person are all rooted in an appreciation of the person’s historical location. In relation to Deaf people, acknowledgement and understanding of an individual’s generation in relation to services may be a less obvious emphasis than the identification of a cultural ‘difference’ or a cultural need. (We return to this point in section 3).

Mapping the historically familiar as a resource for older people’s services is in its infancy in relation to Deaf people. There are a few first person narrative accounts created by family carers. There is a research project to pilot an electronic reminisce resource with the Deaf community and a larger project intending to link the BDA heritage archive project with electronic life history work for older Deaf people and their families. Work on the sign language corpus projects in the UK and elsewhere in the world will eventually yield some resources on sign language usage amongst older Deaf people which may be helpful. Signs used particularly for vocabulary items can change over time. The signs of ‘telephone’ and ‘toilet’ are common examples of this effect. As the shape of the items changed so too did the signs. Understanding and using a vocabulary that is familiar to an older generation can be important.

Acknowledging the significance of a Deaf person’s historical location and generational perspective and incorporating it into approaches to care and support is significantly neglected in service development and would seem an important focus for the future.

2. Framing social care activity with older people

Framing the issues

Understanding the social care needs of older Deaf people is about understanding the ways in which Deaf people will share the same strengths and needs of all older people AND how older Deaf people’s cultural and linguistic identity might interact with those. It would be a mistake to suggest that older Deaf people had fundamentally different social care needs from other older people. It would also be a mistake to say that Deaf people’s needs were exactly the same as any other older people. This complex interaction between *being an older person and being a Deaf person* applies to the recognition, assessment and meeting of needs as well as to the definition of the outcomes of social care for older Deaf people. Also, failure to engage with the interaction between being Deaf and being an older person will likely result in failure to recognise strengths and identify values which support the dignity of the older Deaf individual and enhance quality of life.

How these aspects work together will become clear if we examine first older people’s social care in general and how its domains of activity, underpinning values and intended outcomes have been framed. This will then be used as the basis for examining how and why being Deaf might make a difference (or not) to the identification of social care needs, the execution of social care and the support of best outcomes.

Domains of social care activity

In the mainstream, social care and older people can be thought of as encompassing seven key domains of activity, to a greater or lesser extent in association with health services. Whilst social care and health may not always address distinctly different

issues for older people, they do commonly address different aspects of the same domains consistent with the underpinning knowledge, skills and values of associated professions as well as their statutory responsibilities and duties. The seven domains are presented below as separate but inter-related:

- I. **Physical health** encompasses the maintenance of optimum health, including good nutrition and staying physically active as well as coping with impact of new health conditions that might be associated with, or consequent on, the ageing process. Also chronic/long term health conditions can have different and new effects in older age e.g. a relatively minor arthritis in middle age can become a source of more serious risk in older age if it leads to instability when walking down stairs.
- II. **Mental health.** There are some age-specific changes in the profile of mental health in the older population such as steady rise in the prevalence of dementia, greater vulnerability to depression, and age-related changes in cognition and memory. The expression of life-long mental health problems may be different with increasing age. The maintenance of mental well-being through avoiding isolation and supporting social interaction and aspiration may prove challenging, as familiar structures and social patterns change with older age.
- III. **Housing and care.** Changes in physical and mental health as well as personal circumstances such as the death of a partner prompt changes in living environments (supported housing, day care, residential care etc.) and/or the introduction of support in the home to maintain independence, ensure safety and support quality of life.

IV. Safeguarding: the prevention of and response to neglect and abuse. Abuse refers to psychological, physical, sexual and financial abuse. Neglect refers to “repeated deprivation of assistance needed by the older person for important activities of daily living”. A UK study in 2007 found the prevalence of mistreatment (which encompasses abuse and neglect) for those over 65 and living in private households (i.e. excluding residential care environments) was 2.6% (equating to 227,000 people in the past year). This figure only includes mistreatment by family, friend or care worker. When the definition was widened to encompass neighbours and acquaintances, the prevalence rises to 4% (342,000 who in the past year had experienced mistreatment). There are no data on older Deaf people and safeguarding.

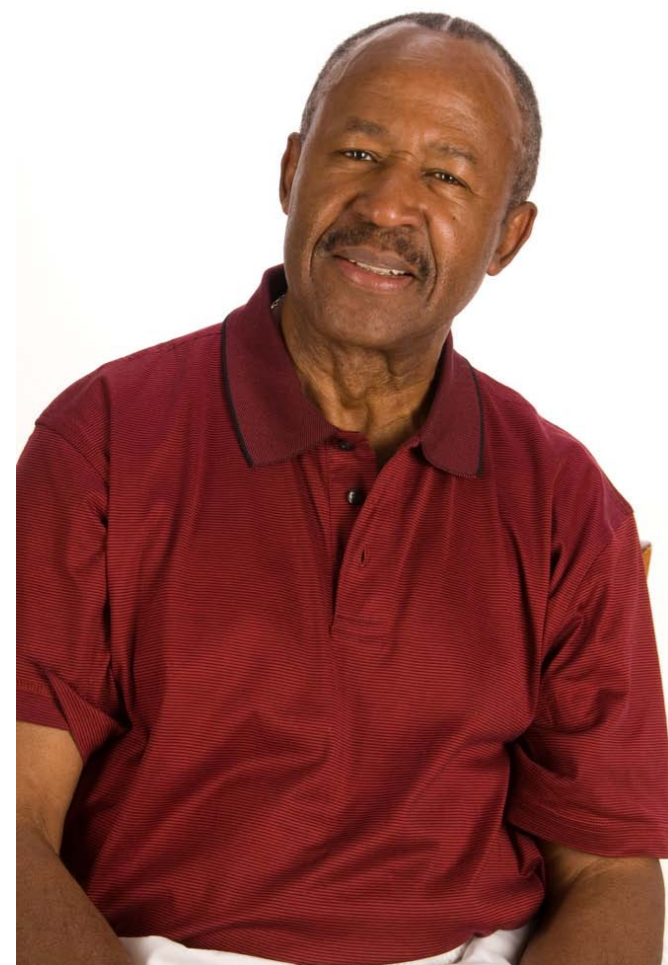
V. Responding to and coping with transitions such as loss and bereavement which become more usual in older life as well as changes in health and well-being that might affect autonomy, independence and a positive sense of self.

VI. Access to information and support to facilitate choice, enable decision making, achieve aspirations and avoid undesired outcomes. The importance of information is seen in examples such as identifying and coping with an illness or health condition that is more common in older age e.g. stroke. The significance of information in decision making is seen in responding to and managing available support such as access to personal budgets to provide tailored care.

VII. Financial and economic well-being. Many older people experience poverty and/or reduced economic circumstances which present challenges to the support of other aspects of well-being such as optimal nutrition, adequate housing, warmth in winter. Older people are especially vulnerable to financial exploitation and abuse.

If we consider social care for older Deaf people from the point of view of domains of activity, we are left with the two fundamental questions:

- ? In what ways do the characteristics of the population of older Deaf people obscure need, hide strengths and hinder effective service provision within these domains of activity?**
- ? To what extent do the characteristics of health and social care provision in the mainstream facilitate or deny equitable access to effective social care services for older Deaf people?**



Outcomes framework for social care provision

Another way of thinking about the health and social care needs of older people is to consider them from an outcomes perspective. Research in 2000 identified three principle outcomes which social care agencies sought to achieve in their work with older people, in whatever domain of activity they might address:

- maintenance of quality of life**, e.g. maintaining acceptable levels of personal comfort and safety, social contact, meaningful activity, routines and control over daily life
- change**, e.g. improving confidence, making the environment more accessible, reducing risk or regaining self-care skills
- impacts of service process**, e.g. whether people feel treated as individuals, valued and respected; whether services fit well with other sources of help and with the preferences and life choices of individual

In 2009, the Department of Health published their consultation on a Common Assessment Framework for Adults. In it they reported the outcomes which adults, including older adults, identified as important were:

- Improved health and emotional well-being
- Improved quality of life
- Making a positive contribution
- Choice and control
- Freedom from discrimination
- Economic well-being
- Personal dignity

If we consider social care for older Deaf people from an outcomes perspective, we are left with two fundamental questions:

- ? Do we know from older Deaf people themselves, their definitions of desired outcomes which support their aspirations, goals and priorities?**
- ? What might facilitate or hinder the achievement of outcomes which are valued by older Deaf people?**

Key principles in the delivery of social care

The provision of social care services for older people whether expressed in statutory guidance, the education of social care professionals or the practicalities of assessment and the delivery of services is underpinned by 5 key values or principles. These relate to all aspects of the social care continuum: identification of need, assessment, provision and delivery of services. They were summarised as:

- I. Designing services around older people’s preferences and needs** rather than older people fitting into the shape and structures of pre-designed services. It also entails giving older people a voice in the design and provision of services.
- II. Personalisation and the promotion of choice.** This is an approach that has driven policies such as personal budgets to enable older people to have greater control over their own care and support priorities and has created a market in the tailored delivery of services.
- III. Cultural sensitivity.** This entails ensuring assessment, care, support and services are not just culturally sensitive but actively promote and respond to cultural values and preferences including those of faith and spirituality.



If we consider social care for older Deaf people from the point of view of underpinning principles of the provision of social care, we are left with two fundamental questions:

? How does the minority cultural-linguistic status of Deaf people impact on the execution of core principles within the provision of social care for them?

? On an individual basis, how should Deaf people's language, culture and values shape the services to which they are entitled?

IV. Equality. The Equality Act 2010 specifically refers to discrimination on grounds of age and promotes a pro-active approach to promoting equality not just avoiding discrimination. Equality intersects with equity in considering the allocation of resources for older people in comparison with other service user groups.

V. Dignity. The Department of Health's 2006 Dignity in Care campaign led to the creation of a 'Dignity Charter' underpinning the provision of care for adults and especially older adults. Autonomy, privacy, respect, prevention of abuse and treating individuals the way they wish to be treated are fundamental to it. The Dignity in Care network continues to be supported by SCIE.

3. How does being Deaf interact with the domains, outcomes and principles underpinning social care activity with older people?

Research which considers social care principles and practice with older people rarely if ever mentions Deaf people. A search under 'hearing', 'hearing loss', 'deaf' or 'Deaf' produced not a single reference in all of the documents drawn on in the previous section of this report. References to minority ethnic communities who might use languages other than English are also very scarce in this material and not in any way linked with Deaf people. Research and practice literature which specifically focuses on older Deaf people and social care is also very limited. In what follows, we summarise a range of evidence from a variety of sources clustered around three main issues. They do not answer directly the questions we have posed about older Deaf people and social care. However they illuminate some relevant aspects, detail priorities and point to future directions for more detailed research and enhanced service provision.

The significance of social networks and social engagement with other Deaf people

Amongst young Deaf people in society today there are multiple and diverse ways to maintain social contact with other Deaf people as well as with hearing people. Real time communication can happen through a signed medium via videophones, webcams and online platforms such as Skype and ooVoo. Texting has been a revolution for Deaf and hearing people alike. Younger generations of Deaf people do not necessarily have to physically meet together to stay in touch through visual language media. Many venues are considered suitable and accessible for social contact rather than only

those designated as 'Deaf spaces' such as Deaf clubs or Deaf sports associations.

For the generation of older people who are now over 65, the creation and maintenance of social networks was far more reliant on in-person real time contact in order to have conversations in BSL. They were much more dependent on specific Deaf-designated meeting places such as Deaf clubs. Although many older Deaf people are users of new information and communication technologies, meeting in person at the Deaf club on a regular basis remains important for a large number of older Deaf people. Meeting socially through a shared language in a space that feels like a second home continues to be significant for Deaf people because:

- I. The experience of **communication, information and social exchange** without barriers to expression or comprehension. This is of greater significance when access to the surrounding majority language e.g. written and spoken English, is not easy
- II. The reinforcement of **identity** and shared values through being with others who are 'like oneself' rather than with others in contrast to whom one is perceived to be 'different'
- III. The **cultural transmission** of values, attitudes, priorities, histories and preferred ways of doing things. This is especially significant when in only a minority of cases Deaf culture passes through familial intergenerational transmission

IV. An experience of **social influence and power** through shared ideals, concerns and campaigns when everyday life is more likely to consist of multiple experiences of disempowerment and barriers to achievement of personal and social goals.

Consequently a few research studies have considered the significance for older Deaf people of social networks and their influence on health and well-being in later life.

A study of 45 Deaf people over the age of 65 in one region in Sweden demonstrated that despite objectively measured high levels of physical illness and depression, Deaf people nonetheless reported high levels of subjective well-being. Whilst they found no significant relationship between the frequency of visits to the Deaf club and reported levels of well-being, they did find a significant relationship between the number of activities within the Deaf club and higher rates of well-being. In other words it is not how often one is present at the Deaf club but the extent of involvement and what is actually done whilst there that makes the difference.

A study of 107 middle and older aged Deaf people (aged 45 to 81) in upper Austria considered the importance of the size of social networks and their composition in promoting health and well-being amongst older Deaf people. They found that a larger social network is positively associated with a higher quality of life. However it was the number of Deaf people in the network which made the difference, rather than the overall size of it or its bilingual/bicultural composition in containing hearing people. They also found that the effect of the Deaf network on quality of life was mediated by extent of the personal resources of the individual, which they defined as self-efficacy and personal communication skills. That said, a reduction in personal resources (someone with lower self-efficacy or poorer personal communication skills) could be compensated for by larger Deaf social networks and vice-versa.

The existence and maintenance of social networks are therefore not just a cultural asset that is highly prized amongst older Deaf people and therefore one that should be respected in its own right, they are also vitally important for the maintenance and promotion of personal well-being in later life.

A study in Wales specifically concerning residential care provision for older Deaf people also confirmed this conclusion. Thirty two Deaf community members over the age of 55, 7 older Deaf people with experience of residential care and 6 service providers/stakeholders participated in the study. Amongst the principle findings were:

- A strong concern that moving into a residential care facility would mean a loss of contact with Deaf cultural and social networks. The concern was not about the loss of communication opportunities in BSL but **the loss of a sense of belonging.**
- Keeping contact with the Deaf club and Deaf social activities was regarded as a priority** even if living in a residential care environment.
- The loss of BSL as a part of everyday life and the loss of contact with life-long friends who were BSL users was a primary **fear** and considered to be **language deprivation.**
- Participants made an explicit link between the loss of cultural and social networks with other BSL users and **deterioration in mental health** consequent on social isolation, lack of sensitivity to cultural needs and language deprivation (no access to BSL users).

The maintenance of cultural and social networks of BSL users is a priority and a primary preventative measure in supporting older Deaf people's health and well-being.

The impact of life-long inequalities and vulnerabilities

Our experiences of physical and mental health in older age are in part consequent on our experiences of them throughout our lives. It is not the case simply that some health-related matters arise in older age because of the ageing process. They do so also in relation to our pre-existing vulnerabilities and strengths, e.g. if poor mental health has been a life-long challenge, then the impact of loss and change in older life might be more stressful and is likely to be met with fewer coping resources. Conversely if we have looked after our physical health and been aware of, and taken preventative steps to optimise health then we are likely to enter older age with stronger health with which to engage any subsequent illness.

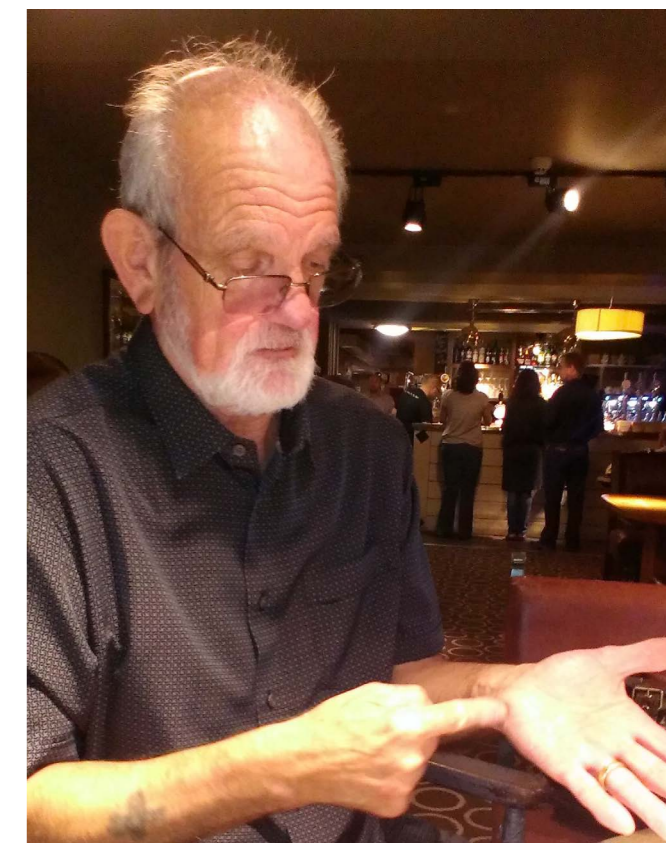
In the case of Deaf people there is significant and mounting evidence that in relation both to physical and mental health they are likely to experience significant inequalities.

- Young Deaf people and adults experience much poorer mental health than their hearing counterparts.
- They have much poorer physical health.
- They experience major barriers in accessing services.
- When engaged with services they are more vulnerable to missed or incorrect diagnoses.

In terms of older Deaf people therefore:

Being Deaf is associated with much poorer health and mental health outcomes on a life-long basis which means older Deaf people are likely to be more vulnerable to the challenges of older age.

In the mainstream, poorer health outcomes are also strongly associated with economic vulnerabilities such as those arising from low income, poor housing and lower levels of educational attainment. The mechanisms



by which these factors impact on health and well-being are complex and none of them determine in any simple causal way poorer health and well-being. However, they all contribute to greater risk of such outcomes and fewer resources (materially, psychologically or socially) to combat such risks.

The vast majority of older Deaf people today will have grown up in eras marked by low expectations of Deaf people, poor educational outcomes, discrimination in employment that marked out some roles or promotions as unsuitable for a Deaf person, stigma and low social status. They are therefore highly unlikely to be financially comfortable in older age and in reality much more likely to experience significant poverty having had fewer opportunities to create economic security for themselves in their older years. However, no strong data exists on the financial circumstances of older Deaf adults.

Economic vulnerabilities associated with being Deaf during working years will impact on older Deaf people's health, well-being and opportunities for care and support.

Communication access and cultural competence in service provision

There are four core issues concerning BSL users which influence issues about older Deaf people and social care, each with a set of consequences. These are outlined below with some examples from literature on how they are manifest.

- 1. The relationship between 'not hearing' and reading.** It is a common misperception that if you cannot hear then at least you can read. However, literacy in English remains a significant challenge for many Deaf people. We have no available literacy data on older Deaf people born before 1960, however a study of 573 school leavers in 1976 (published 1979) found a median reading age of just under 9 years old. Subsequent research has reinforced the findings that literacy remains problematic for many deaf children. There is little evidence to suggest that Deaf children who have had difficulties with literacy in childhood will experience improved literacy in adulthood particular with respect to the generation of Deaf people who are currently over 65.

Therefore:

- **Access to information**, whether about the range of service provision available, details of particular health prevention and promotion strategies or specific appointments and their consequences is highly problematic.

For example, the current Deaf with Dementia project funded by the Alzheimer's Society has investigated the extent to which ordinary Deaf people are informed about ageing and the changes that might occur as a result of dementia. This is because the National Dementia Strategy emphasises the availability of information and community knowledge as one of the central issues in supporting earlier identification and therefore earlier access to treatment and care. It has found that Deaf people find the pre-existing public information about dementia available via web sites and through on-line fora confusing. Whilst it might

seem accessible being in written form, it does not meet their needs both because it is in English and because its presentation feels culturally remote; it is not explained in a way Deaf people feel is meaningful to them and their community. Also Deaf people hold a range of myths and assumptions about dementia which are inaccurate. Whilst this is true of many hearing communities as well, the difference is that because most information is in written form, there are far fewer potential avenues for testing out whether personal knowledge is correct, dispelling myths and seeking more accurate information.

The study has however also demonstrated a strong desire amongst older Deaf people to meet and debate health and social care related issues together if facilitated by an informed expert who can communicate directly without an interpreter and preferably is Deaf themselves. This is a potential source of strength and support amongst older Deaf people that is likely relevant for a range of health and social care issues. Its effectiveness does not just lie in the fact that information is conveyed in BSL, but that it is interactive. The potential for meaningful conversation and debate exists which strengthens knowledge resources. It is qualitatively different from the provision of a DVD in BSL for example which whilst on the face of it accessible, might still fail to be meaningful, e.g. a DVD about dementia in BSL might be technically accurate in the information it conveys but if it uses a range of concepts and ideas which are not familiar to an audience in the first place, the passive form of involvement (watching) does not permit clarification through debate and discussion.

- Abilities to make **informed choices** about personalised care, future provision or simply specify a preference are severely impeded if all relevant information is only available through a written form (English).

For example, a key finding of the study into older Deaf people's preferences concerning residential care in Wales was that participants felt they did not know

enough about the range of choices available concerning housing and support, whether day care, intermediate care, residential care, supported housing etc., to be able to make any plans for their future or to make choices in the present about their needs.

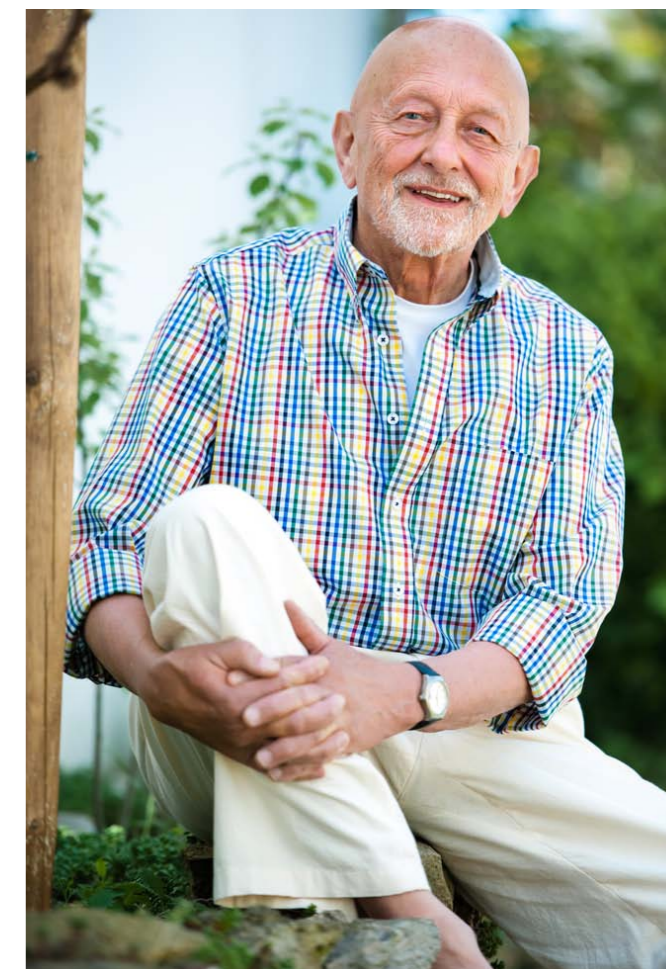
- Professionals harbour **false assumptions** that communication which has occurred directly with a Deaf person through writing things down is accurate and sufficient.

Many Deaf people still experience contact with professional services without an interpreter being present and the professional resorts to writing things down. This is manifest not just in experiences of assessment and diagnosis, but also from the point of view of the carer or family member who might be Deaf.

- Deaf people will experience at best **unequal treatment**, at worst discrimination, in any processes connected with service provision that are largely dependent on the written word e.g. understanding complaints policies and making a written complaint; checking that the details of an assessment carried out with them are correct and confirming by signature that this is the case.

The study of residential care and Deaf people in Wales highlighted the problem of being able to make a complaint or ask for help in a confidential way if there was no direct access to communication in BSL or where written communication in English was required.

- 2. The relationship between BSL and English.** It is a common misconception that BSL is a visual version of English, or uses in a simplified way English expressions with gestures to aid understanding. Also it is commonly assumed that if a Deaf person uses BSL they must also be able to lipread. However, BSL is not based on English, it uses a highly complex and very different grammatical structure. Speaking English and adding signs does not necessarily enable access to English, as the grammatical bases of the languages are so different. Only around 30 to 40% of speech is lipreadable, the



rest is guesswork, dependant largely on contextual clues. Abilities to lipread vary dramatically amongst Deaf people. In part this variation can be associated with different origins of deafness which have varying effects on speech perception over and above abilities to hear.

Therefore:

- There are **negative consequences involved in paying attention to functional language abilities rather than an individual's language preferences.** It is an easy assumption to make that a Deaf person seems to be 'getting by' in English because s/he might articulate some words in spoken English or might seem to indicate they can understand through lipreading. However, whether or not someone might be able to 'get by' in English or through lipreading is of less relevance than whether they should actually do so. A language we are less familiar with or less confident in will constrain our understanding and expression.

For example, many assessments associated with social care provision will require close engagement with the details of an individual's life and context and close identification of their strengths and preferences as well as needs. This is often a result of interactive engagement which builds an holistic picture of the individual through communicative exchanges. If the professional involved does not enable an assessment in a service user's preferred language and/or assumes that communication is adequate enough (from their point of view) they not only run the risk of an incomplete or false assessment but they constrain the service user's rights of involvement, self direction and autonomy.

A study of the practice of social work assessment with Deaf adults argued there were three elements to effective engagement between assessors and Deaf adult service user: (i) judgement about the most appropriate approach to communication; (ii) communication skills at the right level; (iii) ability to evaluate the quality of mutual communication.

A series of reflective questions were suggested to facilitate better practice in adult assessment involving Deaf people:

- ? Does the assessor have knowledge of the full range and variation of communication preferences to be able to judge the most appropriate method of communication in any given situation involving a d/Deaf person?**
- ? Does the assessor have the skills at an appropriate level to carry out the assessment?**
- ? Can an assessor make an appropriate evaluation of their own skills deficits and act accordingly?**
- ? Does the assessor have enough knowledge, skills and experience to be able to evaluate whether communication during the assessment is optimal and if not to consider different strategies/alternatives?**

3. The relationship between BSL, Deaf culture and disability. The cultural meaning and implications of being Deaf are not commonly recognised. It is more likely that deafness is seen as a deficit in hearing and therefore BSL as an adaptation to the deficit, rather than a language associated with a culture that confers a distinct identity. For example, the Equality Act 2010 does not mention BSL but does acknowledge discrimination on grounds of disability including hearing disabilities and deafness. Subsequent guidance on duties associated with the Act mentions BSL as a potential reasonable adaptation for access on grounds of disability, just as adaptations might be made for individuals with sight impairments. Equality is not framed in terms of the citizenship rights of a particular language using group who might be discriminated against on account of linguistic or cultural identity.

Therefore:

- It is important to **examine the basis** on which older Deaf people's social care needs might be assessed, funded and delivered. Therefore;

Being sensitive to and meeting an individual's cultural and linguistic needs is understood readily in terms of hearing people who might be identified as members of ethnic and/or cultural minorities. However, Deaf people are not necessarily perceived as such, with identification of needs consequent on disability (hearing) being more obvious. Would it be usual for example to write into a care plan funding for transportation to the Deaf club on a regular basis under meeting a cultural need? Would the principle of avoiding dependency and promoting independence be understood in terms of collective living with other sign language users, rather than the maintenance of an individual's own home and ability to live alone? Many Deaf people who live alone and have care services within the home experience minimal contact with anybody with whom they can communicate. In these circumstances maintaining independence through remaining at home may have quite the reverse effect.

4. The lack of a workforce who use BSL fluently and/or who are Deaf themselves.

For Deaf people the delivery of services directly in their own and preferred language has several dimensions.

- The avoidance of mediated communication.** Many Deaf people will experience large proportions of their lives through mediated communication (i.e. via interpreters) when not communicating with other Deaf people. Direct communication is prized because of the increased likelihood of interactive rather than directive communication. The opportunity to engage in real-time exchanges (rather than one party or other always being behind as a result of interpretation). Getting to know an individual directly through their communication (many Deaf people will say they do not feel they ever fully 'know' someone with whom they might communicate unless it is direct through a shared language rather than indirectly through an interpreter).

Most contact with social care services and health and social care professionals occurs at particularly sensitive or complex times for older Deaf people e.g. transitions to new care arrangements or changes in health status. Being able to engage with service providers directly rather than second hand is of particular value in reducing the stress and burden of communication and feeling that communication is occurring with someone who is likely to be sensitive to and understand needs. For example, Parker (2010), a Deaf daughter, in her narrative account of her Deaf mother's diagnosis of Alzheimer's, explains what it was like for her both to receive the diagnosis of her mother's condition through an interpreter and to watch her mother's inability to understand what had happened even though an interpreter had been present (brought by the carer, not provided by the hospital):

"Once the doctor had finished all the tests and had looked at the findings, he addressed my mother (through the interpreter) and told her that he'd completed the tests on her, and they showed that she had Alzheimer's

disease, which was affecting her memory. My mother just looked at him blankly, but I burst into tears and was comforted by the nurse. My mother looked round at us and just asked why I was crying. I asked the specialist a couple of questions that I wanted honest answers to... When we left and got outside, I was still very upset and crying hard. The interpreter was trying to console me and my mother joined her, telling me not to cry and asking what was the matter. I couldn't believe she hadn't seen what the doctor had said, but she didn't seem to recall it and I realized she'd not understood, not taken in what he'd said to her. I had to wipe my eyes, pull myself together, calm down and just get both of us home."

- Increased likelihood of cultural competence.** Native users of languages are generally culturally competent in the communities associated with the language use; second language learners will acquire differing degrees of cultural competence depending on their immersion and experience with communities of language users.

Direct service provision from Deaf people and/or fluent BSL users is more likely to promote confidence in the cultural competence of the service provider to be sensitive to and meet the service users' cultural needs. There are many examples where this does not happen, often associated with the issues of language use and access mentioned above. However, cultural competence extends further.

For example, a recent study of palliative care involving Deaf people drew attention to the importance of considering the consequences of some choices of medical intervention being different for an individual who uses visual communication for receptive language in comparison with someone who speaks and is auditory.

For example, if there were an alternative intervention which did not impose physical constraint on using hands or which resulted in lesser degrees of sedation then communication could be maintained longer. Similarly, suggestions to relatives such as keeping on talking to the patient during their final days

because ‘hearing is the last sense to go’ are insulting and insensitive if the patient is deaf and/or the carer a sign language user.

In her account of her Deaf mother’s care as an older Deaf person with dementia, a Deaf daughter recalls the problems she encountered on hospital visiting which resulted from lack of awareness of the significance of interpreters:

“My mum’s Alzheimer’s was beginning to take its toll. She collapsed and was taken into hospital. When my sister and I visited, we took an interpreter with us so we could all have full access to any information from the staff. To our frustration we were told off by the nurses because only two visitors were allowed! They just did not understand the interpreter had a professional role. She was not just another visitor. In the end we were allowed to stay but I was so very upset. A very difficult situation was made worse by their lack of Deaf awareness.”

Concerns about service access in BSL. There are longstanding concerns about the linguistic fluency in BSL of social care professionals, whether social workers or care staff. A national inspection of social work with Deaf people in 1997 raised serious concerns that social work and social care staff working with Deaf adults were frequently required to carry out tasks whose complexity exceeded their linguistic fluency in BSL.

A follow up study of 15 social work teams in 2002 found only marginal improvements in BSL qualifications and the same substantive concerns. More recent evidence points to the significant decline of specialist social work with Deaf people. This is not just an issue of teams merging and not retaining a Deaf or sensory team, it is a fundamental decline in specially trained, qualified and experienced social workers who work with Deaf people. Instead tasks are increasingly carried out by generic workers with or without sign language interpreters. As the evidence reviewed above has already demonstrated, such an approach carries particular risks, is not necessarily appropriate and should raise concerns about Deaf individuals’ rights.



A perceived lack of services available directly in BSL or through service providers who are Deaf also creates additional consequences for Deaf carers. The 2009 GP patient survey revealed that 27% of Deaf respondents had care responsibilities in comparison with 9% of the general population overall. This was interpreted as implying that Deaf people felt under greater obligations to take on caring roles because of the perceived lack of services routinely available in BSL that would be accessible either to them as carers or to those they cared for if Deaf. Several accounts of caring for a parent or spouse with dementia have pointed out the difficulties of accessing support groups if the carer is Deaf. For example, interpreting provision is problematic because nobody accepts responsibility to fund it if the group is run within the voluntary sector; the Deaf carer is the only Deaf person in the group which can inhibit discussion and limit making the most of peer to peer support. Information provided is largely inaccessible for the reasons previously outlined.

“The meeting was a disappointment, through no fault of the participants. I should have known how Dad would react to a group of hearing people. As he’d always done with strangers, my father smiled politely, nodded, answered questions briefly and volunteered nothing. What he really needed was a group of deaf folk – people he would trust – going through the same experience. The Alzheimer’s connection was not nearly enough to break down the walls between hearing and deaf cultures... We never went back.”

Summary

We began this section by asking what is the interaction between being Deaf and being an older person on the domains of social care activity, its purposes framed as outcomes and its underlying principles. We are suggesting that the interactions are complex but gravitate around three core issues:

- I. the significance of social and cultural networks and social engagement with Deaf people
- II. the impact of lifelong inequalities and vulnerabilities
- III. the central importance of language and cultural competence in service access and provision

Further detailed research is required to unpack the processes by which these issues impact on social care with older Deaf people but the evidence as far as it is available and examples of the interactions have been explored.

Factors influencing social care services and older Deaf people.

- Maintenance of social and cultural networks and engagement with other Deaf people
- Impact of lifelong inequalities and vulnerabilities
- Central importance of language and cultural competence in service access and provision

DOMAINS OF SOCIAL CARE ACTIVITY

- Physical health
- Mental health
- Housing and care
- Safeguarding
- Transitions
- Access to information and support
- Financial and economic well-being

OUTCOMES

- Improved health and emotional well-being
- Improved quality of life
- Making a positive contribution
- Choice and control
- Freedom from discrimination
- Economic well-being
- Personal dignity

PRINCIPLES IN SERVICE DELIVERY

- Designing services around older people
- Personalisation and choice promotion
- Cultural sensitivity
- Equality
- Dignity

Conclusions

The aim of this review was to provide information, evidence and analysis which would aid in decision making and forward planning associated with the social care needs of older Deaf people with whom RAD and [sonus] have contact. We have provided:

- Estimates of likely size and typical characteristics of the population
- Frameworks for understanding older people's social care
- Analysis of the intersections of being Deaf and being an older person within frameworks of care

As we have presented this work we have also:

- pointed out the gaps in the evidence base
- indicated key questions requiring further investigation

The main take-home messages from this review are:

Overall the evidence base in this area of specialist practice is sparse and conclusions reached by extrapolation should be approached with caution.



The size of the older Deaf population as a proportion of the general Deaf population is increasing significantly and will continue to do so, requiring a greater attention to resources, needs and effective service delivery.

A conservative estimate of BSL users in the UK over 65 years of age shows the numbers increasing from 8,500 to 11,500 by 2035. A more radical estimate suggests an increase over the same period from 19,720 to 26,680.

Older Deaf people's strengths, life experiences, preferences and characteristics are not necessarily the same as those of younger generations. Therefore service delivery and design needs to be mindful of those.

The consequences of the social, educational and economic circumstances in which today's older generation of Deaf people grew up and have led their adult lives create significant vulnerabilities in older years associated with health, well-being, access to resources and safety.

Deaf people experience life-long inequalities in access to health, education and social care, resulting in significantly poorer health and well-being outcomes. These impact on the challenges of older age over and above the ageing process itself.

Deaf people experience significantly poor access to information about health, care and services. However, access to information in BSL is not enough to promote personalisation of services, informed choice and the execution of personal preferences in the take up of available support and care. Decision making is based on meaningful knowledge, not information alone. Tailoring knowledge acquisition to process of collective debate, discussion and shared information is likely to be more effective.

The maintenance of social and cultural networks is a priority in the maintenance of health and well-being. They have a positive and measurable effect over and above simple respect for cultural identity.

Sensitive services which promote dignity, autonomy and independence require cultural competence over and above access to communication in BSL.

Service providers being able to communicate in BSL is fundamental to the identification of need, assessment, provision of services and effective delivery. Direct and unmediated communication where possible supports principles of sensitive, individualised and culturally appropriate services.

The basis of equality of services for older Deaf people is an issue of citizenship rights, based on language and culture as well as access and adaptation based on disability. This is of importance in the planning and execution of services.

Further questions

In the course of the review we identified **6 key questions** which whilst being the basis for further research are also leading questions appropriate for the planning and provision of social care services from a provider perspective:

- 1** In what ways do the characteristics of the population of older Deaf people obscure need, hide strengths and hinder effective service provision within the domains of activity?
- 2** To what extent do the characteristics of health and social care provision in the mainstream facilitate or deny equitable access to effective social care services for older Deaf people?
- 3** Do we know from older Deaf people themselves, their definitions of desired outcomes which support their aspirations, goals and priorities?
- 4** What might facilitate or hinder the achievement of outcomes which are valued by older Deaf people?
- 5** How does the minority cultural-linguistic status of Deaf people impact on the execution of core principles within the provision of social care for them?
- 6** On an individual basis, how should Deaf people's language, culture and values shape the services to which they are entitled?

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Bay Area Coalition of Deaf Senior Citizens, San Francisco, USA. <http://www.deafseniors.com>

Deaf with dementia research project: <http://www.nursing.manchester.ac.uk/deafwithdementia/DeafwithDementiaprojectteam/>

Dignity in Care Network <http://www.dignityincare.org.uk/>

Sign Health: <http://signhealth.org.uk>

Sources

How was the literature identified?

Multiple strategies were used to identify the relevant literature on which this report is based.

1. Electronic data base searches

- We used four electronic data bases: ASSIA (Applied Social Science Index and Abstracts); CINHAL (Cumulative Index to Nursing and Allied Health Literature); PsychINFO (psychological literature information); and Social Care Online. The data bases were searched using the terms 'deaf AND old', 'deaf AND seniors', 'deaf people AND social work', 'deaf AND care', 'deafness AND care', 'sign language AND older people' for the period 1995 to present day for peer reviewed and scholarly literature written in English. Literature identified as relevant was read and the reference lists of each was also used as a means of identifying further potentially relevant work.

2. Previous research studies

- We used the references and literature underpinning previous research we had carried out as a source for this review as well as the material and conclusions from those studies.

3. Official data sets

- We used a variety of official data sets which are available online including those from ONS (Office of National Statistics), historical archives associated with previous census material.

4. On line searches of practice and organisational provision

- We identified web based materials associated with the provision of care to older Deaf people from around the world and used these to assist us in the conceptualisation of need/unmet need in addition to the research literature as well as to support practice related conclusions.

5. Professional guidance/practice literature

- We reviewed material available through professional organisations such as SCIE as well as the relevance of generic materials available to social work and social care through DH and third sector organisations.



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