

Research into the Deaf audience in the UK

A review of evidence

Final report to the British Sign Language Broadcasting Trust

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Foreword

The British Sign Language Broadcasting Trust (BSLBT) is a small organisation with a unique and challenging remit: to make high-quality, sign-presented programmes that inform, educate and delight the UK Deaf community.

Our definition of the “Deaf community” centres on people who use BSL as their first or preferred language. This is a diverse group, varying in age, ethnicity, background and interests as widely as the general TV audience, and it is also a group that experiences a high degree of social exclusion. Both the diversity and the exclusion pose challenges for BSLBT as we try to target limited resources in the most effective way possible.

We work hard to engage with Deaf people, seeking their feedback and preferences, but are we reaching everyone we should? The need to know more about the audience was the starting point for this research.

We commissioned OPM to conduct a comprehensive review of the existing literature and data about the UK Deaf community and to draw out what it tells us about people’s needs and aspirations. We are grateful to OPM for their rigour and thoroughness.

The report provides a vivid reminder of the degree to which the Deaf community has been marginalised and overlooked, because its principal finding is that very little research has been done in this field. This means that there is little hard evidence to help BSLBT -- or any other provider of services -- to meet the Deaf community's needs and aspirations.

BSLBT will use the report to guide audience engagement work and inform a pragmatic approach to planning, but the need for enhanced knowledge about the Deaf community remains. The report highlights opportunities for agencies tackling isolation and social exclusion to work together on this and BSLBT is open to discussions and collaboration with any organisation that shares our interest in the Deaf community and wishes to build a shared understanding of Deaf people’s lives.



Ruth Griffiths, Executive Chair

The British Sign Language Broadcasting Trust

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Executive summary

The British Sign Language Broadcasting Trust (BSLBT) commissioned the Office for Public Management (OPM) to conduct a review of evidence about the Deaf audience. The purpose of this research is to understand more about the highly marginalised Deaf community within the UK, with regards to demographics and language use, as well as life issues such as integration into the wider world, health status and access to health services, and use and views of television and the internet. The findings will assist BSLBT in using its resources cost effectively to provide future television programming for the Deaf community. It is also hoped the report will add to the wider world's understanding of the life experience of Deaf people and the issues Deaf people face.

This report focuses on Deaf people whose first or preferred language is sign language. They do not view their deafness in medical terms, and reject the notion of deafness as a disability. The Deaf community sees itself as having a distinct social, cultural and linguistic identity. The term 'Deaf community' is generally only used and understood by that minority of deaf people for whom being deaf is a significant part of their cultural identity and not those who view their inability to hear as a disability. Lower case 'deaf' is *mainly used to describe those people who have lost some or all of their hearing in early or later life*. This group, who choose to use speech and lip-reading and regard English as their first language, are not the focus of this report.

From the small body of literature and data available, the key findings are:

Size and demographics of the Deaf community

There are no reliable estimates of the total number of Deaf people in the UK or their demographic profile.

- In 2010 there were 56,400 people registered as being deaf in England, and in 2014 there were at least 48,125 deaf children aged 0 to 19 across England, Northern Ireland, Scotland and Wales
- Studies suggest that the estimated prevalence of permanent bilateral hearing impairment is 1/1000 live births with this potentially rising to at least 2.05/1000 among children aged 9 and older
- Census data shows that there are 15,482 people in England and Wales whose main language is British Sign Language (BSL). However, prevalence data from the GP Patient Survey suggests that 0.44% of the adult population in England, roughly 188,000 people, are deaf and use sign language. According to the Scotland Census there are 12,533 people in Scotland who use BSL at home, but BSL may not necessarily be their first or preferred language. There is no data for Northern Ireland

- There is very little data regarding the demographic profile of the Deaf community aside from the 2011 Census for England and Wales. According to the 2011 Census, 80% of BSL users are white and 19% of BSL users are located in London

Balance of the use of British Sign Language and standard English

There is limited research on the balance of use of BSL and English in Deaf people's everyday lives

- According to the 2011 Census for England and Wales, 65% of people who use BSL as a main language cannot speak English or cannot speak English very well
- The majority of deaf children (87%) rely on spoken English at school, while 9.4% use sign language as their main language or in combination with another language
- Qualitative research with deaf children found that sign language is a very important aspect in their lives and children attending sign bilingual schools are more confident when communicating with non-signing children
- Qualitative research with young deaf people found that the use of BSL at home establishes a positive view of deafness, however many parents are not supportive of BSL and are not keen on their children using BSL as it confirms their child's difference. Instead, parents want their child to pass as 'hearing', and support the use of hearing aids as a means of engaging in the hearing world
- There is no UK data on the percentage of Deaf children born into Deaf families. However, in the USA it is estimated that 4% of deaf children have at least one deaf parent and 92% are from families where both parents are hearing

Educational attainment and language proficiency

There is evidence of significant disparities in the educational attainment of Deaf children compared to hearing children. However, there is no data regarding Deaf adults and there is a shortage of data regarding language proficiencies

- According to the 2011 Census for England and Wales, 65% of BSL users cannot speak English or cannot speak English well
- Language and literacy proficiency among Deaf children is poor, although there is a lack of recent data on this
- The age at which BSL is taught affects the signing ability of Deaf children and adults. Children who have had late access and exposure to BSL may have restricted use
- Educational attainment of Deaf children is far worse than that of hearing children, and this is true at all levels of education. However, data suggests that the attainment gap appears to be narrowing, particularly among the earlier years of education

Integration into the wider world

There are a number of studies exploring the integration of Deaf people into the wider world

- Deaf people are excluded from society and suffer from social isolation
- Deaf people face difficulties in accessing and using local services. This includes a shortage of information and services in BSL, a shortage of specialist support services, a shortage of qualified interpreters, and general lack of deaf awareness
- Deaf people face barriers to employment, and there is evidence to suggest the unemployment rate among Deaf people is higher than the general population
- Deaf children and young people face issues with regard to education and schooling. These are related to social interaction and friendships at school as well as the provision of specialist education services, such as Teachers of the Deaf

Association between Deafness and health or other disabilities

There are comparatively few studies that assess the health status of Deaf people in the UK. However, one recent comprehensive study was the Deaf Health study. **There are a number of studies focussing on access to health services.**

- Evidence suggests that Deaf people have higher prevalence rates of obesity, high blood pressure, mental health issues, and depression compared to the general population, but they have lower prevalence rates of cardiovascular disease, high cholesterol and chronic obstructive pulmonary disease and are less likely to smoke and drink alcohol
- Deaf people are more likely to be under-diagnosed. Even when diagnosed, they are more likely to have poorer treatment and management of potentially serious health conditions
- Deaf people face many barriers when accessing health services. They face difficulties booking and attending health appointments, and in communicating with health professionals. There is often an absence of BSL interpreters at consultations, and Deaf people may instead have to rely on friends and family. Overall, Deaf people may be discouraged from accessing health services
- Deaf people have poor health knowledge, potentially because of a lack of health information in accessible formats

New technologies and social media

There is limited recent research on Deaf people's experiences of new technologies and social media. The literature tends to focus on the use of communication technologies, such as SMS and email, as well as the use of the internet among the Deaf community. The

review did not identify any data on the use of social media, notably Facebook and Twitter, and applications such as FaceTime/Skype.

- Deaf people make use of a number of digital communication methods, including SMS, email, and teletypewriters. There is evidence to suggest that email is the most widely preferred, with SMS is more common among younger Deaf people
- There have been a number of studies focussing on internet use and experiences among Deaf people, but few of these studies have been recent. Nonetheless, they have identified a number of benefits of the internet. The internet provides an alternative way of communicating with other Deaf people, facilitates the development of social networks, and allows Deaf people to access online education and information
- The internet allows Deaf people to pass as hearing online and may facilitate greater integration between Deaf and hearing people. However, this does not necessarily increase the integration of the Deaf community into mainstream society

Television

There is limited recent and robust research on Deaf people's views on television broadcasting. There has been some research but many of the studies pre-date the creation of BSLBT in 2008 and are based on a very small number of participants

- Deaf people want Deaf presenters instead of hearing BSL interpreters, and the accuracy of information in BSL is prioritised over the appearance of the signer
- The most important types of programme for in-vision interpretation are news programmes, educational programmes, and documentaries
- Many Deaf people want both signing *and* subtitles on TV
- Many Deaf people watch TV online

Recommendations

This important review provides a summary, adds to the knowledge base on the Deaf community and has highlighted the extent to which this community is highly marginalised, under-represented, and under-researched. This research has highlighted the lack of data, and poor understanding of the Deaf community. In light of this, our recommendations are:

- **BSLBT to investigate more effective methods of audience engagement**

We recommend that BSLBT explores what effective and realistic audience engagement should look like in the context of its organisational aims, structure and resourcing. For example, BSLBT should take into consideration the finding from this review that there is very little reliable evidence regarding the extent to which new

technologies and social media are changing Deaf people's experiences. This poses questions for engagement strategies that rely solely or largely on social media

- **All major public and charitable services are encouraged to:**
 - Understand and record use of their services
 - In light of this, consider how they might make their services more accessible

Through commissioning this review BLSBT has demonstrated commitment to raising awareness of the urgent need for robust research into the Deaf community, at the same time raising questions around the status quo which is often based on claims and assumptions that may not always be backed by evidence. These have major implications for the extent to which agencies are able to meet the needs of the Deaf community

- **Encourage a collaborative approach to the gathering of new evidence**

We recommend that Deaf charities and other organisations who may hold relevant evidence and data adopt a strategically collaborative approach to sharing data and creating synergies through joint working that will be of benefit to all. For example, it may be fruitful to explore how Deaf charities and others may work together to influence the gathering of national statistics that asks sensible questions of and on the Deaf community. One avenue potentially worth exploring is the 2021 Census

- **Recognise the marginalisation of Deaf people as an important manifestation of the current social policy focus on overcoming isolation**

It can often be easy to regard issues relating to the Deaf community as “minority issues” that are only relevant to specialist organisations. This review, however, challenges this perception by showing that the experiences of the Deaf community are manifestations (and amplifications) of cross-cutting social issues that have wider relevance for society, albeit with important nuances. For example, isolation and exclusion were recognised social problems demanding the highest level of attention from policy and practice. It is important to appreciate that we, as a society, cannot hope to tackle such problems meaningfully if we do not address the needs of some of the most isolated and excluded segments of society. A truly inclusive society requires us to treat every person as a person, first and foremost, and not as an identity label. We recommend that the findings in this review, while relating to the Deaf community, are not treated as “minority issues” that are bracketed off and de-prioritised. Instead, we strongly encourage a genuine person-centred approach that enables us to break down silos and adopt more holistic approaches to solving the problems identified.

1. Introduction

1.1. About the research

1.1.1. Purpose of the research

British Sign Language (BSL) is the most common sign language in the UK, and is the first or preferred language and method of communication among the UK Deaf population. BSL is a language of its own and was recognised by the UK government as an official minority language in 2003, similar to other minority national languages such as Gaelic and Welsh. BSL has its own grammatical structure and syntax, and is not strongly related to or dependent on spoken English.

In 2008, the British Sign Language Broadcasting Trust (BSLBT) was established to increase the amount of sign-presented programming on digital terrestrial television. It commissions content made in BSL by Deaf people for Deaf people and offers an alternative for broadcasters in meeting requirements for the provision of sign language on their channels. In early 2012 BSLBT was granted charitable status, with a remit to promote:

“social inclusion among the Deaf community who are socially excluded from society, or parts of society, as a result of being deaf by encouraging, supporting and developing the provision of broadcasting of sign-presented content (in any media) for the members of the Deaf community.”

BSLBT aims to address the social exclusion of Deaf people. It is the sole provider of television programmes made specifically for the Sign Language community. As well as providing vital information in their native language, it also allows Deaf people to see themselves and their lives reflected, and their experiences and culture shared and acknowledged through their preferred language. This provides Deaf children and young deaf people with role models to identify with, while a geographically fragmented deaf population is brought together and validated as a community. In addition, the programmes provide visibility of the Deaf community to the mainstream world.

BSLBT has recognised the need to undertake new, original research into the core audience for BSLBT's sign-presented programming, i.e. those people in the UK who use BSL as their first or preferred language. Responding to the apparent shortage of research into the Deaf community in the UK, BSLBT commissioned the Office for Public Management (OPM) in November 2014 to conduct a review of evidence about the Deaf audience. The purpose of this research is to understand more about the highly marginalised Deaf community within the UK, with regards to demographics, integration into the wider world, health status and access to health services, use and views of television and the internet, etc.

The research also aims to help the wider world to understand the implications of being Deaf and the life experience of Deaf people. BSLBT believes that, as well as building the evidence for its own strategic planning, this research has the potential to transform what is known

about the highly marginalised Deaf community within the UK. As such, new research is also likely to be of significant use to a range of other agencies that work with, or provide services to, the Deaf community, including health, education, employers and other leisure and recreation providers.

1.1.2. D/deaf and the Deaf community

This report focuses on the Deaf community and this section will clarify what the term ‘Deaf community’ means, but it is first important to distinguish between deaf with a lowercase ‘d’ and Deaf with an uppercase ‘D’. There is often variation as to the use and definitions of ‘Deaf’ or ‘deaf’, but Ladd (2003)¹ provides an in-depth analysis and discussion of Deaf culture and the associated definitions and terms.

Lowercase ‘**deaf**’ is used to refer to: *“those for whom deafness is primarily an audiological experience. It is mainly used to describe those who lost some or all of their hearing in early or later life, and who do not usually wish to have contact with signing Deaf communities, preferring to try and retain their membership of the majority society in which they were socialised”*. This group choose to use speech and lip-reading and regard English as their first language (Ladd 2003).

In contrast, ‘**Deaf**’ is used to refer to: *“those born Deaf or deafened in early (sometimes late) childhood, for whom the sign languages, communities and cultures of the Deaf collective represents their primary experience and allegiance, many of whom perceive their experience as essentially akin to other language minorities”* (Ladd 2003).

Deaf people’s **first or preferred language is sign language**, and they regard themselves as a linguistic and cultural minority (Skelton and Valentine 2009). They do not view themselves in medical terms, and reject the notion of deafness as a disability (Atherton 2009). Deaf with a capital ‘D’ is used in the same way as ‘English’ or ‘French’ to indicate a cultural and linguistic identity and membership of a community, in this case the Deaf community (Valentine and Skelton 2009). The Deaf community sees itself as having a distinct **social, cultural and linguistic identity** and foundation which results from community members being Deaf (Ladd 2003). The term ‘Deaf community’ is generally only used and understood by that minority of deaf people for whom being deaf is a significant part of their cultural identity and not those who view their inability to hear as a disability (Atherton 2009; Ladd 2003).

However, there is often variation in the use of ‘Deaf’ or ‘deaf’. For example, someone defined as ‘deaf’ may or may not be a BSL user (Young 2014). This is particularly evident in research studies where both groups may be included, and distinction between the two is difficult. Thus the term D/deaf is often used in a dual form. In addition, the term ‘hard of hearing’ is often

¹ Ladd, P (2003). Understanding Deaf Culture: In Search of Deafhood

tied in with D/deaf and is used to describe people with mild to severe hearing loss. It is often used to describe people who have lost their hearing gradually.

The purpose of the review is to identify what is known about the Deaf audience and where the gaps in evidence lie, in order to a) inform BSLBT's strategic planning and b) inform potential future research to increase understanding of the Deaf audience and the range and diversity within it. This review focuses on Deaf people who are BSL users, as opposed to deaf people who do not use BSL and those who have no ties with the Deaf community or who have no Deaf cultural affiliations, or people who are hard of hearing or who have age-related deafness.

1.1.3. Research questions

The specific research questions identified by BSLBT for the review are as follows:

1. What are the basic demographics of the Deaf community in the UK – e.g. numbers, age, location, ethnicity, gender?
2. How integrated into the wider world are Deaf people and what factors affect this (e.g. age, family, educational background)?
3. What is the balance of BSL/standard English in their lives?
4. To what degree is Deafness associated with health or disability issues in people's lives?
5. To what extent are new technologies and social media changing Deaf people's experiences?
6. How true are some of the common assertions made about Deaf people, their lives and aspirations?²
7. How wide is the range of experience within the Deaf community and is there polarisation of experience, depending on age, education, income or other similar factors?
8. How can BSLBT best reach, and engage with, the Deaf audience?

1.1.4. Approach

As mentioned, the purpose of this report is to identify what is known about the Deaf community and where the gaps in evidence lie. OPM searched and reviewed the current literature on the Deaf audience in the UK in order to identify any relevant data and evidence to answer the questions listed above. This included both qualitative and quantitative data

² A list of these common assertions can be found in Appendix 1

from a range of methodological approaches, such as surveys, interviews, experimental studies, etc. A literature review was conducted so as to determine what is already understood about the topic and how extensively the topic has already been researched, and to help determine what questions and areas have not been addressed.

OPM also created an annotated bibliography of potentially useful datasets, which could merit fresh analyses in the future, in order to provide further evidence around some of the research questions. For example, analysis of census and large-scale national data may shed further light on the demographics and health of the Deaf community. The bibliography was created by accessing the UK Data Archive, which houses over 6,000 social science data sets, including quantitative data and qualitative data from a wide range of disciplines. A large part of this data archive consists of publicly funded data, including large-scale national statistical surveys.

1.2. This report

This report presents the findings of the literature review. It is based on 81 items which have been reviewed in full (please see the Methodology section for details of the search and selection process).

Important notes for readers

- **This report has focused on items with a clear evidence base. That is, reports which clearly outline their methodology and give the results, rather than policy, campaigning or opinion pieces which do not make their evidence base explicit**
- **For the purpose of fidelity, terminology is used in this review according to usage in the original items reviewed (e.g. if a study uses 'Deaf' with a capital D, this is the term used in describing the findings of that study). Please note that some studies were not consistent in their usage, even within the same study**

The annotated bibliography of datasets has been completed and can be found in Appendix 4 of this report. Fourteen datasets were identified, containing relevant variables, however these are all likely to be of limited value for further analyses because they do not allow analysis of data relating specifically to Deaf people (instead they refer to hearing difficulties and either do not describe their definition of this term and/or do not distinguish between deaf and Deaf).

2. Methodology

2.1. Scoping interviews

A number of stakeholders and experts had already been consulted by BSLBT in the early stages of the design of this research project. OPM revisited some of these key people to seek their input into our approach to the review, asking them to comment on the research questions and to signpost any existing research, published or unpublished, that should be accessed, including very recent material that may not have been included on bibliographic search engines yet.

As the review progressed subsequent interviews informed interviewees about the early findings and gaps in the evidence, and to seek their advice as to whether anything may have been missed and if so where to look.

A list of the seven interviewees, who were drawn from the academic and voluntary sectors, can be found in Appendix 2.

2.2. Literature review

2.2.1. Search

OPM conducted database searches with Professor Alan Gomersall, at the Centre for Evidence-Based Policy and Practice (CEBPP) at King's College, London. Alan is a recognised world expert in literature search and synthesis, regularly contributing to international systematic reviews conducted by the Cochrane Collaboration and the Campbell Collaboration.

Databases searched were as follows:

Database	Sector focus of database
Embase	Biomedical
Psychinfo	Behavioural science and mental health
Health Management Information Consortium (HMIC)	Health and social care management
Social Policy and Practice (SPP)	Social and public policy and practice including physical, mental and community health
International Bibliography of the Social Sciences (IBSS); Applied Social Sciences Index and Abstracts (ASSIA); Sociological Abstracts; Social Services	Social sciences

Abstracts 201014 (searched on Proquest)	
Medline	Life sciences and biomedical
Linguistics and Language Behavior Abstracts (LLBA)	International linguistics and related disciplines in the language sciences

Search terms were drafted based on the research questions and with the input of BSLBT, early scoping interviewees, and Professor Alan Gomersall. An iterative search strategy, trying out different terms in order to produce the most relevant results for each research question. The databases were searched for literature published from 2000 onwards.

A complete log of searches, showing the database, timeframe, search focus and strategy, numbers of results and numbers of results selected can be found in Appendix 3.

2.2.2. Sift and selection

Following the search OPM developed a set of **inclusion standards** to inform a more detailed review of the long list of abstracts and evidence. These provide a set of robust parameters for our review and they ensure that only the most relevant evidence is included for the final review and synthesis. The inclusion criteria varied for different research questions depending on the amount of evidence available. Because of the scarcity of literature, the only key criterion was *relevance* to one or more of the research questions, and a fixed *date range* was not set across any of the questions. Other inclusion/exclusion criteria, agreed with BSLBT, were:

- Location – non-UK evidence was excluded as the focus of the review was on the Deaf audience in the UK. However, some exceptions were made for evidence that was clearly transferable and relevant in the UK context, and/or where there is little UK evidence (e.g. in the case of social media)
- Hearing impairment/loss – while the review aimed to focus on the Deaf audience (i.e. people who use BSL as their main or preferred language), and therefore to exclude evidence relating to people who have hearing impairment, difficulties or loss but who do not use BSL, it was not always possible to separate data on Deaf people from that on ‘deaf’ people. For the purpose of fidelity, the report uses the terminology used in the original studies
- Deafblindness – a few articles have been identified on people with deafblindness. These have been included in the report

Search results were subjected to an initial title/abstract sift and all potentially relevant material was accessed in full. The potentially relevant material was subjected to a full text sift using the inclusion standards, and reasons for inclusion or exclusion were recorded in the evidence database.

2.2.3. Review

Material that met the inclusion standards at this point was read and reviewed in full. Relevant data from each item was extracted and recorded in the database against the research question(s) to which it related.

The reviewed material was subjected to broad content analysis, with key themes and associations drawn out.

As noted earlier, the number of reviewed items on which this report is based is 81.

2.3. Annotated bibliography of datasets

OPM have conducted a scoping and annotation of key British datasets that have relevance for this research. This involved accessing the UK Data Archive based at the University of Essex. This is a repository of all major social research datasets in the UK, in their raw form. A search by key terminology was conducted to identify the range of datasets that contain key variables.

This annotated bibliography of datasets includes:

- Key variables (e.g. types, definitions) used in each dataset
- Coverage of each dataset (e.g. size of sample and sub-samples, country, etc.)
- Name of the dataset
- Year of the dataset

The purpose of the annotated list is to reveal whether (and what) useful information exists on particular issues, and whether evidence is comparable across different datasets.

Fourteen potentially useful datasets, i.e. datasets that might, on analysis, tell us something relevant to one or more of the research questions, were identified in the initial search. However, these are likely to be of limited use due to a lack of specific focus/set of questions on the Deaf community or BSL use. They predominantly ask whether respondents have hearing loss or hearing impairment and as such they do not clarify whether respondents are D/deaf and, importantly, whether they use BSL. The annotated bibliography can be found in Appendix 4 of this report.

3. Findings to date

3.1. A note on the literature evidence

As noted, a full list and description of the literature reviewed so far can be found in a separate Excel database; the database will be completed alongside the final report.

3.1.1. Type of literature evidence

To give a sense of the type of evidence that has been reviewed in full so far, and which this report is based on:

- The majority of items are from the UK, with a handful from other countries including the US, Australia and Spain – these mostly relate to communications technologies and social media, topics on which there is little published evidence in the UK and which may be considered to have some transferability to the UK
- The majority of items are based on primary quantitative or qualitative data (data collected by the researchers themselves, e.g. through surveys, interviews, focus groups) with some analysis of secondary data (data sources are data that already exists, e.g. previous research, official statistics). There was an even mix between qualitative and quantitative data, and many of the studies included multiple research methods, such as surveys, interviews and focus groups
- Most of the studies had a local/regional coverage as opposed to national
- There were a number of studies focussing on children and younger people, with a few studies focussing on elderly people
- Few studies explicitly focus on Deafness, i.e. ‘Deaf’ as a cultural and linguistic identity. Most do not distinguish, i.e. refer to both Deaf and deaf people, or do not specify

3.1.2. Coverage of the research questions

In terms of coverage of the research questions, the evidence base is very small for many of the questions and in some cases there is no evidence at all in key areas. From the items reviewed so far:

- The question with the most coverage is the one around the extent of Deaf people’s integration into the wider world, that is, levels of access to services and participation in social activity outside the Deaf community. In particular, a number of studies focus on education services and the experiences of young Deaf people at school. However, overall the scale of available data is still very small and there are large gaps in the literature. There are important areas and topics that have not been addressed at all

such as economic activity and employment among Deaf people and access/participation in culture, leisure, sport and politics

- The association between Deafness and health conditions or disabilities also receives a good amount of coverage
- There are fewer items providing demographic information about the Deaf population, about the balance of BSL and English in their lives, and about their use of new technologies and social media (as noted, much of the evidence on the latter comes from outside the UK)
- Evidence of the range of experience within the Deaf audience, the accuracy or otherwise of some common assertions about Deaf people, and about how BSLBT can best engage with the Deaf audience are not reported under these specific headings, because studies do not focus explicitly on them. This evidence is reported under the headings where it has most relevance

3.2. Evidence around the research questions

3.2.1. Basic demographics

This research question aimed to identify basic demographics of the Deaf community, and to provide some information on the size of the Deaf population as well as the number of BSL users. For this research question, there was very little evidence and most was based on national government statistics.

Key findings:

There is inconclusive data on the total number of people in the UK who are Deaf:

- In 2010 there were 56,400 people registered as being deaf in England (HSCIC 2010)
- In 2014 there were at least 48,125 deaf children aged 0 to 19 across England, Northern Ireland, Scotland and Wales (CRIDE 2014a)
- The estimated prevalence of permanent bilateral hearing impairment is 1/1000 live births (Bamford et al. 2004; NHS 2011), with this potentially rising to at least 2.05/1000 among children aged 9 and older (Fortnum et al. 2001)

There is inconclusive data on the number of BSL users in the UK:

- Census data shows that there are 15,482 people in England and Wales whose main language is BSL, and 12,533 people in Scotland use BSL at home. There is no census data for Northern Ireland
- However, prevalence data from the GP Patient Survey suggests that there are

188,000 people aged 18 or over in England who are deaf and use sign language

The 2011 Census for England and Wales provides demographic data of BSL users

- 80% of BSL users are white
- 19% of BSL users are located in London

Deaf population

The literature reviewed to date did not identify any studies providing reliable UK-wide estimates of the total number of Deaf people, although one piece of literature provides data on the number of people registered as deaf in England. **The Health and Social Care Information Centre (HSCIC)** produced two reports in 2007 and 2010 on 'People Registered as Deaf or Hard of Hearing'. These publications contain detailed statistics on the number of people registered as deaf and hard of hearing with Councils with Social Services Responsibilities (CSSRs) in England. Registering as deaf or hard of hearing is done through a local authority and requires an audiological assessment. Registering may allow individuals to be entitled to a range of benefits and concessions, such as Disability Living Allowance, Attendance Allowance, travel concessions, reduced TV licence fee, concessions for local libraries and theatres, etc. The 2010 report compared new data against findings from 2007, as well as previous figures obtained from the Department of Health. Following a consultation, it was announced that the 2010 report would not be repeated. According to HSCIC (2010), 56,400 people were registered as deaf in England as of March 2010. This was a 3% increase from 2007 and a 24% increase from 1995. The number of deaf people rose in all age groups, except for those aged under 18, and the largest increase was for those aged 75 and over. The report does not explain this increase, and does not provide any further demographic data, but it is likely that those aged 75 and over are most likely to have age-related deafness. The report also highlighted that the overall rate for the number of people registered as deaf increased from 102 per 100,000 to 109 per 100,000 between 2001 and 2010. In addition, 156,500 people were registered as hard of hearing.

Table 1: The number of people registered as deaf in England (1986-2010), by age.
Source: HSCIC 2010

Year	All ages	Under 18 (%)	16-64 (%)	65-74 (%)	75 or over (%)
1986	34,100	9	60	12	19
1989	37,900	8	60	13	20
1992	41,800	9	58	12	21
1995	45,500	10	57	11	22
1998	50,100	8	54	12	26
2001	50,300	8	54	13	25
2004	55,000	7	53	15	24
2007	54,500	6	53	12	29
2010	56,400	4	53	12	31

Importantly, not everybody who is deaf will have registered. As such, the report notes that *'since registration is not compulsory, these figures will not provide a complete picture of the numbers of people in England who are deaf or hard of hearing'*.

Since 2011, **The Consortium for Research in Deaf Education (CRIDE)** has conducted annual surveys on educational provision for deaf children in England, Northern Ireland, Scotland and Wales. The most recent survey was carried out in 2014 and reported that in 2014 there were at least 48,125 deaf children aged 0 to 19 across England, Northern Ireland, Scotland and Wales (CRIDE 2014a). This was a 7% increase from 2013 and a 16% increase from 2011, although the report highlights that it cannot be certain about the causes of this increase. These surveys were sent out to local authority specialist educational services, but the report does not specify how local authorities generate their data on numbers of deaf children.

Table 2: The number of reported deaf children in the UK (2011-2014). Source: CRIDE 2014a

Country	2011	2012	2013	2014
England	34,927	37,414	37,948	40,614
Northern Ireland	1,238	1,249	1,481	1,574
Wales	2,775	2,743	2,904	2,880
Scotland	2,526	-	2,842	3,057
UK Total	41,464	41,406 (excluding Scotland)	45,175	48,125

The Newborn Hearing Screening Programme (NHSP) is carried out in England, Wales, Scotland and Northern Ireland, and is automatically offered to parents with the aim of identifying moderate, severe and profound hearing impairment in newborn babies within the first few weeks of life, and the vast majority of parents agree to this. In 2010-11, 99.7% of parents in England were offered the screen for their newborn baby, with less than 1% declining. 98.3% of screens were completed within 3 months (NHS 2011). Two reports of the NHSP in England provide similar estimates of the prevalence of bilateral permanent childhood hearing impairment at birth, at 1 in 1,000 births (Bamford et al. 2004, NHS 2011). In 2013 there were 698,512 births in England and Wales³, 56,014 in Scotland⁴, and 24,279 in Northern Ireland⁵. According to the prevalence rates reported above, this would translate to roughly 780 newborns with permanent hearing loss in 2013 (note that this figure has been calculated by OPM, and is intended to provide a rough estimate of the prevalence rates using the studies mentioned).

Bamford et al. (2004) additionally indicate that the incidence nearly doubles by 9 years of age as more children are identified. Similarly, Watkin and Baldwin (2010) found that the rate of moderate or worse bilateral deafness rises to 1.51/1000 by the time children start primary education, and Fortnum et al. (2001) estimate that the prevalence of permanent childhood

³ Office for National Statistics (2014). Births in England and Wales, 2013

⁴ National Records of Scotland (2014). Births, Deaths and other Vital Events: Preliminary figures for 2013 released: <http://www.nrscotland.gov.uk/news/2014/births-deaths-other-preliminary-2013>

⁵ Northern Ireland Statistics and Research Agency (2014). Births in Northern Ireland 2013: http://www.nisra.gov.uk/publications/Births_2013.pdf

hearing impairment rises with age to at least 1.65/1000 live births, and potentially as high as 2.05/1000, among children aged 9 and older. Fortnum et al. (2001) suggest that the higher prevalence may be due to some cases not being detected by the screening test, some children acquiring hearing impairment postnatally, and some children manifesting late onset or progressive hearing impairment.

Table 3: prevalence of bilateral permanent childhood hearing impairment

Study	Prevalence at birth	Prevalence in later childhood
Bamford et al. 2004	1 per 1,000	Nearly doubles by 9 years of age
NHS 2011	1.01 per 1,000	-
Watkin and Baldwin, 2010	0.9 per 1,000	1.51/1000 among children starting primary education
Fortnum et al. 2001	-	Between 1.65/1000 and 2.05/1000 among children aged 9 and older

Numbers of BSL users (as opposed to numbers of Deaf people)

National statistics from census data were the only source of information identified that provided estimates into the size of the Deaf population in the UK, but there were some conflicting estimates. According to the 2011 **Census for England and Wales**, 21,963 people in England and Wales reported a sign language as their main language, with 15,482 people specifically stating that BSL was their main language. This was obtained from respondents answering the question '*What is your main language?*' Emond et al. (2015) suggest that given the difficulties of Deaf people in completing the form and the fact that the census does not obtain a 100% return, there are potentially 20,000 people who use BSL and are members of the Deaf community. A report commissioned by the United Kingdom Council on Deafness used 2011 census data and mid-2010 population estimates to predict that by 2024 there will be 28,200 people in the UK who are '*Deaf and whose preferred language is a sign language*' (Cassiopeia Consultancy 2013), though they do not estimate the number of people who use BSL as their main language.

The **Scotland Census** 2011, on the other hand, asked the question '*Do you use a language other than English at home?*' and reported that 12,533 people in Scotland use BSL at home (NRS 2013). By extrapolating the Scottish figure across the whole of the UK, the British Deaf Association (BDA 2013) estimate that there are more likely to be around 156,000 people using BSL at home in the UK, which is considerably larger than the combined estimates obtained from the Census for England and Wales and Scotland Census. It is important to

note, however, that the question used in the Scotland Census does not ascertain whether BSL is the first or preferred language of the 12,533 respondents. The figure of 12,533 could include hearing individuals who use BSL at home when communicating with a Deaf family member as only 54% reported that they themselves were deaf or had partial hearing loss. Furthermore, 65% of the 12,533 respondents also reported that they speak English very well, only 10% said they do not speak English well, and a further 10% said they do not speak English at all (NRS 2013).

The **GP Patient Survey**⁶ asked respondents (aged 18+) if they were a 'deaf person who uses sign language'. Of the 836,927 respondents to this question, 3,711 (0.44%) stated that they were. This prevalence can be extrapolated using the most recent population statistics from 2013⁷. Using these population estimates and GP Patient Survey prevalence it could be estimated that there are roughly 188,000 people aged 18 or over in England who are deaf and use sign language [Please note that this rough estimate was calculated by OPM, and is not supported by the literature].

Table 4: Data sources for the number of BSL users in the UK

Source	Country	Question	Population numbers
2015 GP Patient Survey	England	'Are you a deaf person who uses sign language?'	188,000 deaf sign language users in England (extrapolated from 0.44% of adult population)
2011 Census for England and Wales	England	'What is your main language?'	14,721 BSL users in England
2011 Census for England and Wales	Wales	'What is your main language?'	761 BSL users in Wales
Scotland Census 2011	Scotland	'Do you use a language other than English at home?'	12,533 BSL users in Scotland 156,000 BSL users in UK (BDA 2013 estimate)

⁶ Ipsos MORI (2015) GP Patient Survey 2015

⁷ Office for National Statistics (2014) Population Estimates for UK, England and Wales, Scotland and Northern Ireland, Mid-2013

Detailed demographics

There are very few sources of detailed demographic data regarding the Deaf community, with the primary source being the 2011 Census for England and Wales. The Census breaks down the 15,483 BSL users⁸ by age, gender, ethnicity, and geographical location.

As shown in Figure 1, the majority of BSL users are under 50 years of age, with very few aged 75 or over. The age groups comprising the largest proportion of BSL users are 45-49 and 40-44.

Figure 1: BSL users by age. Source: 2011 Census for England and Wales

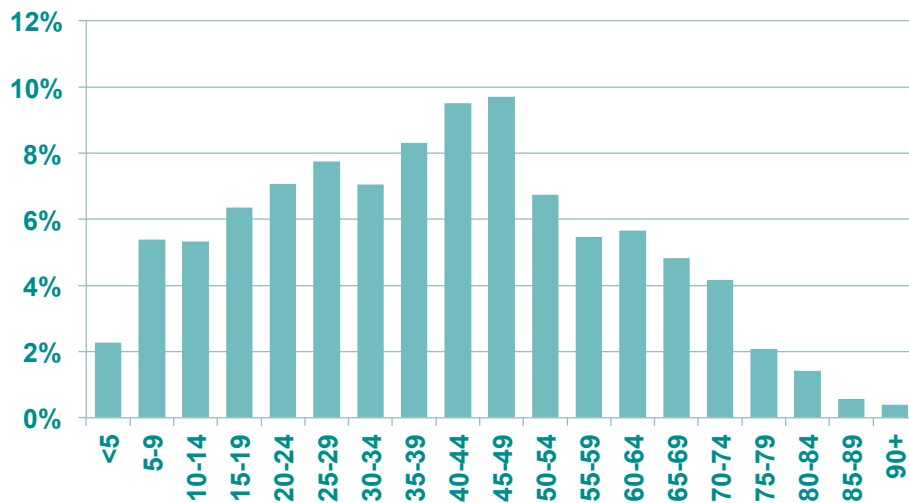
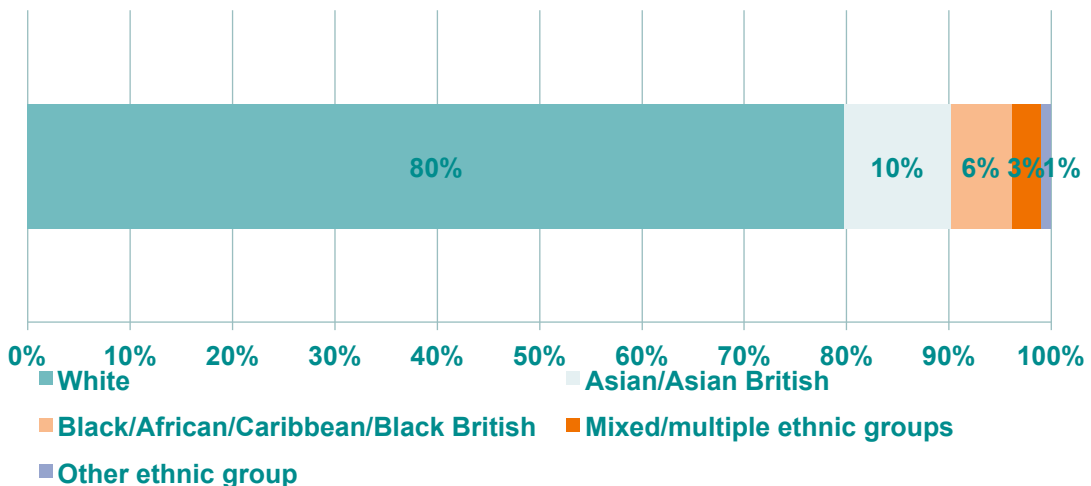


Figure 2 illustrates the ethnic breakdown of BSL users. As shown, 80% are White. 10% are Asian/Asian British.

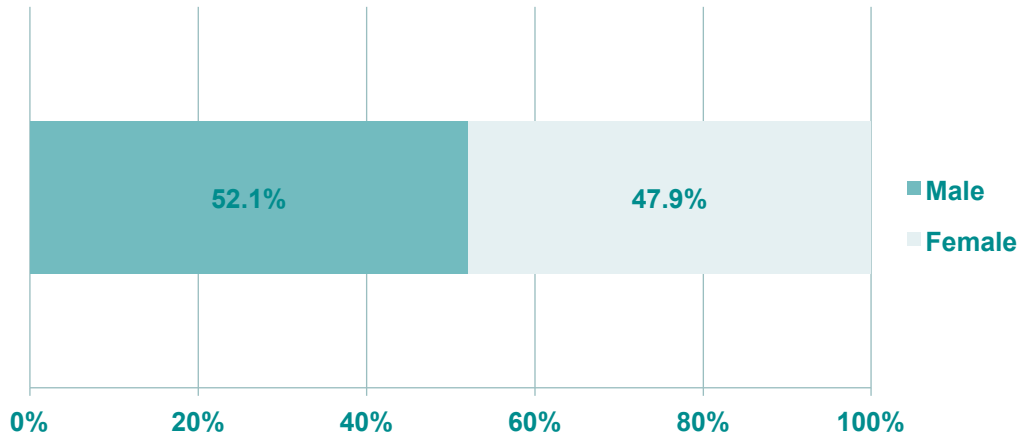
Figure 2: BSL users by ethnic group. Source: 2011 Census for England and Wales



⁸ Those who listed BSL as their main language

As shown in Figure 3, a slightly larger percentage of BSL users are male (52.1%) compared to female (47.9%).

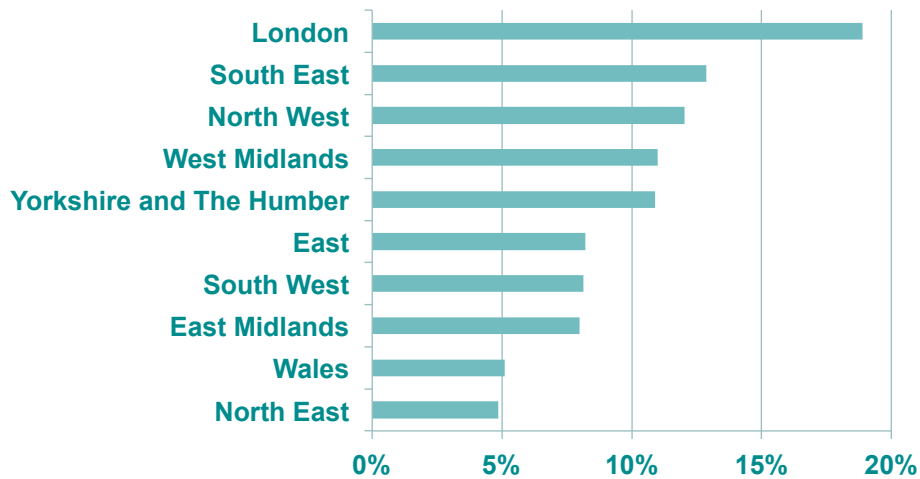
Figure 3: BSL users by sex. Source: 2011 Census for England and Wales



Lastly, Figure 4 shows where BSL users are distributed throughout England and Wales. The area with the largest proportion of BSL users is London, with almost a fifth (19%) located here. This is followed by the South East (13%) and the North West (12%).

Within London, the boroughs with the highest number of BSL users are Croydon (177 BSL users), Wandsworth (128), Enfield (126), Newham (126) and Lewisham (125).

Figure 4: BSL users by region. Source: 2011 Census for England and Wales



3.2.2. Balance of the use of BSL and standard English

This section aimed to understand the different mix of English and BSL in Deaf people’s lives, and whether this depends upon background, childhood, family, education, level of deafness, etc., but few studies explored this.

Key findings:

There is very little data on Deaf people's proficiency in/use of English and BSL

- 65% of people who use BSL as a main language cannot speak English or cannot speak English very well (2011 Census)
- At school the majority of deaf children (87%) rely on spoken English and 9.4% use sign language as their main language or in combination with another language (CRIDE 2014b)

Qualitative research with deaf children found that sign language is a very important aspect in their lives (Sutherland and Young, 2007)

- Most were pleased they attended a sign-bilingual school and felt this made them more confident when communicating with non-signing children

Qualitative research with young deaf people found that the use of BSL at home establishes a positive view of deafness, but that many parents are not supportive of BSL and are not keen on their children using BSL as it confirms their child's difference (Jones 2001)

- Parents want their child to pass as 'hearing', and support the use of hearing aids as a means of engaging in the hearing world

There is no UK data on the percentage of Deaf children born into Deaf families. However, in the US it is estimated that 4% have at least one deaf parent and 92% are from families where both parents are hearing (Mitchell and Karchmer 2004)

It is important to note the range of English language and literacy skills among the Deaf population as some have very low knowledge and usage of English whereas others may be fluent in reading, writing and speaking English, although there is little data to support this. The only relevant data is from the 2011 Census for England and Wales. Out of the 15,487 BSL users, 65% cannot speak English or cannot speak English very well, with the remaining 35% able to speak English very well or well.

CRIDE (2014b) reports that in England roughly 9.4% of deaf children (n=3395) either use sign language as their main language or in some combination with another language at school or in other education settings. Specifically, 1.8% (n=641) use BSL as their main language, 0.4% (n=147) use '[an]other sign language', and 7.2% (n=2607) use English, or another spoken language, together with a sign language. Almost 90% of deaf children do not communicate at all via sign language in their school or other education setting. In a separate study involving interviews with young deaf people attending mainstream schools, young people complained that teachers discouraged them from using BSL (Jones 2001). Along with the fact that 76% of deaf school children attend mainstream schools (NCDS 2009), this may explain why the large majority of deaf children have to rely on spoken English at school, however this has not been explored further in the literature reviewed to date.

Table 5: Number of deaf children in England, by languages mainly used at school /other education setting. Source: CRIDE 2014b

Language	Total	Percentage of responses (where known)
Spoken English	30,324	86.9%
Other spoken language	243	0.7%
Spoken English and other spoken language	735	2.1%
Total (do not use sign language)	31578	89.7%
British Sign Language (BSL)	641	1.8%
Other sign language	147	0.4%
Spoken English together with sign language	2,545	7.3%
Other spoken language together with sign language	62	0.2%
Total (use sign language/sign language with spoken language)	3395	9.4%
Other combination	276	0.9%

The relationship between sign language and English was explored by Sutherland and Young (2007) through workshops, video diaries, and interviews with 8 profoundly deaf children who used BSL as their first language and who were educated in sign-bilingual schools. The study found that sign language is of very high importance in the lives of the deaf children. Children expressed the importance of having deaf peer groups and being able to sign to each other with ease, fluency, and without frustration, with the ability to sign well improving their self-esteem. Most of the children were pleased that their parents chose for them to attend a sign-bilingual school. Attending a sign-bilingual school made the children more confident in using different tools when communicating with non-signing children, for example writing in English when necessary. The study noted that the deaf children's increased confidence might be partly due to them observing how other deaf children cope in similar situations. For example, they become aware that when communication becomes difficult they can resort to using pen and paper instead of giving up altogether (Sutherland and Young 2007).

A common assumption about Deaf children is that 90% are born into hearing families, and that the remaining 10% percent are born into families with one or more deaf parents.

Although our literature review identified a number of studies that referenced this figure, it did

not identify any research supporting this claim among the UK Deaf population. However, this claim is also frequently mentioned in the US literature and has been discussed in depth by Mitchell and Karchmer (2004). They suggest that the 10% figure overestimates the number of Deaf children born into families with one or more deaf parents. They instead estimate that only 4% of children have at least one parent identified as deaf and that 92% of children are from families where both parents are hearing.

Adding to this, interviews with young deaf people found that the **use of BSL at home** established a positive view of deafness, and that young people appreciated their parents' efforts to learn BSL because even basic signing facilitated communication within the family (Jones 2001). However, interviews with parents of deaf young people revealed that many parents viewed the use of BSL as a potential threat, as it confirmed their child's difference and reinforced language barriers. Thus many of these parents were not keen on learning BSL or on their children using BSL (Jones 2001). The authors argue that these parents' views of BSL may have direct implications for their child as many of the young people in their study complained about having to shift between BSL and lip-reading, while not feeling particularly confident in using either. The authors argued that this, in turn, breeds tensions between home life, school and social networks (Jones 2001).

Furthermore, many of the parents in the study by Jones (2001) wanted their child to pass as 'hearing' to enable their children to gain access and engage fully with the oral world. This view was also identified by Burgess and Monk (2013) who suggest that there is a strong desire for deaf children to gain speech and function in the hearing world. Many parents support and value the use of hearing aids as a means of engaging in the hearing world; however this is not always shared among young deaf people. Young deaf people felt that the use of hearing aids highlights their difference, which many were unwilling to publicise, and as such young deaf people's objection to hearing aids is symbolically important (Jones 2001).

The children in the study by Sutherland and Young (2007) talked about the pressures and difficulties of having to learn English, and saw it as being more for the benefit of hearing people than for deaf people themselves. They understood the need to learn and use English, but saw it as a '*hateful chore*'. Yet the children were also aware of the difficulties of hearing people learning to use sign language and said that they would use siblings as interpreters if communication became fraught. In addition, the children were apprehensive about using their voices when communicating with people who had little or no experience of being with deaf people. Some would sometimes speak whilst signing at the same time (Sutherland and Young 2007).

3.2.3. Educational attainment and language proficiency

This section addresses the educational attainment and language proficiency of Deaf people in comparison to hearing people. There is some data on language and literacy proficiency among deaf children, although much of this is relatively old. There is in depth and recent national data on educational attainment.

Key findings:

According to the 2011 Census for England and Wales, 65% of BSL users cannot speak English or cannot speak English well

Language and literacy proficiency among deaf children is poor, although there is a lack of recent data on this.

The age at which BSL is taught affects the signing ability of deaf children and adults:

- Children who have had late access and exposure to BSL may have restricted use

Educational attainment of deaf children is far worse than hearing children:

- This is true at all levels of education
- However, the attainment gap appears to be narrowing, particularly among the earlier years of education

Language and literacy proficiency

It is commonly claimed that D/deaf children aged sixteen have a reading age of nine. This was identified as early as the 1970s as Brown et al. (2004) and Cormier et al. (2012) cite a study from Conrad (1979) which found that the average reading age of a deaf school leaver in the UK is just under nine years of age. Although there have been no major UK studies since that of Conrad (1979), Watson et al. (1999) report that basic levels of literacy within the Deaf community are relatively low, and a review by Powers et al. (1999) found no substantive evidence that reading skills among D/deaf children are significantly improving.

Moreover, Fellingner et al. (2012), in their global review of the mental health of deaf people, identified similar studies in the US with findings that deaf students aged 18 to 19 years read at a level similar to that of the average 8 to 9-year-old hearing student (Traxler 2000; Paul 1998). Further international literature suggests that d/Deaf children have limited opportunities for optimal signed and spoken language acquisition (Marschark 2007), and that the majority of D/deaf children experience significant difficulties in achieving age-appropriate literacy (Mayer 2007). In addition, Burman et al. (2007) analysed writing samples of deaf children taught in BSL at schools for the deaf. They found that writing and spelling skills are poor among deaf children who use BSL. The authors suggest that child BSL-users face difficulties not encountered by hearing children who already speak English because the language the child BSL-user learns to write (English) at school is not the language of instruction in school (BSL) (Burman et al. 2007). Overall, the literature suggests that a large percentage of deaf people are highly deficient in spoken, heard, and written languages (Fellinger et al. 2012). Reflecting this, the 2011 Census for England and Wales found that 65% of BSL users cannot speak English or cannot speak English well.

On the other hand, there are also issues with sign language proficiency as Fellingner et al. (2009) found that with regard to deaf children who use sign language, many who have had late access to it, or insufficient sign-language models at school, have only a restricted use. Mason et al. (2010) used a questionnaire and assessment to identify language impairment in

deaf children acquiring BSL and note that some deaf children's first contact with signing is when they attend school at age four. The authors suggest that "*poor language skills may be explained by sign language being offered late (often only after failure with spoken English) and exposure to poor models of sign language, as most parents and teachers are non-native signers*" (Mason et al. 2010). This is supported by Cormier et al. (2012), who studied the effect of age of acquisition (AoA) of BSL on language proficiency among 30 deaf BSL users. The study found that grammatical judgement decreases as AoA increases, until around the age of eight, thus showing the unique effect of AoA on language proficiency among children. Interestingly, the same did not occur in participants who acquired BSL after the age of eight. The authors find that these later learners had first language proficiency in English instead, which may have been used as a platform for learning BSL as a second language later in life (Cormier et al. 2012).

Educational attainment

National statistics reveal large disparities in educational attainment for deaf children compared to hearing children.

Department for Education figures show that in 2014 40% of deaf children in England achieved 5 **GCSEs** (including English and Maths) at grades A* to C, compared to 69% of children with no Special Educational Needs (SEN; NDCS 2015). Likewise, Welsh Government data also shows significant attainment gaps in Wales in 2012, with 35% of deaf children achieving 5 GCSEs (including English/Welsh, Maths and Science) at grades A* to C compared to 59% of hearing children (NDCS 2013). NDCS (2013) calculated a relative attainment gap to show the likelihood that deaf children will achieve the same as hearing children and concluded that deaf children are 41% less likely to achieve as well as their hearing peers for GCSEs (NDCS 2013).

There is evidence to suggest poor attainment in **A-levels** as 42.7% of pupils with hearing impairments in England in 2013 achieved 2 A-levels or equivalent qualifications by age 19, compared to 65.6% of pupils with no SEN (DfE 2014). Poorer attainment and higher drop-out rates among deaf students are also common within Further Education in England (Young et al. 2015). Similarly, in Scotland young deaf or hard of hearing pupils are much less likely to obtain five Highers or Advanced Highers and instead are much more likely to leave school with low qualifications, or none at all (Fordyce et al. 2013). Hearing impaired students in Scotland also, on average, have far lower overall tariff scores compared to non-additional support needs students, at 289 compared to 439 (Scottish Government 2014b). However, from 2011/12 to 2012/13 the average overall tariff score increased slightly for hearing impaired students from 274 to 289. The number of hearing-impaired pupils leaving school also increased from 146 to 204.

Attainment gaps at **primary school** have been reported in England (NDCS 2015) and Wales (NDCS 2013). In 2014, just over half (54%) of deaf children in England left primary school with the expected benchmark levels of reading, writing and mathematics, compared to 90% of children with no SEN (NDCS 2015). In Wales, 80% of deaf children in 2011 achieved the

Core Subject Indicator (level 2 or above in English/Welsh, Mathematics and Science), compared to 94% of hearing children. (NDCS 2013).

There are also large attainment gaps in **pre-primary school** education in both England (NDCS 2015) and Wales (NDCS 2013). In 2014, over a quarter (26%) of deaf children in England achieved a 'good level of development' in the early years, compared to 66% of children with no identified SEN. Thus nearly three quarters of deaf children arrive at primary school having not achieved a good level of development in the early years (NDCS 2015). However, through comparing three/four-year-old deaf and hearing children's ability to remember and to reproduce the number of items in a set of objects, Zarfaty et al. (2004) argue that lower educational attainment may not be present among preschool children. The study findings suggest that "*preschool deaf children's number representation is at least as advanced as that of hearing children and that they are actually better than hearing children at representing the number of objects in spatial arrays*". The study concludes that the mathematical difficulties older deaf children may encounter at school are not caused by beginning school with poorer number representation, but instead may be due to deaf children having fewer learning opportunities (Zarfaty et al. 2004).

Importantly, the attainment gap appears to be narrowing between deaf children and hearing children, particularly among the earlier years of education. In Wales there have been clear reductions since 2005 in the attainment gap at Key Stages 1, 2 and 3; however it has increased slightly at the GCSE level. In England there have been slight reductions in the attainment gap between deaf children and children with no identified SEN at Key Stages 1 and 2, but there has been little change at GCSE. There is no data for Key Stage 3.

Table 6: Educational attainment of deaf children in England. Source: NDCS 2015

School level	Year	Deaf children	Children with no identified SEN	All children
Key stage 4: Proportion of children achieving expected GCSEs benchmark – 5 GCSEs (including English and Maths) at grades A* to C	2014	40%	69.3%	60.3%
	2013	42.7%	70.4%	60.6%
	2012	37.4%	69.3%	58.8%
	2011	39.7%	69.5%	58.2%
	2010	36%	66.5%	55.1%
	2009	29.4%	61.3%	50.7%
	2008	28.3%	57.8%	48.2%
	2007	27.2%	54.3%	45.8%
Key stage 2: Proportion of children achieving expected level at reading, writing and mathematics	2014	54%	90%	79%
	2013	49%	88%	75%
	2012	44%	88%	74%
	2011	36%	81%	67%
Key stage 1: Proportion of children reaching expected level at Key Stage 1 for reading	2014	66%	97%	90%
	2013	66%	96%	89%
	2012	65%	95%	87%
	2011	57%	95%	85%
	2010	62%	94%	85%
	2009	61%	94%	84%
Key stage 1: Proportion of children reaching expected level at Key Stage 1 for writing	2014	60%	94%	86%
	2013	60%	94%	85%
	2012	58%	93%	83%
	2011	51%	92%	81%
	2010	55%	92%	81%
	2009	53%	92%	81%

Table 7: Educational attainment of deaf children in Wales for Key Stages 1 to 4.**Source: NDCS 2013**

School level	Year	Deaf children	Hearing children	Attainment gap
Key stage 4: Proportion achieving 5 GCSEs, grades A*-C	2012	35%	59%	24%
	2011	46%	58%	11%
	2010	38%	57%	19%
	2009	46%	53%	7%
	2008	38%	52%	14%
	2007	34%	47%	12%
	2006	29%	46%	18%
	2005	28%	43%	15%
Key stage 3: Proportion achieving Core Subject Indicator (level 5 or above in English/Welsh, Mathematics and Science)	2012	69%	85%	16%
	2011	70%	81%	11%
	2010	56%	77%	20%
	2009	53%	73%	20%
	2008	42%	71%	29%
	2007	45%	68%	23%
	2006	44%	69%	26%
	2005	42%	69%	27%
Key stage 2: Proportion achieving Core Subject Indicator (level 4 or above in English/Welsh, Mathematics and Science)	2012	81%	96%	15%
	2011	75%	94%	20%
	2010	71%	93%	22%
	2009	60%	92%	31%
	2008	68%	90%	22%
	2007	49%	89%	40%
	2006	50%	89%	39%
	2005	58%	88%	30%
Key stage 1: Proportion achieving Core Subject Indicator (level 2 or above in English/Welsh, Mathematics and Science)	2011	80%	94%	14%
	2010	76%	93%	17%
	2009	73%	93%	20%
	2008	74%	93%	20%
	2007	68%	92%	24%
	2006	60%	92%	33%
	2005	61%	92%	31%

3.2.4. How integrated into the wider world are Deaf people?

This question addressed a range of issues and experiences around Deaf people's integration into the wider hearing world, including identity, friendships and socialising, as well as access to and use of public services. A number of in-depth studies were identified, with a lot of qualitative data obtained from interviews with D/deaf people.

Key findings:

Deaf people are excluded from society and suffer from social isolation

Deaf people face difficulties in accessing and using local services:

- These include shortages of information and services in BSL, of specialist support services, of qualified interpreters, and a general lack of deaf awareness

Deaf people face barriers to employment, and there is evidence to suggest the unemployment rate among Deaf people is higher than in the general population

Deaf children and young people face issues with regard to education and schooling. These include:

- Social interaction and friendships at school
- Provision of specialist education services (such as Teachers of the Deaf)

Social integration

There is evidence from the literature to suggest that Deaf people are excluded from society and are subject to social isolation. Qualitative research by Skellington Orr et al. (2006) has highlighted difficulties and barriers for Deaf adults to engage in social interaction, with many of the participants expressing that their loss of hearing leads to feelings of isolation.

However, it must also be noted that as well as not having the access to integrate into the hearing world, some deaf people may also not have the BSL competence to belong to the D/deaf community. Skelton and Valentine (2003) argue that the D/deaf community can be closed and exclusionary and as the D/deaf community is relatively small, there are few alternatives for those who do not fit in (Skelton and Valentine 2003). Not being fully accepted within the Deaf world, in addition to the hearing world, can leave deaf people even more isolated (Valentine and Skelton 2007).

Feelings of social isolation have also been expressed by deafblind people (Skellington Orr et al. 2006) and research with Deafblind people suggests that they may also feel isolated from the Deaf community: members of the Deaf community saw Deafblind people as being in some way alien (Kyle and Barnett 2012). Additionally, Skellington Orr et al. (2006) found that deafblind people consider access to a guide/communicator service as a vital means by which to engage in social activities; however many of the deafblind participants stated that they had little weekly contact with a guide/communicator and the contact they did have was needed to

attend health appointments or carry out basic chores. As such, most had little time to use the guide/communicator for social interaction.

Access to and use of services

One of the main needs of deaf people is access to general support, information, advocacy and advice (Skellington Orr et al. 2006). However a number of studies have highlighted the difficulties for d/Deaf people in accessing and using local services. These include a shortage of service **delivery and information in BSL** (BDA 2014a; Hunt et al. 2010; Kyle et al. 2005), **specialist support services** (BDA 2014a; Young et al. 2010), **qualified interpreters** (BDA 2014a; Kyle et al. 2005; Harris and Bamford, 2001), **communicative technologies** utilised by councils, such as Video Relay Services (BDA 2014b), **Teachers of the Deaf** (CRIDE 2014a), and general **deaf awareness** (McCracken and Pettitt, 2011; Kyle et al. 2012b; Kyle et al. 2005).

Interviews with elderly Deaf people in England and Wales highlighted a number of issues they face in accessing council services (BDA 2014a). A key issue was a lack of information in BSL, with many of the interviewees finding it difficult to understand council information in English as this is not their first or preferred language. Similar findings were made by Kyle et al. (2005) who found that Deaf people have very limited access to public services in BSL due to communication difficulties. In their study they did not identify any examples of health care, emergency, or council services in Scotland which were delivered to Deaf people in BSL. In particular, Hunt et al. (2010) identified poor and inadequate residential care provision for Deaf people in Wales, with no specialist provision for Deaf people and no settings where BSL was routinely used by staff. This in turn may affect their quality of life or even cause significant harm (Hunt et al. 2010).

Other issues identified from the interviews with Deaf people included a lack of specialist services for Deaf people (BDA 2014a) and poor use of modern communication technology, such as text messaging and Video Relay Services, to enable Deaf people's access to services (BDA 2014b). There is evidence to suggest that older Deaf people do not feel their views are heard or understood by their local council and, as a result, they may feel isolated and ignored. This, in turn, limits their understanding of council services and access to council consultations (BDA 2014a). Young et al. (2010) also note that there is a shortage of specialist social care services for deaf people. They found that only a third of Local Authorities had specialist teams who are responsible for deaf children and their families, and more than a quarter did not have any qualified social workers who specialise in working with d/Deaf adults and children. Harris and Bamford (2001) conclude that local services are often not set up to meet the needs and requirements of Deaf people and that services are not organised in ways that facilitate the inclusion of Deaf people as full members of society.

One of the biggest issues in accessing public services is the **availability of BSL interpreters** for Deaf people. Findings from the British Deaf Association (2014), Skellington Orr et al. (2006), Kyle et al. (2012; 2005), and Harris and Bamford (2001) demonstrate a lack of appropriately qualified interpreters, resulting in social exclusion and a lack of access to

information for those wishing to use services. Interviews with older Deaf people have highlighted that interpreters used by councils often are not qualified and do not have the signing skills and understanding needed to communicate effectively. Instead, Deaf people may have to rely on family and friends who are not trained in interpreting and thus also have a limited ability to convey accurate information (BDA 2014a; Kyle et al. 2005). In addition, the use of unqualified intermediaries may lead to concerns regarding accountability, privacy, confidentiality and professional behaviour (Kyle et al. 2005). The literature also highlights issues regarding the booking of interpreters, including experiences of when Deaf people's requests for interpreters have been denied (BDA 2014a) or when interpreters were simply not provided as requested (Kyle et al. 2012b), as well as financial costs (Kyle et al. 2012b; 2005).

The literature notes a general lack of deaf awareness among service providers. The lack of skills and knowledge of deafness by staff was captured through interviews with parents and families of deaf children, and this was even found to occur in special schools for children with learning disabilities (McCracken and Pettitt, 2011). Interviews and focus groups with Deaf people found that poor Deaf awareness and the attitudes of hearing people may leave Deaf people feeling annoyed, frustrated and embarrassed when having to use hearing public services, and this may result in them not using the services again (Kyle et al. 2005). From interviews with young Deaf people, Skelton and Valentine (2003) suggest that Deaf people would not face the level of social exclusion and marginalisation that they currently do if more services were provided in BSL and if more people had better levels of Deaf awareness.

Employment

Data from the Labour Force Survey (2006)⁹ suggests that the employment rate among deaf people is lower than that of the general population as only 63% of deaf and hard of hearing respondents were employed at the time of the survey, compared to 75% of the whole population. Findings from a survey carried out as part of the Deaf Health study, compared against the English Housing Survey, also shed light onto the poorer employment status of Deaf people (SignHealth 2013). Just over a third of the Deaf respondents in the study were in full-time work, compared to half of the respondents in the English Housing Survey, and a greater proportion of Deaf respondents were in part-time work. Yet overall there were a greater proportion of Deaf respondents who were unemployed. Adding to this, data shows that deaf or hard of hearing school leavers in Scotland are more likely to be unemployed (Fordyce et al. 2013). From the Scottish Census, only 46% of BSL users are employed compared to 57% of the general population, and 13% of BSL users were recorded as unemployed due to being permanently sick/disabled compared to 5% of the general population (Scottish Government 2015).

⁹ Office for National Statistics. (2006). Labour Force Survey, May 2006

A survey by RNID (2006) further explored barriers to, and experiences of, employment among deaf people. The survey found that deafness was a significant barrier to finding work, and almost three quarters of respondents believed that being deaf made it harder to find a job. Specifically, respondents thought that the attitude of employers towards deaf people was the single largest barrier, followed by the lack of communication support and the lack of suitable jobs. However even after gaining employment, deaf people still face difficulties at the workplace. Just over half of the respondents said their work colleagues were deaf aware, yet almost a quarter said their colleagues were not. As a result of their deafness, over half of the respondents felt socially isolated at work, a quarter felt subject to harassment, and over three quarters felt they were held back on their career path. In addition, issues were raised about the unmet need for BSL interpreters in the workplace, lack of deaf awareness among Jobcentre Plus staff, and general lack of awareness about the Access to Work scheme and its potential benefits for deaf people. Access to Work is a government scheme that helps people with disabilities have equal access to work opportunities. For those who are deaf, this could include having BSL interpreters and communication and equipment support paid for by the Access to Work scheme and employer. In 2014-15, 5,560 out of 36,760 (15%) Access to Work recipients were deaf or hard of hearing¹⁰.

School and education

In the UK there is no national standard for school provision for Deaf children as it instead depends on local authorities. Deaf children may be educated in mainstream hearing schools with varied levels of support, which may or may not have special units for deaf children and/or provide content in BSL, or in specialist schools for the deaf. The language in which deaf children are addressed and taught therefore varies. It may comprise the bilingual use of BSL and English, the use of Sign Supported English (key lexical signs alongside spoken English), or the use of spoken English only (Mason et al. 2010). There are 23 specialist schools for deaf children in the UK¹¹. School provision for deaf children in the UK is varied and depends on local authorities rather than a national standard. Currently, the vast majority of deaf children are educated in mainstream schools; however this has changed considerably from 1960 where the vast majority were educated in special schools¹².

Between 2013 and 2014 there has been a 3% decline in the number of Teachers of the Deaf in the UK (Teachers of the Deaf are qualified teachers who have an additional qualification to teach deaf children). The number of qualified Teachers of the Deaf has declined even more since 2011, by 6% in England, 18% in Northern Ireland, and 16% in Wales (CRIDE 2014a). Evidence suggests that in England there are on average 43 deaf children per Teacher of the

¹⁰ Department for Work and Pensions. (2015). Access to Work - Official Statistics: <https://www.gov.uk/government/statistics/access-to-work-official-statistics-july-2014>

¹¹ Schools for deaf children in the UK: <http://www.batod.org.uk/index.php?id=/links/deafschoollink.htm>

¹² The education of deaf pupils in mainstream schools: <http://www.batod.org.uk/index.php?id=/resources/history/histmssch/histmssch.htm>

Deaf, although this varies greatly throughout England with the lowest ratio at 5.8 children per Teacher and the highest ratio at 142 children per Teacher (NDCS 2009). As noted previously, the large majority (76%) of school children attend mainstream schools, and between 2000 and 2009 there was a 17% reduction in the number of pupils attending schools with specialist provision for the deaf. The number of deaf pupils recorded as attending other types of special school (i.e. special school not specifically for the deaf) has increased, however no reasons for this increase were given (NDCS 2009).

Friendships and social integration at school

The review of the literature identified a few studies focussing on **friendships and social integration** at school (Brennan et al. 2005; Nunes et al. 2001; Jones 2001)

Two studies (Nunes et al. 2001; Jones 2001) conducted interviews with deaf children to provide an insight into their integration in mainstream schools, which most deaf children attend (NDCS 2009). Interviews from a qualitative study involving 9 deaf children and 62 hearing children aged 11-13 (Nunes et al. 2001) suggest that young deaf children are not rejected in mainstream schools, as deaf children in the study did not encounter strong negative feelings in their relationships with the hearing peers, but that they may feel isolated. Interviews with slightly older young deaf people (mean age 15 years and 9 months) revealed a more negative, unhappy, and excluded experience, with young deaf people feeling devalued and excluded at school, citing 'cruelty', being called 'stupid' and 'dislike of deaf people' by their hearing peers (Jones 2001). Findings from Fordyce et al. (2013) add to this, finding that young deaf people are subject to bullying, are socially isolated at schools, in part due to a lack of support at school, and face barriers to participation in class and extra-curricular activities. Deaf young people are more likely to have deaf friends than hearing friends, however there are often few other deaf children at mainstream schools (Jones 2001) and deaf children are less likely to have a friend in the same class than hearing pupils, which may contribute to a feeling of isolation (Nunes et al. 2001). Similarly, the literature suggests that hearing children prefer to have hearing friends over deaf friends, with communication cited as an obstacle to friendship (Nunes et al. 2001).

As there are often few other deaf children at mainstream schools, deaf young people mostly mix with hearing peers (Jones 2001). Jones (2001) discusses how contact with peers influences how deaf young people understand themselves and view their identity. Unfortunately, many of the children in the study who attended a mainstream school highlighted negative experiences of mixing with hearing children, and felt they were excluded and not valued at school as a result of their deafness. Mixing with hearing peers confirmed the "*negative assumptions the wider society holds about deafness*" and that this "*makes it difficult for the young person to maintain a positive Deaf identity*". Additionally, research suggests that deaf children lack confidence at school, especially when in the presence of hearing people (Burgess and Monk 2013). Interestingly, pupils with hearing impairments are slightly more likely to miss school (DfE 2014), but the extent to which this is due to negative experiences and social exclusion is unknown.

On the other hand, evidence from interviews with deaf children who attended special schools for the deaf suggests that mixing with other deaf children in these schools “*contributed to a more positive sense of Deaf identity, often providing valuable role models*” (Jones 2001). These schools enable young deaf people to view deafness not as a disability but as a ‘way of life’, to form friendships and relationships more easily, and to communicate better (Jones 2001). Despite this, many young people in the study by Jones (2001) did not want to be taught in deaf schools as they felt these schools highlighted their difference and isolated them from other young people. They were also concerned about low academic standards and expectations, with these concerns raised by parents as well (Jones 2001). Regardless of whether they attend mainstream schools or specialist deaf schools, evidence suggests that many D/deaf people are ill-prepared for leaving school and entering the adult hearing world (Rogers 2013; Valentine and Skelton 2007).

Nunes et al. (2001) state that schools need to facilitate communication between deaf and hearing children in order to promote integration of deaf children into the social networks of children. However, issues were raised about experiences with teachers. Young deaf people felt they were ‘written off’ by teachers and considered as inferior to hearing students. They also felt that teachers were only interested in hearing children and that they were discouraged from moving on to sixth form and achieving more at school (Jones 2001). Similarly, Valentine and Skelton (2007) found that some of their young D/deaf participants were withdrawn from academic classes and directed into practical courses or assigned undemanding and unsuitable work experience placements, suggesting that they may be discredited at school.

Similar issues about social integration at school have also been explored among deaf students at university. In a study by Brennan et al. (2005), some of the deaf students had a very positive social experience with hearing peers whilst at university, however most lacked involvement in university social life or found social participation difficult and unrewarding. Many instead socialised outside the university, preferring to mix with deaf peers.

3.2.5. Association between Deafness and health or disability issues

This question aimed to address the range of health and disability issues that Deaf people face. This section will consider the **health status** of the Deaf population, as well as the issues they face in **accessing health services**.

Key findings:

Deaf people have higher prevalence rates of obesity, high blood pressure and depression compared to the general population, but they have lower prevalence rates of cardiovascular disease, high cholesterol and chronic obstructive pulmonary disease (COPD) and are less likely to smoke and drink alcohol

Deaf people are more likely to be under-diagnosed. Even when diagnosed, they are more likely to have poorer treatment and management of potentially serious health conditions

Deaf people face many barriers when accessing health services:

- They face difficulties booking and attending health appointments, and communicating with health professionals. There is often an absence of BSL interpreters at consultations, and Deaf people may instead have to rely on friends and family
- Overall, Deaf people may be discouraged from accessing health services

Deaf people have poor health knowledge, potentially due to a lack of health information in accessible formats

Health status

The literature search identified very few studies that assess the health status of Deaf people in the UK, however one comprehensive and recent study was the Deaf Health study (SignHealth 2014). This large-scale study assessed the health of a sample of the Deaf community in the UK through the use of interviews, health assessments (Emond et al. 2015), and a survey (SignHealth 2013). Although the study aimed to use a representative sample, it noted that *“Without any knowledge of the profile of the UK Deaf population it is not possible to calculate the extent to which survey respondents are representative of Deaf people”*. Overall, the study identified poorer health and poorer access to health services among Deaf people when compared with the general population (SignHealth 2014).

Deaf people were generally found to have healthier lifestyles than the rest of the population, in terms of lower rates of smoking and alcohol, and were less likely to have cardiovascular disease or high cholesterol, although Deaf participants still had high rates of cardiovascular disease and nearly one third had a higher than desired level of cholesterol (Emond et al. 2015; SignHealth 2014). Deaf people were more likely to be overweight and obese and, as a result, almost half were at ‘high to very high risk’ of serious illness such as coronary heart disease, osteoarthritis, some cancers and type 2 diabetes, although the prevalence of diabetes was similar to that of the general population (Emond et al. 2015).

Deaf people also reported higher rates of depression compared to the rest of the population (SignHealth 2014). It has been reported elsewhere that over 40% of d/Deaf children experience mental health problems compared with 25% of the hearing population (Department of Health 2005), and that twice as many Deaf people (12% compared to 6% of the general population) have a long-standing psychological or emotional problem (SignHealth 2009). In addition, there are higher rates of psychological distress among deafblind people compared to the general population and those with a hearing impairment (Bodsworth et al. 2011). Research with Deaf people suggests that social isolation and communication difficulties during childhood, as well as being bullied as a result of their deafness, affected their state of mental health later in life (Rogers 2013), and social interaction is seen to be a significant factor in preventing mental illness among Deaf and deafblind individuals (Skellington Orr et al. 2006).

There is data to suggest that, overall, Deaf people/BSL users are more likely to rate their health as being poor, and are more likely to have a long-term health condition (Scottish Government 2014a; SignHealth 2013; SignHealth 2009).

Table 8: The health status of Deaf people compared to the general population. Source: Emond et al. 2015, SignHealth 2014, SignHealth 2013

Health indicator/condition	Deaf population	General population
Smoking	8%	20%
Alcohol consumption (units/week)	5.5 (men), 3.4 (women)	15.9 (men), 7.6 (women)
Obesity	30%	25%
- Overweight	71%	61%
Long-term condition	32%	28%
Cardiovascular disease	7%	13%
High blood pressure	37%	21.1%
- Undiagnosed	15%	6%
- Diagnosed and receiving treatment	36%	57%
- Diagnosed with continued high BP	62%	20%
High cholesterol	32%	57%
- Receiving treatment	31%	79% (men), 71% (women)
Diabetes	6-7%	6-7%
- Undiagnosed	7.6%	2%
COPD	1%	4-5%
Depression	24%	12%

As well as concluding that Deaf people have poorer health, the Deaf Health study also found poor diagnosis, treatment, and management of a number of potentially serious health conditions. The prevalence of diabetes was reported to be similar in the Deaf and general populations, but Deaf people were more likely to be undiagnosed. Underdiagnosis among Deaf people was also reported for cardiovascular disease and high blood pressure (SignHealth 2014). In addition, even when Deaf people were diagnosed they were less likely

to be properly treated for their conditions. Rates of treatment for high blood pressure, high cholesterol, diabetes and cardiovascular disease were lower among Deaf people. This raises questions about whether Deaf people's illnesses are routinely identified, whether the diagnosis is properly conveyed, and whether Deaf people's conditions are sufficiently monitored by clinicians (SignHealth 2014). Overall, the evidence suggests that Deaf people are more likely to be unaware that they have a health condition and are less likely to be properly treated for diagnosed conditions, which may put them at risk of preventable ill-health (such as heart attacks and strokes, and diabetic complications) and even reduced life expectancy (Emond et al.; SignHealth 2014).

Access and use of health services

As discussed previously, Deaf people face many challenges and issues when accessing services, and accessing health services in particular has been found to be a highly stressful experience (Kyle et al. 2005). A number of studies have reported overall poor access and experience of health services due to communication difficulties, poor Deaf awareness, and poor access to health information.

Deaf people face many difficulties when communicating with doctors and medical staff and this creates a major issue and barrier to accessing health services. Generally speaking, health services are not allowing Deaf people to communicate in their preferred language of BSL (SignHealth 2014). As with other public services, one underlying reason for this is **issues with BSL/English interpreters**. Research with D/deaf people has highlighted poor provision or difficulties obtaining registered or qualified interpreters in medical settings (AHL et al. 2012; RNID 2004; Healthwatch Leicester; BDA 2013; BDA 2014d; BDA 2014c; SignHealth 2013; Reeves et al. 2002; Skellington Orr et al. 2006) as well as difficulties with booking interpreters (AHL et al. 2012; BDA 2013; BDA 2014d). Even when interpreters are provided there are still further issues, such as interpreters turning up late (BDA 2013) or poor satisfaction with the level of interpreting skills (AHL et al. 2012; BDA 2013).

In cases where no interpreter is provided, D/deaf people may have to resort to communicating through mime, pen and paper, or lip-reading (Healthwatch Leicester 2014; BDA 2013; BDA 2014d; Skellington Orr et al. 2006; SignHealth 2014), which reduces the quality of information and communication (BDA 2014d) and can lead to medical error (Alexander et al. 2012). This can be made worse by poor Deaf awareness among staff. For example, when consulting with a patient who is trying to lip-read, doctors may not always face the patient or may not speak clearly (AHL 2013; Ubido et al. 2002). Accordingly, there is greater dislike and distrust of doctors among Deaf patients (SignHealth 2009; SignHealth 2014).

In some cases Deaf people may not be able to communicate at all with staff (Healthwatch Leicester 2014). They may also be forced to rely on family or friends to interpret for them which may compromise privacy and confidentiality and, as family and friends may not be experienced and qualified interpreters, may also lead to miscommunication (Healthwatch Leicester 2014; SignHealth 2014). Deaf people may feel embarrassed when a friend or

family member is present in a consultation or may be worried that important information is left out so as to protect their feelings (AHL et al. 2012), and this may be particularly true for young people when a parent or older sibling is present (Jones 2001). It is important to note that there are also issues with confidentiality and privacy, particularly regarding sensitive matters, and mistrust when professional interpreters are used (BDA 2014d; BDA 2014c; Reeves et al. 2002; Skellington Orr et al. 2006).

Additionally, there are not only issues with communication between Deaf people and health professionals, but there is also a lack of communication within the health services, for example between GPs, A&E departments, the ambulance service and hospitals (BDA 2014c). The outcome is that Deaf people have to repeat that they are Deaf and require a sign language interpreter every time they make a booking (BDA 2014c).

Overall, Deaf people may be **discouraged from accessing health services** as a result of communication difficulties and poor provision of interpreters (AHL et al. 2012; Reeves et al. 2002; RNID 2004; SignHealth 2013). RNID (2004) report that 30% of BSL users avoid seeing their family doctor because of communication difficulties, and in the SignHealth (2014) study, over a third of respondents did not think it was worth seeing their GP because the communication was so poor. Deaf people face additional challenges when trying to book appointments (AHL 2013; BDA 2014d; Reeves et al. 2002; RNID 2004; SignHealth 2009; SignHealth 2014), and in GP surgery/hospital waiting rooms where they may not be notified and so may miss their appointment (AHL 2013; BDA 2013; BDA 2014c; BDA 2014d; Reeves et al. 2002; RNID 2004; SignHealth 2014; Ubido et al. 2002). These factors also contribute to poor access and use of health services.

Deaf people may also be discouraged from attending support groups or health events (BDA 2014d). Adding to this, it is suggested that there is a general lack of health support networks and groups for Deaf people, with Parker et al. (2010) referring to the example of dementia support groups in the UK. Instead, the only available support groups available for Deaf people are often those for hearing people. However, this requires a third party or an interpreter in which case the benefits of sharing direct and personal contact with others facing a similar experience are lost (Parker et al. 2010).

Poor communication and poor provision of interpreters may ultimately lead to a **lack of health information or poor understanding of information**. Studies have found that D/deaf patients are left confused after leaving a medical appointment as they may be unsure of their medical condition (AHL et al. 2012; RNID 2004), medical advice (AHL et al. 2012) and their medication (AHL et al. 2012; Reeves et al. 2002; RNID 2004), which may ultimately lead to them taking their medication incorrectly (AHL et al. 2012; RNID 2004). D/deaf patients may generally be unclear about the information they received or unsure as to whether they received all the information they needed (AHL 2013; Reeves et al. 2002; SignHealth 2013), and may face a general lack of information on health matters (Ubido et al. 2002; Healthwatch Leicester 2014).

There is some evidence from international studies that Deaf people have poor health knowledge. This has been identified in American studies assessing cancer knowledge

among Deaf people, which found a 'knowledge gap' with Deaf men and women demonstrating significantly lower knowledge of testicular cancer (Sacks et al. 2013) and ovarian cancer (Jensen et al. 2013), respectively, compared to hearing counterparts. This may be due to the fact that health information is not easily accessible to Deaf people (BDA 2014d; SignHealth 2014). Medical jargon is often used when conveying medical information, either written or verbal, and this is not always properly understood by Deaf people (Ubido et al. 2002; Healthwatch Leicester 2014; BDA 2014d; BDA 2014c).

Deaf people lack access to information in accessible formats, and this is particularly true with regard to health information. For example, NHS and mainstream health promotion material is done via speech and writing and very little information is available in BSL (Alexander et al. 2012; BDA 2014d), and there is a lack of BSL content on NHS websites (BDA 2014d; SignHealth 2014). As such, people from the Deaf community are at risk of poorer health because of poor education and decreased availability and accessibility of health information (Alexander et al. 2012). Additionally, many Deaf people in the Deaf Health study were unsure about what they were taking medication for (SignHealth 2014). Less medical jargon, more information in plain English, and more visual information may help remove some of the barriers that Deaf people face when obtaining health information (BDA 2014d).

Overall, SignHealth (2014) concludes that *"there is a sizeable group of Deaf people who need medical help but do not access a service because of the barriers faced."*

Dementia and Deafness

A recent review of the literature identified clear links between age-related hearing loss, decline in cognitive functioning, and dementia, and it also found that increased risk of dementia is related to the degree of hearing loss. However there have been no prevalence studies of dementia among Deaf BSL users (SCIE 2014). One study, Young et al. 2014, provides a very rough estimate of the number of Deaf people with dementia. Using a population estimate and the Alzheimer's Society prevalence estimates among the elderly, Young et al estimate that there are between 450 and 850 Deaf people with dementia in the UK. Yet they note the lack of data and accuracy on this, stating that *"there is no firm epidemiological evidence from population-based prevalence studies whether Deaf people are more or less likely to experience dementia"*. The authors suggest that there may be very poor awareness and understanding of dementia among the Deaf community, and they comment on the lack of studies focussing on Deaf people's attitudes and awareness of dementia as well as the lack of information and support for Deaf people with dementia.

SCIE (2014) report that the small volume of research carried out on Deaf people with dementia has identified barriers regarding dementia care and, as with healthcare in general among the Deaf population, these include barriers around access to information, knowledge about dementia, communication with professionals, and the lack of Deaf awareness. In addition, Ferguson-Coleman et al. (2014) also suggest that there are structural barriers to accessing, and being aware of, services for dementia, and that current services are poorly equipped to meet the needs of Deaf people with dementia.

Additional disabilities

NCDS (2012) performed a review of UK and international literature to identify the prevalence of additional disabilities with deafness. The study highlighted the lack of research on the prevalence of additional disabilities in children with deafness, and on the [lack of research on the] prevalence of deafness in children with disabilities. However some conclusions were made regarding prevalence. The study found that the estimated prevalence of additional disabilities in children with hearing loss ranged between 4-57% for visual impairment, 2-14% for neurodevelopmental disorder, and 61-88% for Speech Language Disorder. Additionally, deafness was estimated to be prevalent among 2-4.2% of children with Autistic Spectrum Disorder, 2-13% of children with Cerebral Palsy, and 2% of children with Pervasive Developmental Disorder. In the Deaf Health study, almost one fifth of respondents said they had a learning disability, which was far higher than among the general population (SignHealth 2009).

According to the Health and Social Care Information Centre (2014), 143,400 people were registered as blind in England in 2014, with 49,925 registered as having an additional disability. Of these 49,925 people, 5% (roughly 2,500 people) were deaf with speech and 2% (roughly 1,000 people) were deaf without speech. However, as with the HSCIC (2010) report on the number of people registered as deaf or hard of hearing, these numbers are likely to be lower than the true values. In fact, a study from the Centre for Disability Research estimated that in 2010 there were approximately 356,000 people in the UK with co-occurring hearing and vision impairments, and 132,000 people with more severe impairments of both hearing and vision (Robertson and Emerson, 2010). However, three quarters of those with more severe co-occurring hearing and vision impairments were aged 70 or over, suggesting that a large number had age-related deafness and were not Deaf.

Table 9: Estimated number of people in the UK with both hearing and vision impairments, 2010. Source: Robertson and Emerson, 2010

	Impairments of both hearing and vision (upper estimate)	More severe impairments of both hearing and vision (lower estimate)
0-19	21,000	4,000
20-59	56,000	14,000
60-69	57,000	19,000
70+	222,000	95,000
Total	356,000	132,000

3.2.6. New technologies and social media

This section aims to explore the extent to which new technologies and social media are changing Deaf people's experiences. It focuses on the use of modern technologies as a means of communication, such as SMS and email, as well as the use of the internet among the Deaf community. However, the literature review has not yet identified any data on the use of social media, notably Facebook and Twitter, and applications such as FaceTime/Skype among Deaf people.

It is important to note that technology, the internet, and social media are fast moving and constantly changing, particularly in recent years. However, there has been very little research into the use of technology and social media among the Deaf community in recent years. As such, some of the studies discussed in this section are outdated and may not be representative of the most current use of new technologies and social media among the Deaf community.

Key findings:

Deaf people make use of a number of communication methods beside the telephone. These include SMS, email, and teletypewriters:

- There is evidence to suggest that email is the most widely preferred, however SMS is more common among younger Deaf people

There have been a number of studies focussing on internet use and experiences among Deaf people:

- These have identified a number of benefits of the internet. The internet provides an alternative way of communicating with other Deaf people, facilitates the development of social networks, and allows Deaf people to access online education and information
- The internet allows Deaf people to pass as hearing online and may facilitate greater integration between Deaf and hearing people. However, this does not necessarily increase the integration of the Deaf community into mainstream society

Text communication (substitute for telephone)

As Deaf people face barriers to using the telephone, the use of various forms of text communication among Deaf people has been studied. Pilling and Barrett (2007) carried out a survey to identify text communication preferences of deaf people in the UK. Generally, respondents used several forms of text communication, selecting them for particular purposes. Email was the most widely used form of text communication, but SMS was the most used by younger respondents and use of SMS was found to be increasing more than other forms of text communication. A number of reasons for preferring different forms of communication were cited, with ease of use more prominent among younger users and

portability among older ones. The only form of communication where ease of use and portability were not prioritised was teletypewriters (TTY) as independence and the ability to have live conversations were the main reasons for liking this method of communication. Importantly, there was a lack of knowledge regarding text communication among many older participants, with many saying that they would like more information about text communication, and possibly even some training. A study from Australia has observed similar findings, reporting widespread use of and satisfaction with a variety of communication methods including SMS, TTY, relay services, fax, and computers (Power et al. 2007). The same study also identified that Deaf people depend upon a variety of text communication methods and that they use each for particular purposes.

Pilling and Barrett (2007) report that the currently available forms of text communication have made improvements in deaf people's lives, but they do not expand on this. Similar conclusions were made by a Canadian study (Akamatsu et al. 2006), in which Deaf and hard of hearing students and their parents were provided with two-way text messagers and the study showed that participants felt that the availability of various forms of text communication gave them independence, which would have been impossible otherwise.

The internet

A very small number of detailed, qualitative studies have explored the use of the internet among the Deaf community, and the benefits and drawbacks that the internet provides to this community. However, as mentioned previously, these studies are a few years old and may not represent current internet use among the Deaf community.

Valentine and Skelton (2009) conducted a survey of 419 D/deaf people to identify internet use and behaviour within the D/deaf community. Their findings, when compared with the General Household Survey (GHS), show that D/deaf respondents have higher levels of internet access and usage than the general population, with 79% of the D/deaf respondents stating they use the internet every day, compared with only 59% from the GHS. The findings suggest that D/deaf people are more likely to use the internet to look for health information, employment and to email or chat online through instant messaging services. Yet, Power and Power (2009) discuss how many Deaf people are excluded from the benefits of the internet and are unable to take full advantage of the opportunities. They suggest that this may be due to not being able to afford the equipment, or ignorance of the services available, or because many Deaf people have limited spoken and written language skills and are thus hesitant to use systems based upon speech and/or text.

Valentine and Skelton (2008 and 2009) conducted qualitative interviews about the interaction between Deaf people and the internet, and discuss in depth the effect this is having on the Deaf community. They note that the internet has offered Deaf people an alternative way of accessing information and communicating **with other Deaf people** in sign language. The authors suggest that in this sense it is one of the first technologies that has not been aimed at '*normalising Deaf people by enabling them to communicate orally*'. The study compared the online Deaf community with off-line Deaf clubs, and suggests that the internet has

enlarged the Deaf community as a concept, and in reality, as it has '*liberated the UK Deaf community from the emplaced, fixed time/spaces of Deaf clubs*' (Valentine and Skelton, 2008). Valentine and Skelton (2009) argue that the internet enables the promotion and development of Deaf culture, and in their survey, 85% of respondents thought that the internet supports the Deaf community. Furthermore, almost 70% said that using the internet has improved their quality of life. The internet can also be a source of social support, having a positive influence on the online Deaf community (Shoham and Heber 2012). Importantly, the internet may be facilitating Deaf people's integration in hearing society by allowing them to pass as hearing online (Valentine and Skelton 2009).

The internet can facilitate the development of social networks without the need for fixed locations and events provided by Deaf clubs, with Valentine and Skelton (2008) referring to the 'Deaf UK' website which has been influential in facilitating the development of social interactions and friendships between Deaf people dispersed throughout the UK. It has also facilitated global connectivity, providing Deaf people with the information, resources, support and confidence to travel to new places and to meet new people. As Valentine and Skelton (2009) put it, the "*Internet has effectively enabled the Deaf community to be scaled up from a local to a global network*".

Similar findings were discussed by Power and Power (2009) who surveyed sites used by Deaf people throughout Europe (including the UK), such as Deaf-related blogs and vlogs, newsgroups and social network sites. Their findings were that Deaf people are active users of the internet and that new methods of online communication have expanded their connections both within the national and international Deaf cultures, and within the wider community. Furthermore, there is some evidence that online relationships can extend into the real world. An Israeli study (Shoham and Heber 2012) analysed messages in an online forum for D/deaf people and found that a large number of messages were about activities taking place outside the virtual forum, meaning that the community had crossed the boundaries of the internet, establishing a non-virtual community where members interacted in daily life (Shoham and Heber 2012).

There are clear indications that the internet brings with it both benefits and drawbacks. On one hand, the internet can contribute to reducing the risk of Deaf people being misinformed or discriminated against by hearing people (Valentine and Skelton 2009). On the other hand, the internet can contribute to the "*maintenance and normalisation of hearing hegemony, leaving the discrimination D/deaf people encounter in off-line space unchallenged*" (Valentine and Skelton 2009).

Valentine and Skelton (2008) note that the internet can facilitate greater integration **between Deaf and hearing people**. However, at the same time, the authors warn that the internet may not increase the integration of the Deaf community **into mainstream society** as '*Deaf people's ability to participate in mainstream society online does not necessarily translate into social inclusion in the off-line hearing community*'. Deaf communities are using the internet to maintain exclusive online and off-line communities for different groups of D/deaf people, only engaging with hearing people when necessary. They are not using the technology to initiate

new relationships with hearing people and offline communities. The study reports that many Deaf people often pass as hearing online; in the survey 40% of those who use the internet reported that they deliberately conceal their D/deaf identity online. The authors discuss how the internet has enabled Deaf people to be incorporated into hearing society as they can pass as hearing online and avoid face-to-face contact with hearing people in the real world. However, the authors argue that the internet has, paradoxically, facilitated D/deaf people's '*existence in, but separatism from, the offline hearing world*'. Additionally, participants from the study by Valentine and Skelton (2009) used email to inform hearing people how to communicate with deaf people. However, some participants felt they were so reliant on email to communicate with hearing people that they were losing the skills and confidence to communicate face-to-face.

Improving services through new technologies

The literature search identified two studies which examined the effects, or potential effects, of using new technologies to enhance access to health services for Deaf people. In a US study, Wilson and Wells (2009) examined effectiveness and feasibility of using telehealth as a means of delivering health care to deaf people, and found it to be cost-effective, with high satisfaction among the deaf participants. In the UK, the British Deaf Association addressed the use of BSL interpreting provision within health settings in Scotland (BDA 2013). The study used a survey and face-to-face meetings to gather D/deaf people's thoughts and views about the use and potential benefits of online interpreting. Most participants had little knowledge and experience of online interpreting, yet nonetheless some thought it could speed up access to GPs by, for example, avoiding delays due to a shortage of available interpreters. Some suggested it may be a useful alternative when local interpreters are unavailable and may be useful for last-minute appointments. However, confidentiality was a major concern, with many participants expressing distrust of online interpreting services. In contrast, others stated that it would allow them to record online conversations, in case they needed to make a complaint about an interpreter. Importantly, participants raised concerns about regional variations in BSL used by online interpreters, believing that using an interpreter from a different geographical area could have a negative effect on communication. Despite the mixed reactions, the large majority preferred face-to-face interpreting.

Accessing information and education online

Findings from the literature suggest that the internet may enable Deaf people to access information and education that may not have been previously accessible. This is particularly true regarding health information and research from the US illustrates that Deaf people access the internet to obtain health information from health websites, but that they also use online messaging services to discuss health matters with family and friends (Karras and Rintamaki 2012). Findings from Valentine and Skelton (2009) suggest that accessing health information online enables D/deaf people to avoid communication barriers and confidentiality issues that can occur when using an interpreter to access this information. The depth of

information online also allows them to engage more effectively with health professionals (Valentine and Skelton 2009). However, as discussed previously, studies suggest that there is a lack of BSL content on health and NHS websites (BDA 2014d; SignHealth 2014), and there is evidence to suggest a strong need for more information about public services in BSL online (Kyle et al. 2005). In addition, studies from the US have shown that online educational videos in American Sign Language with English captioning and voiceover could offer an effective means of increasing cancer knowledge among Deaf people (Jensen et al. 2013; Sacks et al. 2013).

Access to information was also discussed by Shoham and Heber (2012), who found in their study on the Israeli D/deaf community that the most interesting subjects to participants on online fora were employment, rights, technical aspects of deafness such as hearing aids, adjusting to deafness and hearing loss, and social activities. This emphasizes the importance of online fora as sources of information for the D/deaf community (Shoham and Heber 2012).

Valentine and Skelton (2009) report on the educational and literacy benefits of the internet for D/deaf people and regular communication with hearing people can increase their exposure to written text, increase their familiarity with vocabulary and grammatical structures, and enhance their literacy development. Furthermore, e-learning offers the opportunity to educate and engage D/deaf people who had poor experiences of the education system (Valentine and Skelton, 2009). Maiorana-Basas and Pagliaro (2014) support this, as their study of Deaf and hard of hearing people in the US found that the internet and technology may provide educational benefits for the Deaf community and has the potential to enhance and support education. However, they note that the lack of captioning of online audio and video content could limit accessibility. Lastly, including sign language search cues online, as a means of video-based navigation, may improve access to online knowledge and education for Deaf people (Fajardo et al. 2010)

3.2.7. Television

Some research has focussed on Deaf people's needs and experiences of television viewing, particularly with reference to BSL programming, however there are few recent studies.

Key findings:

There has been some research on Deaf people's views on television broadcasting:

- Deaf people want Deaf presenters instead of BSL interpreters, but the accuracy of information in BSL is prioritised over the appearance of the signer
- The most important types of programme for in-vision interpretation are news programmes, educational programmes, and documentaries
- There is demand for a Deaf TV channel which should be Deaf-led, in BSL, and with a distinct Deaf perspective
- Many Deaf people want access to mainstream programming on TV via subtitling

and they also want the full range of programmes made in sign language as well

- Many Deaf people watch TV online

A review of projects carried out by the Deaf Studies Trust (Kyle 2007) sheds some valuable light on this topic. In a 2000 study, *'Deaf people in the Community'*, 240 Deaf people were interviewed on various aspects of their lifestyle, including television viewing. Respondents were asked about their views on having Deaf presenters on TV as opposed to having hearing BSL interpreters. Ninety percent thought having a Deaf presenter on television was acceptable, whereas only 60% thought having a hearing interpreter was acceptable. However, the provision of information in BSL was considered to be a much higher priority than the appearance of the signer (whether a Deaf presenter or hearing interpreter). Adding to this, a more recent study from the Deaf Studies Trust by Kyle and Jackson (2008) found that Deaf participants preferred Deaf presenters and Deaf actors to be used. They also expressed the view that there should be training for presenters/interpreters, and even monitoring of signing on TV.

Participants in *'Deaf people in the community'* were asked in which programmes it was important to have a signer on screen. The most important choices were news programmes, educational programmes, and documentaries. The least important type of programme was, perhaps unsurprisingly, sport, followed by soap operas and films. Supporting this, a more recent study found that the favourite TV programme among deaf or hard of hearing participants was news, followed by documentaries (Wu et al. 2014). Likewise in another study by the Deaf Studies Trust in 2003, *'See Hear Now'*, news programmes were most popular although soaps were also popular among Deaf people when asked what their favourite programmes were. Relaxation was the most common reason for watching TV, followed by getting the news and information (Kyle 2007).

Kyle et al. (2007) suggest that there is a considerable demand for a Deaf TV channel. A follow-up study in 2001-02 to *'Deaf people in the community'* (*'Deaf people in the community 2'*) further explored the television needs of Deaf people and the demand for a Deaf channel. Almost three quarters of respondents (74%, n=101) said they wanted a separate Deaf TV channel, and support for this was slightly higher among the younger respondents. Fewer (45%, n=36) of the participants in the *'See Hear Now'* study thought that Deaf people should have their own channel, yet there is still evidence to demonstrate a strong desire and support for a Deaf TV channel among the Deaf community. Deaf participants in the study by Kyle and Jackson (2008) expressed that they wanted the same television as hearing people have, but that it should be Deaf-led, in BSL, and with a distinct Deaf perspective¹³. In addition, 78% of the respondents (n=107) in *'Deaf people in the community 2'* said they would watch a separate Deaf TV channel every day. Over half of the respondents stated that they would be

¹³ These research findings by Kyle and Jackson (2008) fed into the creation of BSLBT

willing to pay for this type of service and almost a half (48%, n=66) said they would pay more if the channel and programming was run by Deaf people. Importantly, the large majority of participants in the 'See Hear Now' study wanted both signing *and* subtitles on TV, as opposed to signing only.

Research also suggests a need for Deaf programmes or BSL interpreting online as well as on TV. Wu et al. (2014) found that 33% (n=79) of their 240 deaf and hard of hearing survey respondents watched television via online platforms such as BBC iPlayer, and 7% (n=16) used social media, such as YouTube. In an earlier study of 100 Deaf people (Kyle and Jackson 2008), 18% (n=18) said they use the internet to watch TV and this was more common among participants under the age of 50 (29%) as opposed to those over the age of 50 (3%).

Participants in the study by Kyle and Jackson (2008) discussed some of the broader importance of having Deaf TV. The Deaf participants said they feel empathy when watching a programme in BSL, and voiced their rationale for watching signed TV "*as a statement of the identity and culture of Deaf people, as a means of community enrichment and encouragement of empathy, as an educational tool and as a means of information access*". Adding to this, in a study by the National Deaf Children's Society (2005) young deaf people wanted more equal representation of deaf people on TV and teachers felt that having sign language shown on TV programmes at school reduces the attached stigma of 'being different', increases deaf awareness, and raises the status of deaf children.

4. Conclusions and recommendations

4.1. Conclusions

This project set out to understand more about the existing research available on the highly marginalised Deaf community within the UK, and to help the wider world to understand the implications of being Deaf and the life experience of Deaf people. This review has highlighted the extent to which **the Deaf community is indeed highly marginalised and under-represented**, and has highlighted that **Deaf people face many issues in everyday life**. However, a key finding from this report is the **lack of data and understanding of the Deaf community**, and the extent to which this community is under-researched. As such there are still many aspects of the Deaf community that are unknown, and many gaps in the evidence. A significant contributor to this is the fact that few studies explicitly focus on Deafness, i.e. 'Deaf' as a cultural and linguistic identity, and this report has identified a need for more research focussing specifically on the Deaf community. This review provides a rare and unique overview of what is known about the Deaf audience and where the gaps in evidence lie, and will likely be of significant use to a range of other agencies that work with, or provide services to the Deaf community, including health, education, employers and other leisure and recreation providers.

The review reached the following conclusions:

There are no reliable estimates of the total number of Deaf people in the UK or their demographic profile

Even a recent large-scale study which attempted to assess the health of the Deaf community in the UK noted that *"without any knowledge of the profile of the UK Deaf population it is not possible to calculate the extent to which survey respondents are representative of Deaf people"* (SignHealth 2013). Similarly, there are no comprehensive, robust and reliable, UK-wide estimates of the total number of people who use BSL as their main language or the demographic profile of people who use BSL as their main language. The UK Census 2011 and the Scotland Census 2011 provided a good opportunity to estimate the total number of people who use BSL as their main language but they provided conflicting estimates which are widely believed to be under-estimates and there are limitations to the way the questions were posed.

There are a number of studies exploring the integration of Deaf people into the wider world

These studies explore the extent to which Deaf people are integrated into the wider world, with a lot of qualitative data obtained from interviews with D/deaf people. Overall, the evidence suggests that Deaf people are excluded from society and suffer from social isolation. Deaf people face difficulties in accessing and using local services hindered by a shortage of information and services in BSL, of specialist support services, of qualified interpreters, and by general lack of deaf awareness. Deaf people face barriers to

employment, and there is evidence to suggest the unemployment rate among Deaf people is higher than in the general population.

There is evidence of significant disparities in the educational attainment of Deaf children compared to hearing children

The review identified the shortage of data in this area, and there is no data regarding deaf adults. The age at which BSL is taught affects the signing ability of deaf children and adults. Children who have had late access and exposure to BSL may have restricted use. There are large disparities in the educational attainment of deaf children compared to hearing children. However the attainment gap does appear to be narrowing, particularly in the early years of education.

There are comparatively few studies that assess the health status of Deaf people in the UK

One recent comprehensive study was the Deaf Health study (SignHealth 2014). There is some evidence to suggest that Deaf people have higher prevalence rates of obesity, high blood pressure and depression compared to the general population, but they have lower prevalence rates of cardiovascular disease, high cholesterol and chronic obstructive pulmonary disease (COPD) and are less likely to smoke and drink alcohol. Deaf people are more likely to be under-diagnosed. Even when diagnosed, they are more likely to have poorer treatment and management of potentially serious health conditions. There is a lot of evidence, however, highlighting the many barriers that Deaf people face when accessing health services. Notably, they face difficulties booking and attending health appointments, and communicating with health professionals, and there is often an absence of BSL interpreters at consultations, which may result in Deaf people having to rely on friends and family.

There is limited research on the balance of use of BSL and English in Deaf people's everyday lives

A report by CRIDE (2014b) notes that in England roughly 9.4% of deaf children either use sign language as their main language or in some combination with another language at school or other education settings and almost 90% of deaf children do not communicate at all in sign language in their school or other education setting. Young deaf people attending mainstream schools complained that teachers discouraged them from using BSL (Jones 2001). This assertion, coupled with the fact that 76% of deaf school children attend mainstream schools (NCDS 2009), may explain why the large majority of deaf children have to rely on spoken English at school, however this has not been explored further in the literature reviewed to date.

There is limited recent research on Deaf people's experiences of new technologies and social media

The literature, much of which comes from outside the UK and is several years old, tends to focus on the use of technologies such as SMS and email as means of communication, as well as the use of the internet among the Deaf community. However, the review did

not identify any data on the use of social media, notably Facebook and Twitter, and applications such as FaceTime/Skype among Deaf people. Technology, the internet, and social media are fast moving and constantly changing, particularly in recent years, and we are not confident that evidence found is representative of the most current use of new technologies and social media among the Deaf community. Nonetheless, a number of studies focusing on internet use and experiences among Deaf people identified the benefits of the internet as an alternative way of communicating with other Deaf people, facilitating the development of social networks, and allowing Deaf people to access online education and information. The internet allows Deaf people to pass as hearing online and may facilitate greater integration between Deaf and hearing people. However, this does not necessarily increase the integration of the Deaf community into mainstream society.

There is limited recent and robust research on Deaf people's views on television broadcasting

There has been some research on Deaf peoples' views on television broadcasting, but many of the studies pre-date the creation of BSLBT in 2008 and are based on a very small number of participants. This research suggests that Deaf people want Deaf presenters instead of BSL interpreters to provide access to mainstream programmes and there is demand for a Deaf TV channel which is Deaf-led, in BSL, and with a distinct Deaf perspective. Deaf participants said they feel empathy when watching a programme in BSL, and voiced their rationale for watching TV programmes presented in sign language *"as a statement of the identity and culture of Deaf people, as a means of community enrichment and encouragement of empathy, as an educational tool and as a means of information access"* (Kyle and Jackson 2008).

An aim of this research was to identify how BSLBT can best reach, and engage with, the Deaf audience. However, with so little reliable evidence regarding the extent to which new technologies and social media are changing Deaf people's experiences and Deaf people's views on television broadcasting this is potentially a priority research question going forward, a question best answered by the Deaf community themselves. However, we first need to fully understand the extent and profile of the Deaf audience.

4.2. Recommendations

This important review provides a summary, and adds to the knowledge base on the Deaf community and has highlighted the extent to which this community is highly marginalised, under-represented, and under-researched. Perhaps more importantly, this research has highlighted the lack of data and poor understanding of the Deaf community.

Based on the evidence available our recommendations are:

All major public and charitable services are encouraged to:

- Understand and record use of their services
- In the light of this, consider how they might make their services more accessible

Through commissioning this review BLSBT has demonstrated commitment to raising awareness of the urgent need for robust research into the Deaf community, at the same time raising questions around the status quo which is often based on claims and assumptions that may not always be backed by evidence. These have major implications for the extent to which agencies are able to meet the needs of the Deaf community.

BSLBT to investigate more effective methods of audience engagement

The quality of programmes obviously benefits from better audience engagement. At the same time, BSLBT is aware that audience engagement is not straightforward, particularly in the context of a dearth of good evidence relating to the size, distribution and demographics of the Deaf community. We recommend that BSLBT explores what effective and realistic audience engagement should look like in the context of its organisational aims, structure and resourcing. For example, BSLBT should take into consideration the finding from this review that there is very little reliable evidence regarding the extent to which new technologies and social media are changing Deaf people's experiences. This poses questions for engagement strategies that rely solely or largely on social media.

Associated with this, we recommend that any plan for audience engagement should not strive for representativeness at this stage. This is unrealistic given the current knowledge base and the often spurious nature of the numbers circulating around on various aspects of the Deaf community. Instead, we recommend starting small, working with what is known and learning from that, before cascading wider incrementally.

Encourage a collaborative approach to the gathering of new evidence

BSLBT is not a lobbying organisation and neither is it an agency responsible for evidence production. There are a number of other organisations that are much better resourced and better placed to address the lack of evidence currently available. These include public bodies and large charitable organisations, amongst others, with an interest in this area, or who would benefit from having better evidence on the Deaf community. They may be organisations working within and for the Deaf community as well as organisations with broader interests, such as health and social care agencies. We recommend that these organisations respond to this review by playing a more proactive role in commissioning and contributing to the evidence base.

In recognition of the dearth of evidence and the fact that it will take time for new research to be commissioned and made available, we further recommend that Deaf charities and other organisations who may hold relevant evidence and data adopt a strategically collaborative approach to sharing data and creating synergies through joint working that will be of benefit to all. For example, it may be fruitful to explore how Deaf charities and others may work together to influence the gathering of national statistics that asks sensible questions of and on the Deaf community. One avenue potentially worth exploring is the 2021 Census. As discussed, there are limitations to the way the questions were posed in the 2011 Census and planning for and development of the 2021 Census is now under way, offering an opportunity for change.

Recognise the marginalisation of Deaf people as an important manifestation of the current social policy focus on overcoming isolation

It can often be easy to regard issues relating to the Deaf community as “minority issues” that are only relevant to specialist organisations. This review, however, challenges this perception by showing that the experiences of the Deaf community are manifestations (and amplifications) of cross-cutting social issues that have wider relevance for society, albeit with important nuances. For example, isolation and exclusion are recognised social problems demanding the highest level of attention from policy and practice. It is important to appreciate that we, as a society, cannot hope to tackle such problems meaningfully if we do not address the needs of some of the most isolated and excluded segments of society. A truly inclusive society requires us to treat every person as a person, first and foremost, and not as an identity label. We recommend that the findings in this review, while relating to the Deaf community, are not treated as “minority issues” that are bracketed off and de-prioritised. Instead, we strongly encourage a genuine person-centred approach that enables us to break down silos and adopt more holistic approaches to solving the problems identified.

References

The following are items reviewed to date; an updated list of references will be provided for the final report.

Action on Hearing Loss, ASLI, NRCPD, BDA, SignHealth, Signature, and BSMHD (2012). Survey of BSL users about access to communication support in healthcare.

Action on Hearing Loss (2013). Access all areas? A report into the experiences of people with hearing loss when accessing healthcare. [Online]. Available at:

<http://www.actiononhearingloss.org.uk/supporting-you/policy-research-and-influencing/research/access-all-areas.aspx>

Alexander, A., Ladd, P. and Powell, S. (2012). Deafness might damage your health. *Lancet*, 379 (9820), p.979-981.

Bamford, J., Ankjell, H., Crockett, R., Marteau, T., McCracken, W., Parker, D., Tattersall, H. et al. (2004). Report of the evaluation of the first phase of implementation of the NHSP. Volume One: Studies, Results and Recommendations. University of Manchester Audiology and Deafness Research Group: Manchester.

Bodsworth, S. M., Clare, I. C. H. and Simblett, S. K. (2011). Deafblindness and mental health: Psychological distress and unmet need among adults with dual sensory impairment. *British Journal of Visual Impairment*, 29 (1), p.6-26.

Brennan, M., Grimes, M. and Thoutenhoofd, E. (2005). Deaf students in Scottish Higher Education. The University of Edinburgh Moray House School of Education: Edinburgh

British Deaf Association (2013). Report on NHS BSL/English interpreting provision within health settings in Scotland. [Online]. Available at:

http://www.bda.org.uk/uploads/BDA/files/BDA_EDDJ_Report_On_Council_Services_2014.pdf

British Deaf Association (2014a). Report on access to council services for older Deaf people in England and Wales. [Online]. Available at:

http://www.bda.org.uk/uploads/BDA/files/BDA_EDDJ_Report_On_Council_Services_2014.pdf

British Deaf Association (2014b). Access to council services for Deaf people in Birmingham. [Online]. Available at:

http://www.bda.org.uk/uploads/BDA/files/BDA_Access_to_Council_Ser_for_Deaf_People_in_Birm_Report_11-2014.pdf

British Deaf Association (2014c). Report on access to health services for older Deaf people in England and Wales. [Online]. Available at:

http://www.bda.org.uk/uploads/BDA/files/BDA_EDDJ_Report_On_Access_to_Health_Services_2014.pdf

British Deaf Association (2014d). Report on health services provision to BSL users in Scotland. [Online]. Available at:

http://www.bda.org.uk/uploads/BDA/files/BDA_Report_on_Health_Services_Provision_to_BSL_Users_in_Scotland.pdf

Burgess, G. and Monk, S. (2013). Scoping study on service use by the Cambridgeshire D/deaf communities. Cambridge Centre for Housing & Planning Research: Cambridge.

Burman, D., Nunes, T. and Evans, D. (2007). Writing profiles of deaf children taught through British Sign Language. *Deafness and Education International*, 9 (1), p.2-23.

Cassiopeia Consultancy (2013). Impact assessment: telephony equivalency for d/Deaf people for UKCoD and Deaf Access to Communication group - Need, demand and cost of relay services for d/Deaf people in the UK.

Consortium for Research in Deaf Education (2014a). CRIDE report on 2014 survey on educational provision for deaf children: UK-wide summary.

Consortium for Research in Deaf Education (2014b). CRIDE report on 2014 survey on educational provision for deaf children: England.

Cormier, K., Schembri, A., Vinson, D. and Orfanidou, E (2012). First language acquisition differs from second language acquisition in prelingually deaf signers: Evidence from sensitivity to grammaticality judgement in British Sign Language. *Cognition*, 124 (1), p.50-65.

Department for Education (2014). Children with Special Educational Needs 2014: An Analysis. Department for Education: London.

Department of Health. (2002). A sign of the times: modernising mental health services for people who are Deaf. Department of Health: London.

Emond, A., Ridd, M., Sutherland, H., Allsop, L., Alexander, A. and Kyle, J. (2015). The current health of the signing Deaf community in the UK compared with the general population: a cross-sectional study. *BMJ Open*, 5 (1).

Fajardo, I., Parra, E. and Canas, J. J. (2010). Do sign language videos improve web navigation for Deaf signer users? *Journal of Deaf Studies and Deaf Education*.

Fellinger, J., Holzinger, D. and Pollard, R. (2012). Mental health of deaf people. *Lancet*, 379, p.1037-44.

Ferguson-Coleman, E., Keady, J., and Young, A. (2014). Dementia and the Deaf community: knowledge and service access. *Aging & Mental Health*, 18 (6), p.674-682.

Fordyce, M., Riddell, S., O'Neill, R. and Weedon, E. (2013). Post-school transitions of people who are deaf or hard of hearing. The University of Edinburgh Centre for Research in Education, Inclusion and Diversity: Edinburgh.

Fortnum, H. M., Summerfield, A. Q., Marshall, D. H., Davis, A. C. and Bamford, J. M. (2001). Prevalence of permanent childhood hearing impairment in the United Kingdom and implications for universal neonatal hearing screening: questionnaire based ascertainment study. *BMJ*, 323 (536).

- Harris, J. and Bamford, C. (2001). The uphill struggle: services for Deaf and hard of hearing people – issues of equality participation and access. *Disability & Society*, 16 (7), p.969-979.
- Healthwatch Leicester (2014). Deaf community speaks up on local health services. [Online]. Available at:
http://www.bda.org.uk/uploads/BDA/files/Deaf_Community_Speaks_Up_On_Local_Health_Services_Healthwatch-Leicester_Nov-2014.pdf
- Hunt, R., Oram, R. and Young, A. (2010). Older people who use BSL – preferences for residential care provision in Wales. The University of Manchester Social Research with Deaf People Group: Manchester.
- Jensen, L. G., Nakaji, M., Harry, K. M., Gallegos, N., Malcarne, V. L., and Sadler, G. R. (2013). Ovarian cancer: Deaf and hearing women’s knowledge before and after an educational video. *Journal of Cancer Education*, 28 (4), p.647-655.
- Jones, L., Atkin, K. and Ahmad, W. I. U. (2001). Supporting Asian deaf young people and their families: the role of professionals and services. *Disability & Society*, 16 (1), p.51-70.
- Karras, E. and Rintamaki, L. S. (2012). An examination of online health information seeking by Deaf people. *Health Communication*, 27 (2), p.194-204.
- Kyle, J. (2007). Sign on Television: Analysis of Data - Based on projects carried out by the Deaf Studies Trust 1993-2005. [Online]. Available at:
http://stakeholders.ofcom.org.uk/binaries/consultations/signing/responses/deafstudies_annex.pdf
- Kyle, J., Sutherland, H. and Stockley, S. (2012). Legal Choices – Silent Process: Engaging Legal Services when you do not hear. Deaf Studies Trust: Bristol.
- Kyle, J., Reilly, A. M., Allsop, L., Clark, M., Dury, A. (2005). Investigation of access to public services in Scotland using British Sign Language. Scottish Executive Social Research: Edinburgh.
- Kyle, J. and Barnett, S. (2012). Deafblind worlds. Deaf Studies Trust and Sense.
- Kyle, J. and Jackson, D. (2008). Sign on TV: What Deaf people want. Deaf Studies Trust
- Maiorana-Basas, M. and Pagliaro, C. M. (2014). Technology use among adults who are deaf and hard of hearing: A national survey. *Journal of Deaf Studies and Education*.
- Mason, K., Rowley, K., Marshall, C. R., Atkinson, J., Herman, R., Woll, B. and Morgan, G. (2010). Identifying specific language impairment in deaf children acquiring British Sign Language: Implications for theory and practice. *British Journal of Developmental Psychology*, 28 (1), p.33-49.
- McCracken, W. and Pettitt, B. (2011). Complex needs, complex challenges: a report on research into the experiences of families with deaf children with additional complex needs. National Deaf Children’s Society: London.
- The National Deaf Children’s Society (2005). In their own words: Young deaf people’s access to television. London: The National Deaf Children’s Society.

The National Deaf Children's Society (2009). England - 2009 NDCS Education Survey. [Online]. Available at:

http://www.ndcs.org.uk/professional_support/national_data/england_2009_ndcs.html

The National Deaf Children's Society (2012). Prevalence of additional disabilities with deafness: A review of the literature. London: The National Deaf Children's Society.

The National Deaf Children's Society (2013). NDCS spreadsheet of attainment data in Wales. [Online]. Available at:

http://www.ndcs.org.uk/professional_support/national_data/education_data_in.html

The National Deaf Children's Society (2014). NDCS note on Department for Education figures on attainment for deaf children in 2014 (England). [Online]. Available at:

www.ndcs.org.uk/document.rm?id=9952

The Health and Social Care Information Centre (2010). People registered deaf or hard of hearing year ending 31 March 2010, in England. The Health and Social Care Information Centre.

The Health and Social Care Information Centre (2014). Registered blind and partially sighted people - year ending 31 March 2014, England. The Health and Social Care Information Centre.

Mitchell, R. E. and Karchmer, M. A. (2004). Chasing the mythical ten percent: parental hearing status of deaf and hard of hearing students in the United States. *Sign Language Studies*, 4 (2), p.138-163.

NHS Newborn Hearing Screening Programme (2011). NHS Newborn Hearing Screening Programme 2010-11: Annual report and 2009-10 data report. London: NHS Newborn Hearing Screening Programme.

Nunes, T., Pretzlik, U., and Olsson, J. (2001). Deaf children's social relationships in mainstream schools. *Deafness & Education International*, 3 (3), p.123-136.

Parker, J., Young, A. and Rogers, K. (2010). 'My Mum's Story': a Deaf daughter discusses her Deaf mother's experience of dementia. *Dementia: the International Journal of Social Research and Practice*, 9 (1), p.5-20.

Pilling, D. and Barrett, P. (2007). Text communication preferences of deaf people in the United Kingdom. *Journal of Deaf Studies and Deaf Education*, 13 (1), p.92-103.

Power, D. and Power, M. R. (2009). Communication and culture: Signing Deaf people online in Europe. *Technology and Disability*, 21 (4), p.127-134.

Power, M. R., Power, D., and Horstmanshof, L. (2007). Deaf people communicating via SMS, TTY, relay service, fax, and computers in Australia. *Journal of Deaf Studies and Deaf Education*, 12 (1), p.80-92.

Reeves, D., Kokoruwe, B., Dobbins, J. and Newton, V. (2002). Access to primary care and Accident & Emergency services for Deaf people in the North West. [Online]. Available at:

http://www.population-health.manchester.ac.uk/primarycare/npcrdc-archive/Publications/Deaf_Access_final_report.pdf

Robertson, J. and Emerson, E. (2010). Estimating the number of people with co-occurring vision and hearing impairments in the UK. Lancaster: Centre for Disability Research, Lancaster University.

Rogers, K. D. (2013). Deaf people and mental well-being: Exploring and measuring mental well-being in British Sign Language. PhD. University of Manchester.

Royal National Institute for Deaf People (2004). A simple cure: A national report into deaf and hard of hearing people's experiences of the National Health Service. London: Royal National Institute for Deaf People.

Royal National Institute for Deaf People (2006). Opportunity blocked: The employment experiences of deaf and hard of hearing people. London: Royal National Institute for Deaf People.

Sacks, L., Nakaji, M., Harry, K. M., Oen, M., Malcarne, V. L. and Sadler, G. R. (2013). Testicular Cancer Knowledge among Deaf and Hearing Men. *Journal of Cancer Education*, 28 (3), p.503-508.

Scottish Government (2014a). Analysis of Equality Results from the 2011 Census. Edinburgh: The Scottish Government

Scottish Government (2014b). Summary statistics for attainment, leaver destinations and healthy living, No. 4: 2014 Edition. [Online]. Available at: <http://www.gov.scot/Resource/0045/00453110.pdf>

Scottish Government (2015). Analysis of Equality Results from the 2011 Census – Part 2. Edinburgh: The Scottish Government

Shoham, S., and Heber, M. (2012). Characteristics of a virtual community for individuals who are d/deaf and hard of hearing. *American Annals of the Deaf*, 157 (3), p.251-263.

SignHealth (2009). Why are you still missing me? A report following the publication of the GP Patient Survey 2009. Beaconsfield: SignHealth.

SignHealth (2013). Research into the health of deaf people. [Online]. Available at: <http://www.signhealth.org.uk/v3/wp-content/uploads/2014/03/SignHealth-Deaf-Health-Survey-Report.pdf>

SignHealth (2014). A report into the health of Deaf people in the UK. [Online]. Available at: <http://www.signhealth.org.uk/sick-of-it-report-professionals/>

Skellington Orr, K., Leven, T., Bryan, R. and Wilson, E. (2006). Community care and mental health services for adults with sensory impairment in Scotland: research publication. Edinburgh: Scottish Executive.

Skelton, T., and Valentine, G. (2003). 'It feels like being Deaf is normal': an exploration into the complexities of defining D/deafness and young D/deaf people's identities. *The Canadian Geographer/Le Géographe Canadien*, 47 (4), p.451-466.

Social Care Institute for Excellence (2014). Dementia Gateway: Sensory loss and dementia. [Online]. Available at: <http://www.scie.org.uk/publications/dementia/living-with-dementia/sensory-loss/files/sensory-loss-research.pdf?res=true>

Sutherland, H., and Young, A. (2007). 'Hate English! Why?...' Signs and English from deaf children's perception. Results from a preliminary study of deaf children's experiences of sign bilingual education. *Deafness & Education International*, 9 (4), p.197-213.

Ubido, J., Huntington, J., and Warburton, D. (2002). Inequalities in access to healthcare faced by women who are deaf. *Health & Social Care in the Community*, 10 (4), p.247-253.

Valentine, G., and Skelton, T. (2007). Re-defining 'norms': D/deaf young people's transitions to independence. *The Sociological Review*, 55 (1), p.104-123.

Valentine, G., and Skelton, T. (2008). Changing spaces: the role of the internet in shaping deaf geographies. *Social & Cultural Geography*, 9 (5), p.469-485.

Valentine, G., and Skelton, T. (2009). 'An umbilical cord to the world': The role of the Internet in D/deaf people's information and communication practices. *Information, Communication & Society*, 12 (1), p.44-65.

Watkin, P. M., and Baldwin, M. (2010). Identifying deafness in early childhood: requirements after the newborn hearing screen. *Archives of Disease in Childhood*.

Wilson, J. A. and Wells, M. G. (2009). Telehealth and the deaf: a comparison study. *Journal of Deaf Studies and Deaf Education*, 14 (3), p.386-402.

Wu, Y., Price, E., & Evans, L. (2014). *Digital Television and Deaf/Hard of Hearing Audiences in Wales*. Swansea: Swansea University College of Arts and Humanities.

Young, A., Hunt, R., Oram, R. and Smith, C. (2010). The impact of integrated Children's Services on the scope, delivery and quality of social care services for deaf children and their families: Phase 2 report. London: The National Deaf Children's Society.

Young, A., Ferguson-Coleman, E., and Keady, J. (2014). Understanding Dementia: Effective information access from the Deaf community's perspective. *Health & Social Care in the Community*.

Young, A., Oram, R., Squires, G., Sutherland, H. (2015). Identifying effective practice in the provision of education and education support services for 16-19 year old deaf young people in Further Education in England. Manchester: The University of Manchester.

Zarfaty, Y., Nunes, T., and Bryant, P. (2004). The performance of young deaf children in spatial and temporal number tasks. *Journal of Deaf Studies and Deaf Education*, 9 (3), p.315-326.

Harris,

Appendices

Appendix 1. Common assertions about Deaf people

The following is a list of common assertions that BSLBT is aware of, anecdotally, as being made about the Deaf community. The review looked for evidence which related to these (either confirming or contradicting the assertions):

- 50,000 – 70,000 people in the UK use BSL as their first language
- 90% of Deaf children are born into hearing families
- 90% of Deaf children are in mainstream education
- Deaf children at 16 have a reading age of 9
- There is a higher incidence of mental illness among Deaf people compared to the hearing population
- Deaf people want 100% of TV and online programmes to have subtitles
- Deaf people want their own TV channel
- Deaf people want the full range of TV programmes (ie news, documentaries, reality TV, soaps, comedy, drama) to be presented in BSL *as well as* access to mainstream TV
- Deaf people don't want an interpreter on screen in all programmes eg: soaps

Appendix 2. List of interviewees

Name	Organisation/role
Jeff McWhinney	Board member, British Sign Language Broadcasting Trust Founder and Chair, SignVideo - Significan't (UK) Ltd
Prof Bencie Woll	Deafness Cognition and Language Research Centre, University College London
Dr Paddy Ladd ¹⁴	Deaf scholar, author and researcher, formerly of the Centre for Deaf Studies at the University of Bristol
Prof Graham Turner	Director of the Centre for Translating and Interpreting Studies in Scotland, Heriot-Watt University
Susan Daniels	CEO, National Deaf Children's Society
Dr Jan Sheldon	CEO, Royal Association of Deaf People
Jim Kyle ¹⁵	Former Professor of Deaf Studies, Centre for Deaf Studies at the University of Bristol

¹⁴ Provided input via email

¹⁵ As above