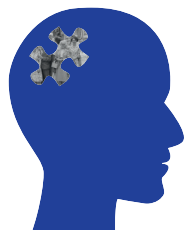




Deaf people with dementia and care homes in Scotland

*Navigating effective care home
service provision in Scotland
for Deaf people with dementia
and their families*

March 2022



Introduction



Introduction to the findings of the Deaf Dementia Research Project

I am delighted to have been asked to write an introduction to this excellent research report, which the British Deaf Association Scotland has produced in partnership with the University of Manchester. The Life Changes Trust was pleased to fund the research through our 'Digging Deeper' funding programme, and it is an important companion to 'The Deaf Dementia Experience in Scotland: A Toolkit for All', which was published by the British Deaf Association Scotland in 2019 with funding from the Life Changes Trust.

Similar to the Toolkit, this particular piece of research emphasises the human rights of Deaf BSL users in relation to residential and social care, as well as the importance of understanding the needs of Deaf people living with dementia, and their unpaid carers, families and friends. Informed by the opinions and experience of Deaf BSL users, it also highlights the value of a person-centred approach to providing support to Deaf BSL users with dementia and unpaid carers.

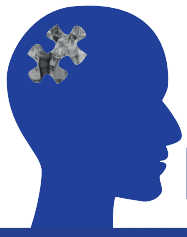
This individual approach is vital if each person is to receive the best care and assistance to which they are entitled.

The research will also be helpful to care homes, social care providers, keyworkers, BSL/English interpreters and everyone else involved in providing support to Deaf BSL users who are living with dementia or providing support to someone living with dementia.

The report is another important contribution to improving the lives of Deaf BSL users affected by dementia in Scotland. It is the responsibility of us all to ensure that it is used to develop a more personal, rights-based approach to providing support across the social care sector.

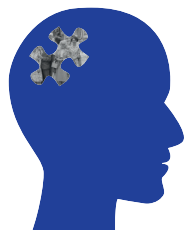
Arlene Crockett

Joint CEO/Director of Evidence & Influencing
Dementia Programme, Life Changes Trust



Dedication

This report acknowledges, honours and is dedicated to the older generation of Deaf people who have led the way in fighting for equality for Deaf people, recognition of BSL as a language and celebrating the joy of BSL, the Deaf community and Deaf culture. Many of this generation are now reaching older age with the added challenge of dementia affecting them and their families. Services are not yet adequate to meet their needs and to support those who care for them. The evidence in this report concerning care homes and Deaf people with dementia is one step towards that goal of culturally appropriate, linguistically accessible high-quality services for Deaf BSL users with dementia in Scotland.



Executive summary

Introduction

This report is about care homes in Scotland and Deaf people with dementia. It is funded by the Life Changes Trust. The project was led by BDA Scotland in partnership with SORD (Social Research with Deaf people), University of Manchester. The research was trying to find out how to improve care homes for Deaf people with dementia from the point of view of Deaf people and from the point of view of care home providers.

All data were collected by Deaf researchers in BSL through interviews and focus groups. BSL/English interpreters were available for hearing people working at care homes. The study was carried out remotely through Zoom because of the COVID-19 pandemic.

Main Findings

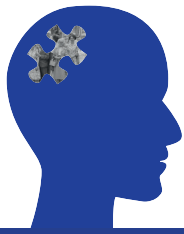
Deaf perspectives and Care Home perspectives are quite different. Sometimes Deaf people and care home staff identified the same problem, but thought about it in different ways. Sometimes the priorities of Deaf people were very different from those of care homes. We have compared and contrasted these different points of view throughout as they show cultural differences but also opportunities to learn from each other.

Language and communication

Everyone thought that language and communication was a key issue but Deaf people and care home staff saw it differently. Care home staff saw the difficulties as arising from “deafness” which to them meant difficulties in hearing, speaking and understanding spoken language. For Deaf people, the key issue was the gradual loss of BSL. Without good regular communication in BSL then a resident’s language would decline. Keeping BSL alive was seen as the main priority. For care home staff the priority was how to get round the barrier of not being able to communicate in written/spoken English. They did not give the same importance to the preservation of BSL.

Cultural needs

Managers and staff at care homes have difficulties understanding what Deaf culture is. This can create problems for them fulfilling a duty to respect cultural requirements and differences. They do not feel supported to understand Deaf culture or its implications for care.



Executive summary

Transition into care homes

Care home managers and staff recognise Deaf people are not aware of all the available care home options. They emphasise the need for more publicity and a greater role for social workers in informing Deaf people. From Deaf people's point of view the issue is centred in language – there is very little information in BSL that Deaf people can look at to support them make decisions about care homes.

Care homes are not always aware of the importance of booking BSL/English interpreters for contact with potential Deaf residents, family or carers who may be BSL users also. They are also not sure how to book an interpreter and their responsibility to do so.

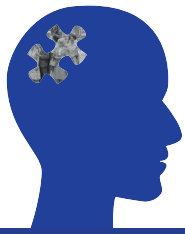
Social workers are an important part of assessment and information to support a Deaf person moving into residential care and specifying their needs and preferences. However, there is a big difference between the information provided by social workers in general and information provided from an assessment done by a social worker who is a BSL user and understands Deaf culture. The quality is much better.

Deaf family and carers can feel alienated from the processes surrounding assessment and decision making about whether someone should move into a care home. They find that often they are excluded from key conversations because there is not a BSL/English interpreter or it is assumed they will understand written English. Sometimes social workers and care home staff find it easier to communicate with the hearing person in the family rather than directly with the Deaf principal carer. This makes Deaf people feel side-lined.

Requirements for effective care provision

People working in care homes need more information about Deaf people's needs. They usually focus on people with hearing loss but do not necessarily understand the needs of BSL users.

Deaf people expect that the Deaf person with dementia should be able to maintain a social life. They focus on the importance of avoiding isolation and of contact with BSL users to avoid language decline.



Executive summary

Sometimes other Deaf people in the community are reluctant to continue contact with their Deaf friend when they move into a care home because they do not understand the impact of dementia and can feel that there is a stigma if someone is Deaf and has dementia.

Care home staff are worried that Deaf befrienders and others coming into the care home to socialise and support a Deaf person may not understand how to change their communication to match the needs of someone with dementia.

There is general agreement that having more Deaf BSL staff in care homes would be helpful but achieving this would be challenging. Care home managers were concerned about attitudinal barriers that might prevent their employment. Also, the very few residents who are Deaf with dementia are scattered across many care homes so it would not be cost-effective.

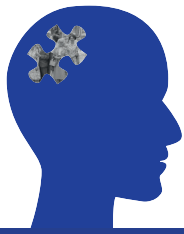
Care home managers and staff are open to the idea of specialised Deaf units. However, they are concerned with inflexible old buildings that do not allow such space, and with segregating Deaf residents. Members of the Deaf community are interested in the idea of establishing specialised Deaf units. However, they are concerned with geographical isolation from their families and Deaf communities if they need to travel to join such units.

Deaf people were very worried that it is very hard for care home staff to recognise Deaf residents needs or to monitor their wellbeing. Deaf people felt they had to take on the responsibility to be very vigilant and constantly checking that their family member or friend was all right and their needs were being attended to.

Overall Conclusion

Everyone involved in this research acknowledges that there is a still a lot of work to do to meet goal 41 of the Scottish Government's BSL National Plan 2017 – 2023 that says:

Work with local authorities, providers and service users to improve the way that adult social care is delivered, including how residential care is commissioned and how care and support is delivered to people at home. The voices and experiences of service users, including BSL users will be at the centre of these reforms and will shape planning and implementation and improve outcomes.



Executive summary

What might help?¹

The training and employment of **Deaf BSL cultural advocates** who are Deaf BSL users with special additional training in older people and dementia. They could support people with dementia considering care homes and make their wishes and fears known clearly. They could support Deaf family members to be able to be fully informed of options, and argue for their needs, wishes and priorities.

Better **BSL** and **Deaf cultural training** for care home providers. This is different from general deaf awareness training.

Creating **guidelines** for best care for Deaf people with dementia in care homes and supporting care homes to implement this through contact with **organisations** such as BDA Scotland who can work with them.

Forming a group of Deaf befrienders with special training in dementia who might visit residents, engage them in **culturally Deaf-friendly** activities and add to their social stimulation.

Employing **Deaf BSL staff**.

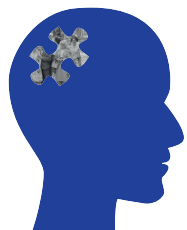
Provide simple '**how to**' **guides** for care home staff including e.g. how to book an interpreter, how to set up remote videocalls for a resident in BSL with Deaf family and friends.

Provide basic information about care homes, choices and decision making in an accessible **BSL format** for family, friends and carers.

Create a '**Deaf all about me**' template for care homes to use with residents and their family and friends that builds a picture of a Deaf residents' life, preferences, history and family/community from a Deaf point of view. Existing templates may not emphasise what is important for a Deaf person.

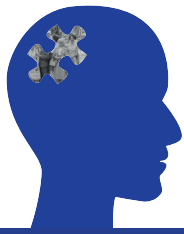
Enhance protocols of inspection to include specific items relating culturally **Deaf BSL users** if they are living in a care home and appoint a **Deaf care inspector** for care homes in Scotland.

¹ More detailed recommendations set against timescales are available in the final section of the report.



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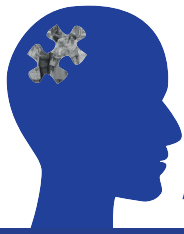
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A note on terminology

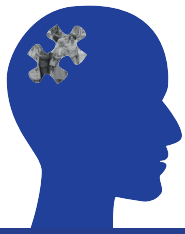
In some places, this report uses terminology that does not reflect BDA's standards and preferred usage concerning Deaf people who are BSL users. This was deliberately done to better depict **the participants' perspectives and their assumptions** about the issues that were discussed during the interviews. For example, some participants equate being Deaf with "hearing loss", whereas for the BDA being culturally Deaf cannot be described by hearing status and we acknowledge that the use of "hearing loss", in particular, may offend some readers. It is nonetheless the terminology used by some participants in the project and we wanted to ensure that this is clearly reflected. Also, some participants talk loosely about "sign language" without clearly specifying that they refer to BSL. Where that has happened, we have faithfully reproduced it. There are also vague mentions of "deaf associations" in some interviews without a specific mention as to whether the British Deaf Association Scotland was being referred to or another Deaf-led charity, or a local Deaf club. It is not our place to 'correct' this language with our own assumptions about what might have been meant.

In many cases, keeping participants' use of language, even if it is different from that preferred by the BDA, is an important way to **highlight the differences in thinking between hearing and culturally Deaf people**. In such cases, we have added "**double inverted commas**" to signal that the chosen language is that of the participants and not necessarily language that the BDA would endorse nor the authors of this report.



A note on accessibility

This version of this report in written English is not primarily aimed at Deaf BSL users. It is aimed at policy makers, service providers, educators and academics working in this field with power to change the circumstances surrounding best care for Deaf people with dementia in the care home sector in Scotland. It is a faithful reflection in English of the ‘voice’, views and vision of the Deaf people who participated in their own preferred language: BSL. It enables hearing people who are not fluent in this language and rarely interact with Deaf BSL users to become aware of this community and its strengths and needs. We acknowledge that the report is written in a level of English that is likely to be more complex than that used by many Deaf people as their second language. However, we have in places **put in bold key phrases and key points to aid readability** for second language English users. When contrasting the **Care Home Perspectives** and the **Deaf Perspectives** we have maintained a difference in colour for the headings to make this contrast more easily recognised and easier to follow. We would draw attention to the accompanying **executive summary** document and **summary in BSL** aimed at the families, carers and people with dementia for whom BSL is first and preferred language. This is available on the BDA website. The findings from this report are also being communicated in a range of Deaf-led live events that will engage many sectors of the Deaf community in Scotland and provide opportunities to comment and to add the work within it.



Glossary

BSL = British Sign Language.

BSL (Scotland) Act 2015 = Act that protects BSL as an indigenous language of the Deaf community in Scotland.

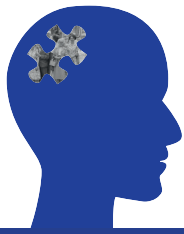
BSL/English interpreter = An interpreter of BSL and English, different from interpreters used for spoken languages or other signed languages.

Deaf = A cultural way of being, not reducible to hearing status. Related to being a visually oriented person and user of a signed language such as BSL.

BSL awareness = A programme of awareness centred not in the needs emanating from the hearing status of a person but in the needs of users of a visual-gestural language like BSL.

Deaf community = The community of visually oriented Deaf people sharing a common signed language like BSL and common cultural references and experiences in a hearing-oriented world.

Deaf organisations = Loose term that can refer to the British Deaf Association, a Deaf-led charity.



Introduction

Focus

This research report is about Deaf people who use British Sign Language (BSL), who experience dementia, and about care homes in Scotland. The study was undertaken because of concerns that care home provision in Scotland might not be adequate to meet Deaf people's needs. Although over 70% of the over 70s will experience some degree of what is commonly referred to as "hearing loss"², and care homes mostly are aware of their needs, this is not the population that is the focus of this study. Rather it is **the community of Deaf BSL users in Scotland** some of whom may require residential care if they have dementia, and their families. According to the Census 2011 there are over 12,500 Deaf BSL users in Scotland.

British Sign Language (BSL)

BSL is not a visual representation of English, as it is an entirely separate language that is grammatically distinct in its own right.³ Its users comprise a cultural-linguistic community with its own cultural norms, traditions, ways of being, preferences and histories⁴. The BSL (Scotland) Act 2015 promotes that across the public sector, information and services are made accessible to BSL users.⁵ The BSL National Plan⁶ (Number 41) stipulates that work needs to be undertaken with local authorities, providers and service users **to improve the way that adult social care is delivered, including how residential care is commissioned and how care and support is delivered to people at home.**

Dementia and Deaf BSL users

There is not a special kind of dementia associated with Deaf BSL users but there are some different impacts and challenges faced by Deaf people who experience dementia and their families and care partners.

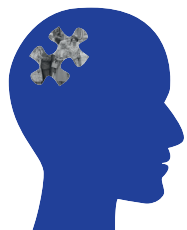
² Population estimates for the UK, England and Wales, Scotland and Northern Ireland: mid-2018
<https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/bulletins/annualmidyearpopulationestimates/mid2018>

³ Sutton-Spence, R., Woll, B. (1999). *The Linguistics of British Sign Language: an introduction*. Cambridge. Cambridge University Press.

⁴ Ladd, P. (2003). *Understanding Deaf Culture: In search of Deafhood*. Clevedon: Multilingual Matters.

⁵ <http://bslscotlandact2015.scot/public-services/>

⁶ <https://www.gov.scot/publications/british-sign-language-bsl-national-plan-2017-2023/>



Introduction

Information, knowledge and understanding

Access to health and care-related information about dementia that is in BSL has been very poor⁷. Projects such as the **BDA Scotland Dementia Toolkit**⁸ have helped to change that situation but information does not guarantee understanding. We all need the opportunity to discuss what dementia means, whether our understanding is right, and to see what other people in our circle for friends, family and community think.⁹ Unfortunately, there has been stigma surrounding dementia in some parts of the Deaf community as a result of misinformation, lack of knowledge and fear. This can lead to some Deaf people experiencing dementia and their families feeling cut off from their own community and social supports while not being able to access mainstream avenues of information and support in their own language. Such **isolation can make the effects of dementia worse**.

Services

In many aspects of health and social care, Deaf people experience inadequate communication in BSL, lack of good BSL/English interpreter provision, and poor cultural competence amongst professionals they meet.¹⁰ Very few service providers are themselves Deaf BSL users. Professionals are not always aware of how to work with BSL/English interpreters. In the case of Deaf people experiencing dementia, it has been shown that **professionals easily miss the early signs of dementia amongst visual language users, Deaf carers feel unsupported by professionals** with whom they find it hard to communicate and who lack connections with the Deaf community. It is only relatively recently that assessments to screen for and diagnose dementia in validated BSL versions have become available.¹¹ Good quality clinical assessments are rare.¹² All of these factors combine to mean that early identification of dementia can be unusual for Deaf people and therefore, the benefits of early provision of support, and in some cases, medication are missed.

⁷ Young, A.M., Ferguson-Coleman, E., Keady, J. (2016). Understanding dementia: effective information access from the Deaf community's perspective. *Health and Social Care in the Community*. <http://onlinelibrary.wiley.com/doi/10.1111/hsc.12181/pdf>

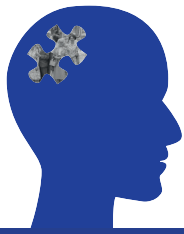
⁸ Dementia Toolkit, BDA Scotland. <https://bda.org.uk/dementiatoolkit/>

⁹ Ferguson-Coleman, E., Keady, J., Young, A. (2014). Dementia and the Deaf community: knowledge and service access. *Aging and Mental Health*, 18 (6), 674-682. doi: 10.1080/13607863.2014.880405 <https://www.tandfonline.com/doi/abs/10.1080/13607863.2014.880405>

¹⁰ Ferguson-Coleman, E., Johnston, A., Young, A., de Sainte Croix, R., Capper, C., Brown, F., Redfern, P., Smyth, B. (2018). How do we know what we don't know? Exploring Deaf people's experiences of supporting their Deaf family member living with dementia. *Dementia*. <https://doi.org/10.1177/1471301218798993>

¹¹ Atkinson, J., Denmark, T., Marshall, J., Mummery, C., Woll, B. (2015). Detecting Cognitive Impairment and Dementia in Deaf People: The British Sign Language Cognitive Screening Test. *ARCHIVES OF CLINICAL NEUROPSYCHOLOGY*, 30 (7), 694-711. doi:10.1093/arclin/acv042

¹² Harris, M.J., Au, D., Judd, K., Atkinson, J.R., Bergson, M., Mummery, C.J. (2021). Evaluation of a specialist cognitive clinic for the Deaf community. *CLINICAL MEDICINE*, 21 (4), E375-E379. doi:10.7861/clinmed.2020-1098



Introduction

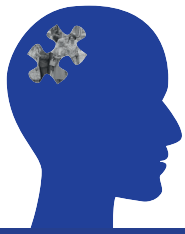
Care homes and Deaf people with dementia

Residential care home provision is only one of many sources of support for people with dementia. It is often seen as a last resort when efforts to maintain a person's independence in their own home is no longer possible¹³. However, it is an important option to ensure someone, despite the onset of dementia, remains safe, well looked after, unafraid, and potentially enjoys the best quality of life possible. It is also a very difficult step for someone with dementia to take and for their family and care partner(s) to contemplate. Previous research¹⁴ has shown that **Deaf carers often feel they do not have enough information about care options for Deaf people to feel confident that a care home may be the best solution** for someone they care for. Where specialist care home provision exists that is set up for Deaf BSL users, it can mean making a choice for a loved one to live a long way away, or to settle for a local care home with apprehension that the care home staff will not know how to communicate with the Deaf person. **Limited communication and interaction are enduring concerns for all care home residents** because of the need to maintain high levels of stimulation and involvement to support best health. However, in the case of Deaf BSL users it can be a major anxiety, for families and service providers alike. Most care homes and their staff may never have cared for a Deaf BSL user, will not be able to use BSL, and do not know how to value the importance of being culturally Deaf. They are unlikely to understand the cultural norms of all forms of communication including simple things like using touch and how to get someone's attention. **The isolation that an older person may feel can be made considerably worse by being in an environment where they are the only culturally Deaf resident and the only BSL user.**¹⁵

¹³ Domiciliary care and day care services are an important part of dementia care and are often put in place in addition to unpaid family carer in the early stages of dementia. These too have barriers for Deaf people as many home care and day care services are not staffed by people who can communicate in BSL. That is not the focus of this report but is an important aspect to consider in the matrix of care and support services for Deaf people with dementia.

¹⁴ Hunt R., Oram S., Young, A. (2011). Deaf older people's preferences for residential care. Report to the Welsh Assembly Government. [https://www.research.manchester.ac.uk/portal/en/publications/deaf-older-peoples-preferences-for-residential-care\(fb5617ae-d8cb-4886-a7c1-cc85c2fa2f66\).html](https://www.research.manchester.ac.uk/portal/en/publications/deaf-older-peoples-preferences-for-residential-care(fb5617ae-d8cb-4886-a7c1-cc85c2fa2f66).html)

¹⁵ Young, A.M. (2014). Older Deaf People and Social Care. Commissioned evidence review. RAD and SONUS. http://royaldeaf.org.uk/files/files/RAD%20GENERAL/Documents/older_deaf_people_and_social_care.pdf



Introduction

The purpose of this study

With those considerations in mind, this study set out to provide useful evidence from both the perspective of care home providers and Deaf people in Scotland about what the current difficulties might be, to spotlight good practice where it exists, to understand what might assist care home providers to feel confident and equipped to meet the needs of Deaf people with dementia, and to understand in more detail the perspective and concerns of Deaf people who are currently carers, those who are just thinking about their own futures, and those of Deaf family and friends.

Funded by the Life Changes Trust, and the National Lottery and carried out by BDA Scotland and the SORD team at the University of Manchester, **the formal research questions** that were investigated were:

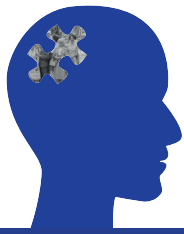
1. What are the current experiences of social care services for older Deaf BSL users living with dementia in Scotland?
2. What are the expectations of older Deaf people who use BSL (and their families) when they are transitioning into dementia-specific residential care?
3. What is required for care homes in Scotland to be in a position to provide effective care for older Deaf people (with dementia) who use BSL as their first language and how might that be achieved?

Who took part and how was the research carried out?¹⁶

All data were collected by Deaf researchers in BSL (with BSL/English interpreters available for the hearing care home managers and staff). Participants were divided into four studies according to their characteristics:

- Study 1 included **care homes in Scotland with experience** of Deaf people with dementia.
- Study 2 included **care homes in Scotland without experience** of Deaf people with dementia.
- Study 3 included **Deaf carers** of Deaf people with dementia.
- Study 4 included **members** of the wider Deaf community.

¹⁶ See Appendix 1 for additional details and insights concerning the process of data collection



Introduction

A thematic content analysis approach was applied to the **17 interviews and 2 focus groups**. Ethical approval for the data collection in this project was granted by The East Midlands – Leicester South Research Ethics Committee: Rec reference number 21/EM/0066, IRAS Project ID: 294815.

Table 1: Distribution of care homes and Deaf individuals across Scotland

| Area | Care homes | Deaf individuals |
|---------------------|------------|------------------|
| Central Belt | 6 | 5 |
| East of Scotland | 1 | 3 |
| Highlands & Islands | 3 | 2 |
| South West Scotland | 3 | 3 |

Figure 1: Distribution of care homes across Scotland

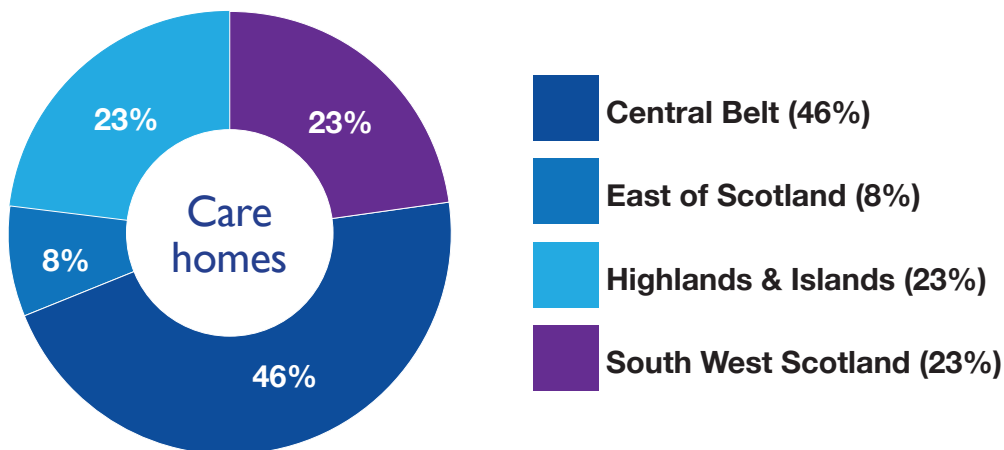
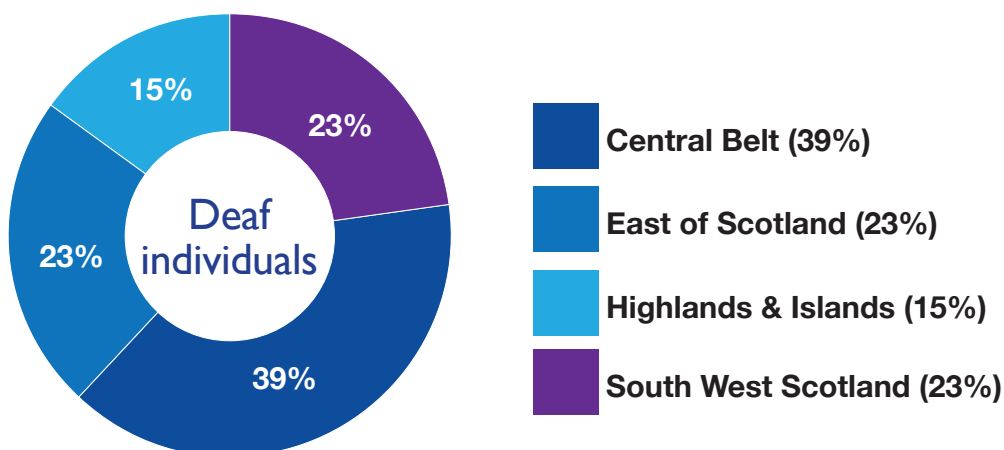
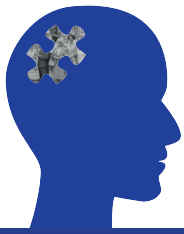


Figure 2: Distribution of Deaf individuals across Scotland





Introduction

Table 2: Demographic information

| | Care homes staff | Deaf individuals |
|--------|------------------|------------------|
| Male | 2 | 2 |
| Female | 15 | 11 |

Figure 3: Demographic information of care homes staff

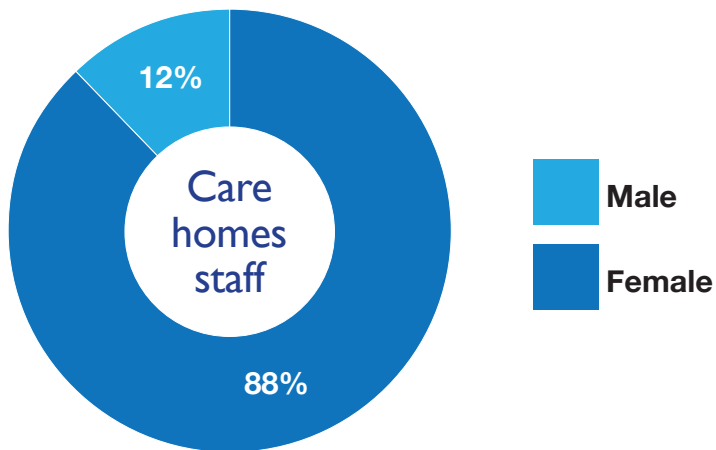
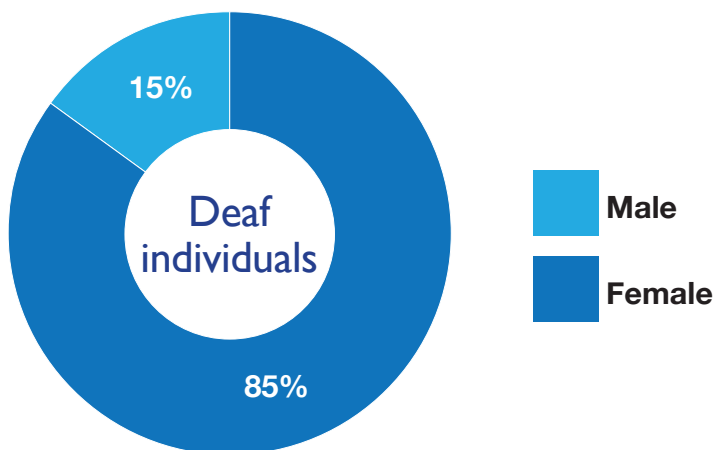
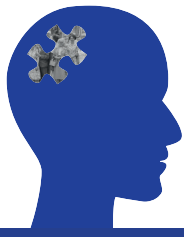


Figure 4: Demographic information of Deaf individuals





Introduction

A note on Covid-19

This project was initiated and started collecting data just as **Covid-19** was at its height. Our initial plans to visit care homes, to interview people in person and to organise Deaf community events in person including focus groups had to be altered. **All data were collected remotely through Zoom.** This was not ideal but we wish to acknowledge everyone’s acceptance of this change and participation regardless. For care home managers, **participation in the study was especially challenging** because of the considerable pressure care homes faced during the early days of the pandemic, the enormous stress they were under and the losses they were enduring. We especially wish to thank them for their participation nonetheless and recognition that this topic is one of concern. For members of the Deaf community who were interviewed, **we acknowledge their resilience** in keeping going, particularly those who were carers of relatives and friends with dementia, when prized sources of information and social support were further cut off as a consequence of the pandemic. We appreciate very much your continued involvement and support of the project.

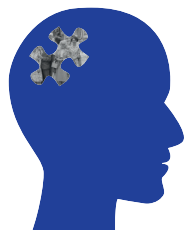
How we have organised the presentation of the findings

Findings from the different studies were combined (See Table 3). Study 1 (care homes with **past or present experience** of Deaf people with dementia) and Study 2 (**care homes without experience of Deaf people with dementia**) are combined into a single **Care Home Perspectives** and printed as purple throughout. **Deaf carers** (Study 3) and the **wider Deaf community** (Study 4) are also combined and presented as a single group referred to as **Deaf Perspectives** and printed as blue throughout.

Table 3: Combination of studies for presentation of findings

| STUDIES | | | |
|---|--|--|--|
| Study 1: Care home managers and staff with experience of Deaf people with dementia | Study 2: Care home managers and staff without experience of Deaf people with dementia | Study 3: Deaf carers of Deaf people with dementia | Study 4: Wider Deaf community with or without direct experience of care for Deaf person with dementia |
| ↓ | | ↓ | |
| CARE HOME PERSPECTIVES | | DEAF PERSPECTIVES | |





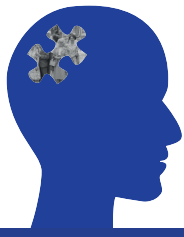
Introduction

In the care home studies, although those in each study differed in their experience, and therefore their ability to recognise the needs of Deaf people with dementia, they presented similar assumptions about how such needs are met. They also displayed similar difficulties in trying to understand the cultural needs of Deaf people. In the Deaf community studies, although they differed in direct experience of Deaf people with dementia, they had similar expectations of what social services for Deaf people with dementia should look like. **Contrasting the perspectives of care homes and Deaf people are the centre of this analysis** which is presented in order of the original research questions.

There were three main themes that emerged from careful watching and reading of all the data collected. These are showing in summary below along with the sub-themes from each group. Although it may seem that there was consensus between the different groups of people who gave data to this study, there was not. **Each of the themes and sub-themes had a different emphasis and different components depending on whether it was explained by care home managers and keyworker staff or Deaf people.** We will particularly emphasise this point as we go through the main findings because it is too easy to assume that everyone identifies the same problems, without realising that they do so **through a different cultural perspective** (whether that is a care home provider professional perspective or a Deaf community/Deaf cultural perspective).

Table 4: Structure of themes presented in findings

| | Care Home Perspectives | Deaf Perspectives |
|--|--|---|
| Experiences of care services | <ul style="list-style-type: none"> ● Communication difficulties ● Adaptations in communication ● Understanding Deaf culture | <ul style="list-style-type: none"> ● Losing BSL ● Preserving BSL ● Continued care check |
| Expectations about transition into care | <ul style="list-style-type: none"> ● Lack of awareness of options when choosing a care home ● Keeping social interaction and identity | <ul style="list-style-type: none"> ● Lack of awareness of options when choosing a care home ● Keeping culture and community |
| Requirements for effective care provision | <ul style="list-style-type: none"> ● Information about Deaf people's needs ● Changes for Deaf people with dementia in care homes ● Changes in connection with external services | <ul style="list-style-type: none"> ● Information about care homes ● Information about dementia ● Support for carers ● Changes in community for Deaf people with dementia ● Issues in connection with external services |



Experiences

Experiences of social care services for older Deaf BSL users living with dementia in Scotland in care homes

Language and communication

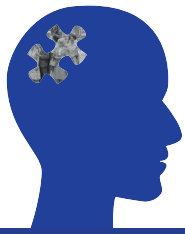
Both those interviewed from a Care Home perspective and those Deaf people interviewed identified **language as a key issue in experiences for Deaf people in care home settings** and when they had dementia. However, the emphasis was different from each perspective.

Care Home perspective

From the Care Home perspective, “**communication difficulties**” were the main issue discussed about their experiences of Deaf BSL users with dementia. These were difficulties they had in communicating with Deaf residents and the problems Deaf people had in communicating with others. They centred on problems with spoken language, not on the ways in which dementia might interfere with BSL use from the resident’s point of view. **The priority was on finding ways to get round this problem in the here and now. Directly meeting the residents’ language needs in BSL was thought to require a longer-term strategy.** Care home participants positioned residents’ difficulties mainly in terms of “their deafness” which has meant that spoken English is a less useful means of communication. However, care home managers and staff did also acknowledge their own limited knowledge of BSL:

“ *It is very, very difficult to communicate with those residents and I think most of the staff had the same feelings, we’ve not been trained with sign language.*
Care home manager ”

Adaptations to interpersonal communication were largely thought of in simple visual terms. This included writing things down, pointing, and use of gestures. Care home managers and staff mentioned many useful resources that emphasise visual communication, including the use of flashcards, picture boards, picture books, signing cards, pictorial menus, or notepads. It is notable that these were visual strategies used for people with dementia who required simplified English/communication. They were just being applied to BSL users. It may well be the case that they were useful but the motivation for their use mixed up the language needs of a BSL user with the communication needs of someone with



Experiences

dementia. **They were not specially designed to make communication with a BSL user easier.** Visual adaptations specifically for Deaf residents were not common such as the use of flashing/visual doorbells. There was ample knowledge of them it was just very few care homes actually had them installed. Good signage around the home was however emphasised.

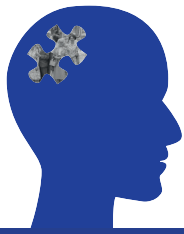
Although BSL training for staff is considered desirable, it is seen more as a long-term strategy. In terms of communication with external services such as medical appointments, care home managers and staff said they would **rely on family members** who signed to facilitate these or book BSL/English interpreters. However, **most of the care home staff and managers were not sure how to book BSL/English interpreters.**

When asked about Deaf culture, most care home staff and managers had difficulties understanding the notion, often mentioning concepts of culture linked with religion and food choices. At least in one case, there was mention of the importance of keeping contact with a Deaf community and on another two occasions, the visual orientation of Deaf people was mentioned:

“ [Deaf culture is] the way you live your life, I would imagine. How you perceive the world and things around you. And it'd be from a different perspective from which I see the world because I get to hear. **Keyworker** ”

The **general lack of awareness of Deaf culture** meant that people working in care homes could not easily recognise the particular needs related with this cultural affiliation. After being prompted by the interviewer about the importance of visual and tactile contact, most care homes reported practices of ensuring visual contact and the acceptability of tapping people on their shoulders or rubbing their hands in cases where they “could not hear well”. These practices were not framed necessarily as related with Deaf culture by care homes and instead were considered appropriate manners for residents with “impairments”. In all cases, **care home staff and managers were open to the idea of learning about Deaf culture and emphasise the need for further guidance in this area.**

Those working in care homes with experience with Deaf people with dementia recognised the **difficulties produced by the intersection of “deafness”, aging, and dementia.** For example, the loss of vision produces reading difficulties



Experiences

and dementia progression can cause the loss of BSL, making visual ways of communication less useful over time:



We used pictures with the resident. At the beginning it was not too bad but when dementia progressed, we found it very, very difficult because we didn't know what the lady really wanted. **Care home manager**

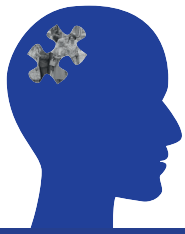


Overall, the experience of **caring for a Deaf person with dementia was considered smooth when the Deaf person could understand written English** or when their dementia had not adversely affected their mood. If the residents established their own routines and followed them, they were also considered easier to care for. However, **most of the time, the experience of care home staff caring for a Deaf person with dementia was seen as difficult and frustrating.** This was largely because of lack of previous experience meeting the needs of Deaf people with dementia and lack of information available about how to better meet those needs on top of the communication difficulties experienced. Overall, care home staff and managers concluded that **caring for a Deaf person with dementia requires more consideration and planning.**

Deaf community perspective

Language was also the primary focus for members of the Deaf community. However, this was not about difficulties between Deaf and hearing people communicating. It was much more focussed on **the impact of dementia on Deaf people's BSL.** As BSL is a primary marker of identity and pride, **changes in the ability to use BSL are highly significant for many Deaf people in the Deaf community.** Participants were aware of a range of potential effects on BSL because of dementia. These include signing becoming more gestural (i.e. not being a grammatically correct language), signs being used more in isolation rather than in full sentences, use of old signs that are no longer current, smaller signing space¹⁷, restricted sign vocabulary, less use of facial expressions while signing (which can affect the intended meaning) and reduced abilities in fingerspelling. Participants were aware that some Deaf people with dementia retain receptive comprehension of BSL, but for others, **BSL can become perplexing and difficult to follow.** Participants also mentioned that orally educated Deaf people may go back to using more speech or others may simply become quiet, losing their

¹⁷ From a hearing person's perspective this would be akin to someone slowing down their sentences, tapering off at the end of the sentence in not being able to fill the blanks, with missing words or using the wrong word to describe something.



Experiences

language altogether. For Deaf carers, such changes could be challenging and frustrating as they are no longer able to make themselves understood or able to understand the Deaf person with dementia. It might be **hard to understand the needs of a Deaf person with dementia experiencing language changes combined with sudden mood changes that might accompany dementia**. Lack of formal training about how to cope with such changes and low levels of support from other people often created feelings of loneliness and helplessness amongst Deaf carers.

Consequently, difficulties in communication from Deaf peoples' perspective were less to do with making care home staff/Deaf resident communication easier and more about how to prevent or slow down the decline in BSL use that they saw happening. **Regular visits to Deaf residents by other BSL users or pairing with signing persons in care homes are thus highly valued to avoid BSL decline:**

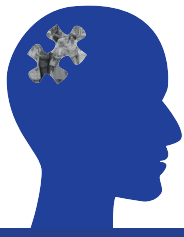
“ *On the first day at the care home, I knew my friend works there, and she signs, and we spent time with my mother (...). Then I heard that my friend had been moved, and I thought, but what about my mother! And the care home said, well she'll have moved to a different role, co-ordinating activities... I couldn't believe it, I was so cross. They never told us. So that's why I have to make sure that I visit regularly so I can sign with my mother.* **Deaf carer** ”

Efforts at gestural communication by care home staff are appreciated but they are not considered enough for stopping BSL decline:

“ *The problem is (...) all they get is just a thumbs up and the sign for a cup of tea, the communication is so limited.* **Deaf citizen**¹⁸ ”

Care home staff use of written English with Deaf care home residents was seen as evidence that they are not always conscious of Deaf person's difficulties in understanding English as a second language. Also, **as dementia progresses, participants pointed out that Deaf people stop understanding care home staff who cannot communicate in BSL.**

¹⁸ The label of 'Deaf Citizen' refers to people who participated in Study 4. They are Deaf people who have no direct experience of being a carer or who have been a carer in the past but not anymore.

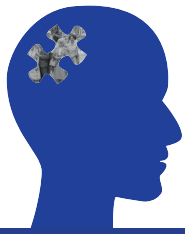


Experiences

In most cases, Deaf relatives become mediators in communication with care home staff. This was very strongly emphasised because without regular visits by Deaf relatives, participants were concerned that the needs of the Deaf person in the care home would not be recognised and not be met. They, the Deaf community and Deaf relatives, had to therefore remain vigilant. A fundamental consequence of lack of effective communication in BSL was **Deaf relatives accepting responsibility for a process of continued care based on their understanding of the resident’s language and culture** and without which their care needs would not be met.

Table 5: Summary of contrasting perspectives on experiences of care

| Care Home Perspectives | Deaf Perspectives |
|--|---|
| LANGUAGE AND COMMUNICATION | |
| Communication difficulties result from a resident’s “ deafness ”. | Main difficulty in communication is the impact of dementia on BSL and an individual’s ability to interact, communicate and understand in their own language . |
| It is harder if resident is unable to use spoken language . Use of gesture, visual cues and technologies used for people with dementia help communication with BSL users. | Dementia strongly effects any ability that a Deaf BSL user has to communicate or understand in English which is not their preference. |
| BSL | |
| BSL for staff would be useful but training is a long-term goal, not an immediate priority. | Main priority is keeping BSL alive and keeping a resident stimulated in their own language to prevent/slow down BSL decline . |
| MEETING RESIDENTS’ NEEDS | |
| Deaf culture not appreciated as asset, feature of identity and need that requires meeting. | It becomes the personal responsibility of Deaf relatives and community to visit and communicate and ensure cultural identity is maintained. |
| Intersection of dementia and “ deafness ” makes planning and organisation of care complex. | It is the intersection of dementia and BSL that is the problem, not “ deafness ”. |
| | Care needs will go unmet without external vigilance and checking. |



Expectations

Expectations about transition processes of older Deaf people who use BSL into dementia-specific residential care

Transition and settling in

Although it seems that care homes managers and staff, and Deaf carers and community members seem to identify the same issues, it is notable that they emphasise different features of similar problems. This is likely to indicate that their approaches to solutions may reflect different priorities, something we discuss in the later section on recommendations. As noted in the introduction, the move to a care home is often the last in a long line of support processes that have preceded it; not the first care choice. This context should be kept in mind when reading the following.

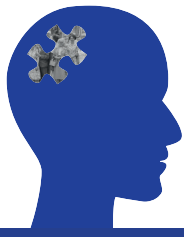
Care Home perspective

Care home staff and managers are very conscious of **Deaf people's limited awareness of care homes and their right to choose**:

*You need to be informed of... what the choices are, what options are. So that is not always very well communicated even to our hearing residents, let alone to anybody who is deaf. **Keyworker***

They highlighted the **role of social workers** in informing Deaf people with dementia and their relatives about care homes, outlining and narrowing down the options for them. This was mentioned in the wider context of acknowledging the fact that there needs to be more accessible advertising, an improvement of families' access to and use of information, especially for those who are not proficient in accessing online resources. Care home staff and managers generally assumed that important criteria for choosing a care home for all residents were closeness to family to facilitate visits and familiarity with the care home.

Participants emphasised the importance of promoting good relationships between residents and with staff and keeping contact with local communities. In the case of Deaf residents, some mentioned keeping contact with the local Deaf club. Two participants were aware that socialisation was not only a matter of company, but also of identity and belonging and without this, a Deaf resident could feel very



Expectations

isolated. For Deaf people, that meant **maintaining social relations with the Deaf community regardless of geography**:

“ I think it is really, really important that link with the deaf community is maintained. He didn't have many links in [name of place] and, I mean, even off-island, it's really important that people don't have to change who they are.

Keyworker ”

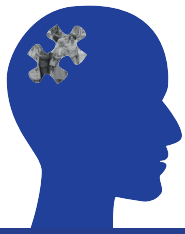
Given the everyday communication barriers that residents faced, participants emphasised the **positive nature of family visits** as being with signing family members offer an opportunity for good quality communication and maintenance of their Deaf identities.

However, the idea of a **Deaf befriender** (someone from the Deaf community who would visit and enable social interaction in BSL) was received with some ambiguity by care homes. On the one hand, they are open to the idea and consider it could be highly beneficial for the Deaf resident. On the other hand, they were not sure if communication difficulties could create unnecessary anxiety in the Deaf person with dementia, as the Deaf befriender may not be clear about how to adapt their communication with a Deaf person with dementia.

Deaf community perspective

Individuals from the Deaf community also emphasised Deaf people's general lack of awareness of options regarding care home choices. However, the reasons for this were perceived differently than from the Care Home perspective. Deaf participants connected the lack of knowledge and awareness of options to the fact that there is **very little accessible information in BSL about the care home sector or individual care homes**. Procedures surrounding assessment and entry into residential provision may be poorly understood because there is little effort to make them accessible to a Deaf person. This can result in **Deaf people feeling alienated from the decision-making process** and furthermore, hearing professionals or family members are then being perceived as taking over the decision-making process, which in turn, can remove the autonomy of the Deaf person:

“ I didn't really understand what it meant at the time the decision was made so it was made really without my input(...) it was a joke, really, the way they tried to discuss it: pen and paper. And it was so frustrating in the end my own health became affected. **Deaf citizen** ”



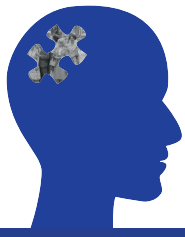
Expectations

Deaf individuals mentioned many criteria for choosing a care home. The most important ones were **closeness to family and the presence of BSL users**. Geographical proximity with family allows continuous visits to check the state of care and, in the case of family with BSL users, they also promote opportunities for good quality communication. However, in some cases, **proximity with family could mean that there is isolation from the Deaf club** and community with which the resident is most familiar. For example, moving to be close to a son/daughter might mean moving out the area.

The presence of other Deaf residents who are BSL users is seen as promoting good socialisation and protects from language decline. This was however very rare. Most Deaf people would be the only Deaf BSL user in any given residential home and this was a source of considerable fear and anxiety. Signing staff were to be welcomed and thought to help to promote good care because the Deaf person with dementia's care needs then become more transparent. However this was rare also, with **only a few Deaf people working in care homes in Scotland**. For Deaf individuals who feel unsure about living with other Deaf residents, the option of domiciliary care with a BSL user being the care provider is also seen as helping both aspects of good care and BSL-based interaction. This may not be an option, however, depending on the level of dementia a person may be experiencing and also the availability, or not, of a Deaf BSL care provider. Other criteria for choosing a care home were their **proximity to local Deaf clubs or care homes with specialised knowledge in dementia**. Low-cost care homes were looked at with suspicion, assuming that low cost meant low quality services.

People from the Deaf community also expect to maintain good social relationships after entering a care home. Constant visits from family members are considered important for the wellbeing of Deaf people with dementia. **Conversations with a signing relative means quality time**. Even after dementia progresses and BSL becomes less useful to communicate with each other, Deaf relatives are robust in their knowledge that relationships remain strong and Deaf residents enjoy spending time with their families.

Keeping contact with the broader Deaf community is also considered important, offering a mixture of friendship and good quality interaction through signed communication. However, there are reports of members of the Deaf community refraining from communicating with the Deaf person with dementia



Expectations

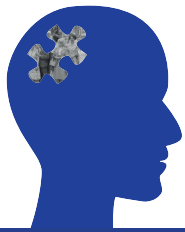
out of fear, due to a general lack of knowledge of dementia and the decline in their use of BSL:

“They [other Deaf people] were frightened. Yes, frightened. They didn’t know how to communicate with him [Deaf person with dementia]” . Deaf carer ”

Given such experiences, families may choose to prevent the Deaf person with dementia meeting other people from the Deaf community to preserve their wellbeing. Participants felt that **Deaf people need education about dementia through accessible means to keep relationships strong over time**. This education and awareness raising is preferred to happen through BSL via Deaf-led workshops.

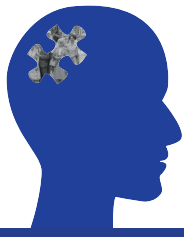
Table 6: Summary of contrasting perspectives on transition to care homes

| Care Home Perspectives | Deaf Perspectives |
|--|---|
| MAKING CHOICES | |
| Limited knowledge about care home options is true for everyone. | There are specific barriers that Deaf people face that are different because of language access . |
| Barriers to information exist because care home do not advertise well and not everyone has access to the internet. | There is very little accessible information in BSL enabling independent understanding of options available. |
| For potential Deaf residents, social workers need to take a more prominent role and helping people make choices . | Procedures for decision making alienate Deaf people leaving hearing people taking power to make choices and excluding Deaf people’s autonomy. |
| CLOSENESS TO FAMILY IS A KEY CONSIDERATION | |
| Family visits prevent isolation and support socialisation so closeness to family is a key priority in thinking about transition to residential care. | Visitors who use BSL is a key consideration in preventing isolation and supporting socialisation . Family was always thought of as BSL user relatives. |



Expectations

| Care Home Perspectives | Deaf Perspectives |
|---|---|
| ROLE OF THE WIDER DEAF COMMUNITY | |
| Maintaining social links with the Deaf club can be very important in prevention of isolation. | Continued contact with the local Deaf community is very important but may conflict with nearness to family. Not everyone in the Deaf community will understand the needs of Deaf people with dementia and may stigmatise them or be unhelpful. |
| Deaf Befrienders may not work because they may be unable to meet the resident's changed communication needs because of their dementia. | Deaf Befrienders is a good idea to maintain BSL contact and socialisation with other Deaf people. But there may be other considerations to do with privacy and stigma if the Befriender was part of the community but not family. |



Requirements

Requirements for effective care provision for older Deaf people (with dementia) who use BSL as their first language

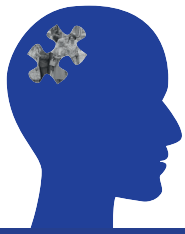
Care Home perspectives

Participants strongly pointed out that **care homes need more information on the needs of individual Deaf people with dementia** who may be resident with them. They generally know less about them than with other hearing residents, so they have different strategies to obtain information about their residents. **Family members were often mentioned as valuable sources of information**, assuming there is a relative who is a BSL user and who can act as a mediator in communication. Participants said that barriers to communication with Deaf relatives are circumvented by using written English and passing notes or communicating by email. They did not mention using a BSL/English interpreter to find out more about a resident in depth from a Deaf relative.

The role of social workers in providing information about the needs of Deaf residents was highlighted and greatly appreciated:

“ *The social worker would contact us and they would do a community shared assessment so that is really detailed with all his background and all the information of his necessities. So we need to have that first to see if we can meet the individual's needs.* **Care home manager** ”

Participants have **high expectations of the assessments made by social workers** as sources of information, but real-life experiences differ. Some social workers provided very rich and individualised assessments, while others gave generic reports. There appeared to be a clear division of levels of reporting by noting which assessments were carried out in BSL as opposed to those that were not. **Those social workers who used BSL were generally seen as providing more detailed information.** Nonetheless, social workers are strongly recognised as the first point of contact between Deaf people and care homes.



Requirements

Deaf “associations” are also mentioned as valuable sources of information to advise care homes about residents’ needs:

“ We’ve got picture books, flashcards... he’s got his flashing doorbell. Again, that is something we never thought about, until this group [Deaf association] came to visit [name of person] and they told us. **Care home manager** ”

Deaf “organisations” (without clear reference to which ones they contacted) are seen as representing **local sources of information on the needs of Deaf people in general**, not necessarily of individual residents. They are also identified as providers of interpreting services. In one case, they organised continued visits to a Deaf resident with dementia to mediate communication and clarify the resident’s care needs. Generally, there is low awareness of the BDA Scotland’s Deaf with Dementia Toolkit¹⁹.

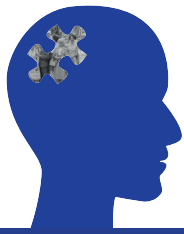
Other sources of information identified included hospitals or previous care homes, both of which kept contact and checked the state of care for the Deaf person with dementia in their new environment. Information thus obtained from these varied sources usually includes basic care needs, routines, preferred ways of communication and experiences in previous care homes. **The information only sometimes covered the individual’s past, their identity, their history or personal narratives and biographies.** This is notable given the more general emphasis over the past 15 years on the personhood of people with dementia and the importance of those who care understanding and having knowledge of the individual’s biography as a significant context for care^{20 21}.

When invited to think about future possibilities, care home staff and managers **emphasise measures focused on training staff, particularly around “deafness” and dementia.** Training in BSL is also desirable, but it is considered a more long-term strategy. The low numbers of Deaf people entering care homes produces concerns over the ‘use it or lose it’ nature of BSL learning. When offered the idea, managers say they are willing to hire a Deaf staff member who is a BSL user but feel this would require overcoming attitudinal barriers within the care home sector.

¹⁹ Dementia Toolkit, BDA Scotland. <https://bda.org.uk/dementiatoolkit/>

²⁰ Kindell, J., Burrow, S., Wilkinson, R., & Keady, J. D. (2014). Life story resources in dementia care: a review. *Quality in ageing and older adults*, 15(3), 151–161. <https://doi.org/10.1108/QAOA-02-2014-0003>

²¹ Kitwood, T. (1997) *Dementia reconsidered: The person comes first*. Open University Press, Buckingham.



Requirements

The role of “Deaf organisations” is also highlighted by people working in care homes. It was felt that these organisations could inform social workers and Deaf individuals about care homes, offer introductions to BSL to care home staff, and teach about the needs of Deaf people with dementia. Care home managers are also interested in the idea of organising open days, in which members of Deaf organisations could enter the care home, assess, and even evaluate how support is given to Deaf individuals.

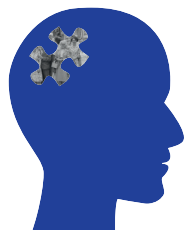
Finally, care home managers and staff consider that the role of social workers should be strengthened. **Assessments made by social workers can have a great impact on how care homes meet the Deaf with dementia people’s needs.** However, social workers often lack the knowledge of Deaf people’s needs and require BSL skills to obtain and deliver information to Deaf individuals:

“*Years ago we had a social worker who specialised in [inaudible] deaf, blind (...) when he retired, he was replaced by a social worker but not one who had a specialist area in deaf, blind people. I definitely think that would be beneficial because he knew of things that the day-to-day social worker didn’t know much about.* **Keyworker**”

Other measures for the future mentioned by people working in care homes include: an awareness campaign on the specific needs of Deaf people with dementia, creating standards by which care homes can be judged by local authorities, a funding campaign to increase the resources in care homes, and more involvement from dementia-specific organisations such as Alzheimer Scotland.

When offered the idea of **establishing a unit within a generic care home specifically designed for Deaf people**, opinions differed. For most, the idea had never been considered before, with some people finding it interesting and being open to the idea, and with others weakly opposing it. There were two main reasons why they opposed the idea. Firstly, many care homes use older buildings that are not flexible enough to have a dedicated space. Secondly, some care homes work under principles of equality, under which **a Deaf unit would be interpreted as segregation:**

“*In a bigger care home, I could see that would work, so people have their own little community within, like a little hub within the care home. At our house, though, we are one big community.* **Care home manager**”



Requirements

Other reasons for opposing the idea include the difficulty in gathering enough Deaf residents and problems in interaction due to decreased social skills amongst Deaf people with dementia.

Deaf community perspectives

A strong emphasis was that **people from the Deaf community need better information about care homes and dementia**. This information includes availability of services that meet Deaf people's needs, location of care homes and their convenience in terms of the possibility of regular visits, whether there are any Deaf staff who sign. At present, **it is mainly Deaf peers from the community and Deaf relatives who act as information sources**.

Social workers were identified as key informants about care homes, but their usefulness is met with more ambiguity. This is because although they are knowledgeable about dementia and the care home sector, they are not necessarily considered experts on Deaf people's needs, and vice versa:

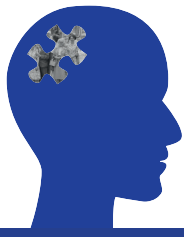


In terms of social workers, you have a dilemma. You can get support from a deaf specialist social worker or one with experience working with people with dementia but who can't sign. **Deaf citizen**



Yet, social workers' involvement often ensures progression in the process of finding a care home. When social workers remember to include BSL/English interpreters for meetings with relatives and carers, then these meetings are seen as very informative. However, it was also remarked that **social workers' lack of knowledge about Deaf people's needs may mean that they inadvertently leave out Deaf relatives from the process of choosing a care home**, losing a valuable source of information on the Deaf individual with dementia.

Deaf carers are often left alone on an individual basis to look for information about dementia and care homes. How successful this process depends to a large extent on the level of proficiency in written English that a Deaf person may have. One participant mentioned that they used a local library. More often, **the Deaf community was considered a useful and more accessible source of information on dementia**. A Deaf friend with personal experience was seen as a source of valuable information. It was suggested that a Deaf organisation could offer specialised training via BSL through workshops, live broadcasts



Requirements

or informative videos in websites. Deaf organisations are preferred due to the possibility of understanding information that has been provided in BSL. **Hearing groups that provide support for caring for someone with dementia are not deemed accessible**, so they are not usually considered as workable options.

When thinking about desired changes in the future, people from the Deaf community wish for better conditions for Deaf people living in care homes and their carers. **Deaf people with dementia living in their own homes often need better links with the Deaf community**. This may include arranging Deaf club members to visit people in their own homes or vice versa. Having people who support Deaf carers in their role allow them to have breaks and avoid feeling overburdened.

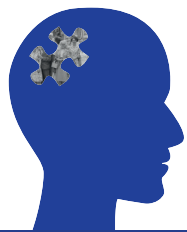


[I wish] a support person to help me. The social worker was not enough. I wanted something deeper. Someone to be there for me (...). It was just too long, on my own. I just wished there was someone there for me. Yes, I have friends. But that was not enough for me. **Deaf carer**



Groups of peers who are also Deaf carers may offer mutual support through BSL. **Specialised training in dementia for Deaf carers through BSL is preferred** with no complicated jargon and technical concepts.

Members of the Deaf community also wished for changes to conditions for Deaf people with dementia living in care homes. They wanted to see more **improved contact with Deaf BSL users**, including visits to Deaf clubs accompanied by members of staff or organising members from Deaf communities to visit the care home. Deaf befrienders are also highly valued. Training for staff should include BSL skills and BSL awareness with a focus on Deaf people. Additionally, **a Deaf person or a social worker with signing skills should make regular visits to care homes to check that the care matches the needs of the Deaf person with dementia**. Finally, most members of the Deaf community valued the idea of a specialist Deaf unit within a care home yet expressed concerns around the Deaf person needing to move too far away from family and community, or if they did not get on with other Deaf people residing in the same unit.



Requirements

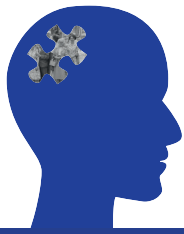
Deaf carers also wished for better connections between services external to care homes and the care home. It is also considered important that those services share accessible information with the Deaf community:

“ One thing, my doctor. I mean the hospital doctor. He told me, oh your husband’s got dementia. That’s all. That’s all! Bye bye, you can go home now. And that annoyed me. They didn’t tell me what to do next. What will happen next. Nothing. I had to work everything out myself. **Deaf carer** ”

It was felt that social workers, Deaf organisations, hospitals, and care homes should share information with one another. Recommendations included that information must be accessible to Deaf people, and **social services should use plain English, consider booking interpreters and make more use of videocalls**. There is a general feeling that **the BSL (Scotland) Act 2015 is not being observed** and should be strengthened. External services could also hire Deaf workers as a liaison with the Deaf community and to facilitate communication with Deaf people with dementia.

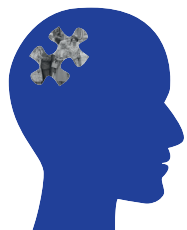
Table 7: Summary of contrasting perspectives on requirements for effective care provision

| Care Home Perspectives | Deaf Perspectives |
|---|---|
| DETAILED AND GOOD QUALITY INFORMATION ON RESIDENTS AND THEIR NEEDS | |
| Information about the resident from their family and their friends is vital and can be improved on. It can be obtained via written English communication. | Being included in information gathering on the resident including use of BSL/English interpreters to enable this process (not pen and paper) to aid detailed understanding by the care home about the resident. |
| Little reference to information about the individual, their biography, history, identity or social context . Information more seen in terms of assessment of needs and provision required. | Implicit understanding that the culture, social network and community of a Deaf person is important to include in information about them but the importance of presenting this biographical information to assist with care planning and meeting care needs and treating resident as an individual not discussed. |



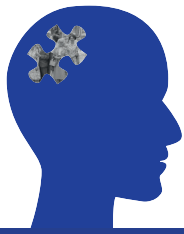
Requirements

| Care Home Perspectives | Deaf Perspectives |
|---|---|
| <p>Detailed information from social workers about assessment of care needs and suitable provision is very helpful. Their role should be strengthened with regard to Deaf people moving into care homes.</p> | <p>Not enough to rely on social workers for information because they may not know enough about Deaf people.</p> |
| <p>Deaf organisations have a role in advising care homes on how to better support residents and perhaps this could be formalised so they are invited to audit the suitability of provision for Deaf residents.</p> | <p>Deaf friends, the Deaf community and Deaf people with experience of caring for someone with dementia are best sources for understating care needs and best way to meet them in residential settings.</p> |
| <p>EMPLOYMENT OF DEAF PEOPLE AS STAFF</p> | |
| <p>Not spontaneously brought up. When offered as a consideration it was not dismissed but there was concern that there would be barriers in progressing this idea. Some would be attitudinal, some practical.</p> | <p>Considered potentially important in offering possibility of better recognition of care needs and ensuring these are met. But this is not just about care in the home, it is also about the co-ordination of all services. Consideration might be given to a Deaf liaison worker role.</p> |
| <p>IS A SPECIALIST DEAF UNIT WITHIN A CARE HOME A GOOD IDEA?</p> | |
| <p>Possibly. Main concern is that this would involve treating one set of residents very differently instead of promoting equality of all. A unit could be disruptive to overall sense of one community within a care home.</p> | <p>Possibly. Main concern is whether its location would mean that it created more difficulties for friends and family visiting.</p> |
| <p>Dementia will reduce social skills and ability for Deaf people in a unit to interact with each other.</p> | <p>A unit, if it were not located close by, might cut off a resident from their local Deaf community.</p> |
| <p>Some buildings would just not be suitable to enable this to happen.</p> | <p>Deaf people together in one unit may simply not get on with each other. Just because they are all Deaf does not mean they will.</p> |



Requirements

| Care Home Perspectives | Deaf Perspectives |
|--|---|
| OTHER CONSIDERATIONS FOR MORE EFFECTIVE CARE | |
| More involvement from mainstream dementia associations with the specific needs of Deaf people. | Deaf-led training for carers, family and friends about how to best support a Deaf person with dementia. |
| Greater funding for specialist provision for populations such as Deaf people with dementia who may need something more or different. | Information about care home provision, what happens in care homes, what options are available etc. all available in BSL . |
| Greater awareness raising in the wider professional and general population communities about Deaf people with dementia and their carers and family about the challenge they face. | Routine provision of interpreters by any professionals involved in the planning and delivery of care to a Deaf resident when they are communicating with a family member or friend or other Deaf care provider . |
| Focus on features of an individual's history and identity . | Better co-ordination of the range of service providers along the dementia care journey in a way that is accessible to Deaf people in terms of information, knowledge transfer and involvement at all stages. Perhaps this could be facilitated by the employment of a Deaf liaison worker . |
| Not mentioned. | The duties and requirements of the BSL (Scotland) Act 2015 are not being observed with regard to effective care home provision for Deaf people with dementia. |



Concluding Summary and Recommendations

The following **summarises key points from the research**. Sections are then followed by **potential solutions and recommendations**. These may include topics that, from our perspective, were notably missing from the data collected but available in the wider literature and from other practice of which we are aware. However, we have been careful to indicate potential solutions and recommendations beginning from where the participants in this study were starting. For care home managers and staff the ‘ask’ may seem too huge and so we have moderated this discussion in terms of **more immediate wins and longer term perspectives requiring different levels of investment, whether of time or money**. Nobody wants an ideal plan that will never work. We have shown stops along the way that are entirely possible **with good partnership working and the primary involvement of the BSL community in Scotland**.

Meeting legal duties and aspirations

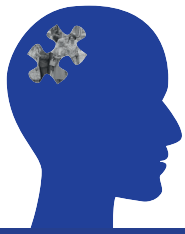
The Scottish Government’s BSL National Plan 2017 – 2023 includes as one of its goals (No. 41):

‘Work with local authorities, providers and service users to improve the way that **adult social care is delivered, including how residential care is commissioned and how care and support is delivered to people at home**. The voices and experiences of service users, including BSL users* will be at the centre of these reforms and will shape planning and implementation and improve outcomes.’

The evidence in this report clearly shows that there is a long way to go in meeting the needs of Deaf people with dementia in residential care, supporting their Deaf families and carers, and enabling care home providers and staff to deliver high quality care.

Potential solutions and recommendations

- ☛ **Short term:** use the information and evidence in this report to consider ways in which current provision might be improved in line with **local BSL Plans**.
- ☛ **Medium term:** consider the **whole care pathway for Deaf people** with dementia and the ways in which it may be possible to improve all elements (**initial assessment, home care, day care, family support etc.**) preventing (if appropriate) or delaying the need for residential care. It should not be the first option for Deaf people with dementia because community based services are not adequate to meeting their needs.



Concluding Summary and Recommendations

- ☛ **Longer term:** look to models of residential care designed around the **cultural-linguistic** needs of Deaf people specifically. Examples such as De Gelderhorst²² in the Netherlands or the establishment of **Deaf Units** to bring Deaf people together in already existing care homes may not be realistic for Scotland but more cost-benefit evaluation is required to rule in or rule out such a **specialist, centralised care facility** and whether it would be welcomed by family, carers and the Deaf community or not.

Meeting linguistic needs and requirements

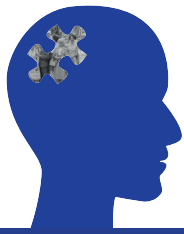
For Deaf people, **ensuring that a Deaf person with dementia has regular communication in BSL is a fundamental need**. Without regular interaction in BSL, the decline in language that accompanies dementia will be much quicker. As BSL is the core or heart of a Deaf person's identity, the decline in BSL is a serious maker of loss of identity. Also, the Deaf person in the care home will be even more isolated without the stimulation of interaction in BSL and the impact of dementia will be worse.

The priority and gravity given by Deaf people to the maintenance of communication in BSL is far greater than that appreciated or expressed by care home providers and staff. Their concerns to improve socialisation and stimulation centre on overcoming barriers that are created by a person's "deafness" (the condition of not hearing) rather than fully appreciating the significance of a Deaf person's lifelong language use. **It is BSL not deafness that is at the heart of the care needs of a Deaf person with dementia.** The lack of staff who are Deaf in care homes, the rarity with which care homes may have residents who are BSL users and the focus on overcoming spoken/written language barriers mean that improvements in BSL communication within care homes are consigned to a longer-term goal. For Deaf people it is seen as an immediate need.

Potential solutions and recommendations

- ☛ **Short term:** Require care homes and their staff to undertake **introductory BSL training** prior to accepting any Deaf residents.
- ☛ Increase the use and routine available of **tablets to facilitate BSL communication** with friends and family even if they are not present.
- ☛ **Permit flexible visiting hours** to make the most of when Deaf visitors are able to come to support Deaf residents/family/friends.

²² <https://www.gelderhorst.nl/>



Concluding Summary and Recommendations

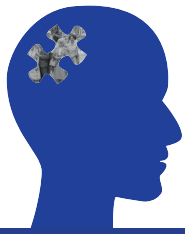
- Obtain **guidance** from the **British Deaf Association** and/or other Deaf organisations on how to book **BSL/English interpreters** experienced in working with older Deaf people with dementia.
- **Medium Term: employ Deaf staff** who are BSL users in care positions within care homes. It may be possible to have a peripatetic Deaf formal carer staff for example shared between several care homes if numbers of residents do not justify one in every home.
- **Longer Term: commission research** into the value of Deaf staff who are BSL users for ALL residents with dementia regardless of hearing status. Deaf people have an everyday, life-long experience of making themselves understood with other people despite not sharing a first language. This can be considered an asset and calls for investigating whether the visual, tactile gifts of Deaf people might be of benefit to any resident with dementia seeking alternative means to relate to the world and be understood by others.

Meeting cultural needs and requirements

Social care provision, of whatever kind, has a duty to respect, support and maintain an individual's cultural identity. Whilst this might be easily appreciated amongst hearing people in terms of faith, religion, ethnicity and cultural practices arising from heritage, it was not easily seen or appreciated with regard to Deaf BSL users. **There was little or no evidence of care home providers being aware of Deaf culture**, what needs might arise from it and how it might be respected. This was not care homes' fault. They were strongly aware they had received little information, training or guidance on this aspect of caring for a Deaf person with dementia and would welcome it.

Potential solutions and recommendations

- **Short Term:** work with **specialist Deaf organisations** such as **BDA Scotland** who also have experience of dementia to provide inductions for care home providers about how to meet Deaf cultural needs, obtain **specialised equipment and resources** such as BSL videos, and foster connectedness with the wider Deaf community. In this respect the BDA Scotland **Deaf Dementia toolkit** is useful.
- **Medium term:** expand training for Deaf people about dementia to understand its impact and how they may help support Deaf people with dementia. E.g. expansion of the **Dementia Friends training** for Deaf people in Scotland. This will help to break down attitudinal barriers and facilitate cooperation between care homes and their local Deaf community.



Concluding Summary and Recommendations

- Set up **befriender training** for Deaf people to support Deaf residents in care homes.
- **Longer term: train a group of Deaf citizens** to be care home supports to provide regular audits of provision through Deaf eyes, make recommendations for increasing cultural inclusiveness and support communication within the community of the care home that includes Deaf residents with dementia.

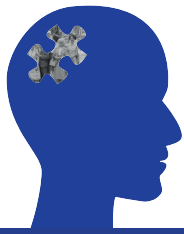
Choice, information and decision-making about care homes

From both a care home perspective and a Deaf perspective, **choice and information about care homes was a big issue**. However, for care home providers, the problem was seen as one that was common to everyone contemplating residential care for themselves or others: the difficulty in accessing good quality information about what is available in a way that is easy to navigate. By contrast, from Deaf perspectives the issue was **not having any information that was accessible in BSL that they could independently consult about care home provision and available options**. This was a basic language barrier, not a problem of where to find the information. Many Deaf people relied on the first-hand knowledge of other Deaf people in their community as a source of information about dementia and about care provision rather than other information sources.

Where a Deaf resident's close family are Deaf, maintaining good communication through BSL during any decision-making process about entry into residential care is vital. Unfortunately, **some Deaf carers have had experiences of being effectively excluded from joint decision making** because social workers have not booked BSL/English interpreters, or hearing family members have been relied on, or meetings with care home staff have not included interpreters. This has been alienating and disempowering for some Deaf family/carers. Care home managers and staff revealed their lack of awareness of the priority to book BSL/English interpreters when communicating with Deaf family and had not been provided with suitable training and in many cases were unaware of their legal obligations or practically how to do so.

Potential solutions and recommendations

- **Short term:** consider the use of a **specially trained Deaf BSL advocate** to represent and explain and explore further the needs and wishes of Deaf people and Deaf carers and family contemplating residential care.



Concluding Summary and Recommendations

- Provide care homes with **easy-to-use information** about how to find and book and pay for an interpreter
- **Medium term:** train a cohort of **Deaf BSL advocates** for Deaf people drawn from the Deaf community with specialist knowledge of older people's social care in all of its aspects.

Information about residents' needs

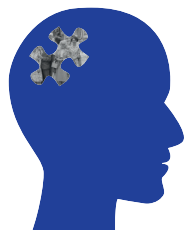
Care home providers drew attention to the importance of **having good information about an individual's assessed needs, their preferences, and the impact of dementia on them**. In this respect they relied heavily on social work assessment and evidence from previous care providers (e.g. hospitals or previous care homes). However, care home staff were unaware that social work assessors could be very different. Some may not have an understanding of Deaf culture, be informed about the Deaf community and Deaf identity nor able to use BSL. This was a key point from Deaf perspectives because the reliability of an assessment to address a Deaf person's needs within their own cultural-linguistic context was seen as crucial to their future care.

The concept of Deafhood²³, that is, the exploration of the multiple and dynamic ways of being Deaf throughout life, in some ways parallels that of Personhood that has been widely used in thinking about dementia care and the preservation and support of the unique identity of the individual with dementia through their care process and through dementia. **Personhood understood as Deafhood was not evident in the knowledge available to care providers nor how they approached the care and support of their Deaf residents.**

Potential solutions and recommendations

- **Short term:** create a '**Deaf all about me**' template that is specifically tailored to what is important for a Deaf person in terms of their identity and history and culture and ensure it is distributed to care homes likely to receive Deaf residents with instructions on how it might be completed with the aid of family and friends
- **Medium term:** work with **local authority social workers** and **specialist social workers** with Deaf people, and Deaf organisations to produce some additional **guidance on the assessment** of needs of Deaf people entering residential care that supplements what is usually used and highlights specific issues of language and culture and understanding.

²³ Ladd, P. (2003). *Understanding Deaf culture: In search of Deafhood*. Multilingual Matters.



Concluding Summary and Recommendations

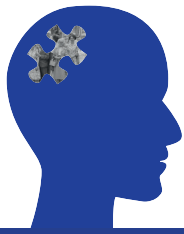
The intersection of dementia and being a Deaf BSL user

Care home staff saw that, in their terms, “deafness” can make dementia worse. They saw “deafness” (in the sense of not hearing or using spoken language), as a barrier to social interaction, being able to mix with others or to join in a range of activities in the care home setting. Consequently, **many of the routines, communication and activities that may slow down cognitive decline and improve mood were not available to Deaf residents.** This was a source of concern to care home staff and they tried to overcome some of the communication barriers by using simplified communication aids that had been designed for hearing people with dementia.

From a Deaf perspective, the intersection of dementia and being Deaf was viewed differently. Dementia affected how BSL was produced and how much someone could understand BSL. Therefore, not only was access to other BSL users required but interaction with people who could adapt their BSL to the changes that dementia was bringing to the language for Deaf people. Simplified English would not work because English is a second language for most Deaf people anyway, making it less clear and accessible than BSL. Furthermore, the ability to read in English or try to understand spoken language were made even worse by dementia. **BSL that matches the needs of a Deaf user with dementia was what was required. Not simplified visual English based communication.** However, Deaf participants realised that this was a very big ask for care homes where very few Deaf staff who are BSL users were employed if at all. Care home providers also recognised that there were institutional and attitudinal barriers to employing more Deaf staff who are BSL users with implicit concerns that they would not be able to do the job or fit in with other staff.

Potential solutions and recommendations

- ☛ **Short term:** create a **recommended activities** and interests guide for Deaf people with dementia in residential care homes including culturally specific recommendations for available resources (e.g. black and white silent movies like Charles Chaplin or Laurel & Hardy).
- ☛ **Medium term:** use **Deaf befrienders** and/or visits from **local Deaf clubs** and centres to support and stimulate Deaf people in care homes provided they have the ability to modify their BSL to meet the requirements of Deaf people with dementia.



Concluding Summary and Recommendations

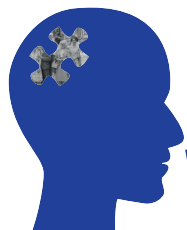
Monitoring and meeting care needs of Deaf people dementia

No care home manager or key worker was very satisfied that they were optimally meeting the needs of a Deaf resident with dementia nor confident that would be able to in the future. It was not that there was ‘bad practice’. Rather staff needed help and guidance and wanted to do the right thing but were not being supported. They felt that dementia organisations in Scotland should be more aware of the complexities of Deaf BSL users with dementia. They wanted more support from external Deaf organisations, but were unclear exactly who they meant or what that support would entail. They were not sure that a special unit for Deaf people within a care home or a care home just for Deaf people would be the answer. **To care home managers and staff it would feel more like segregation than solving a problem.**

From Deaf people’s perspectives there was acute and immediate concern that because of staff’s lack of BSL, cultural awareness, or knowledge of how to interact with a Deaf person affected by dementia, that residents’ care needs were not being met. People were genuinely scared that any deterioration, pain, anxiety, or basic care needs would simply not be recognised if staff could not communicate with a Deaf person. Family described **the need to maintain vigilance and take on the role of visiting constantly to monitor if a Deaf resident needed something and was being appropriately cared for.**

Potential solutions and recommendations

- ☛ **Short term:** Deaf organisations such as **BDA Scotland** provide a Deaf carer support group that is Deaf-led in BSL. The sharing of knowledge and emotional support from those groups can be useful even after the Deaf person with dementia becomes a resident in a care home, as Deaf carers hardly stop making sure that the needs of the Deaf person with dementia are met.
- ☛ **Medium term:** create, in partnership with residential care providers and others, a **Standards for Good Care of Deaf people with Dementia** guide and checklist, including the Deaf with dementia toolkit.
- ☛ **Longer term:** incorporate into the protocols of routine **care home inspections** the Standards for Good Care of Deaf people with Dementia guide and checklist and appoint a **Deaf Care Inspector** for care homes in Scotland.



Who are the project team?

This study, funded by the Life Changes Trust, has been led by the British Deaf Association Scotland in partnership with the Social Research for Deaf People (SORD) group at the University of Manchester.

<https://sites.manchester.ac.uk/sord/>



Avril Hepner (British Deaf Association, BSL Scotland Manager) was the director of the project and led the original application for funding, contributed to the recommendations of the report, has had oversight of all aspects of the project and been the project leader.



Rosemary Oram (British Deaf Association) was responsible for co-creation of the data collection instruments and data collection.



Carolyn Denmark (British Deaf Association) was responsible for data collection and contributed to the recommendations of the report.



Dr Emma Ferguson-Coleman (SORD, University of Manchester) contributed to the initial funding application, acted as an advisor throughout the project, and supported the production of the final manuscript report and contributed to the final recommendations.



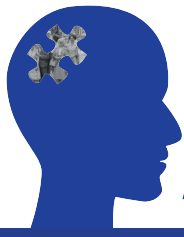
Celia Hulme (SORD, University of Manchester) was responsible for the ethical application to support data collection and submission of all subsequent amendments to it.



Dr Cristian Iturriaga (SORD, University of Manchester) led the analysis of the data and writing of the results and contributed the final recommendations.



Professor Alys Young (SORD, University of Manchester) contributed to the original funding application, was responsible for the writing of the introduction and study background, contributed to the data analysis and recommendations, and provided research oversight and support throughout the project.



Additional Information

Thanks

Sincere thanks to all care home managers and keyworkers, families and carers of Deaf people with dementia and others in the Deaf community for their participation. This report would not have been possible without you.

Special thanks to the BDA's Visual Language Service (VLS) for design of final report and creating the accompanying information in BSL.

Access in BSL

A short version of the main findings of this report is available in BSL via <https://bda.org.uk/dementiaresearch/>

Further Information

For any other information about this project and the report please contact: Avril Hepner, BSL Scotland Manager, BDA Scotland.
Email address: cado.sthscot@bda.org.uk

See BDA website for further contact: <https://bda.org.uk/glasgow-office/>

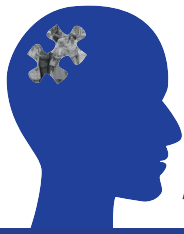


Appendix 1

A note on data collection and communication with care homes

All data in this research study whether from care home managers and keyworkers or from Deaf community members, families and carers, was collected in BSL by a researcher who is Deaf and uses BSL. This raised some issues, particularly with respect to arrangements for interviews with care home providers that of themselves are illustrative of some of the unconscious difficulties and barriers that may face Deaf family members or potential residents in their liaison with care services. Initial contact with care home providers via email proved to be not effective, with emails frequently remaining unanswered even when repeated. Contact via telephone was more effective and directly responded to often immediately. This illustrates an unconscious bias towards spoken and telephonic communication but of course by definition this does not work well for Deaf people. The researcher was in a position to use a BSL/English interpreter in these instances but that would not be the case for most Deaf family members for example seeking to contact a care home provider. How to ensure that equal weight is given to all forms of communication with staff and care home providers is an important consideration in the promotion of equity of services.

It was also evident from the several times when arrangements for interviews fell through that care homes were under considerable pressure: staff were ill, or alternative duties had to be prioritised or there were staff changes meaning the person who had agreed to be involved was no longer working there. These circumstances were made worse by the data collection occurring in the latter stages of the pandemic (October 2021 to February 2022). Nonetheless, the researcher experienced limited attempts to forewarn her of changes in arrangements or communication to rearrange meetings. The extent to which this lack of liaison was more acute because of perceived difficulties in contacting a Deaf person (rather than picking up the phone quickly to ring a hearing person) is unknown. In reality, a quick text message or email could have been sent but that was not always something that could be relied on.



Appendix 2

Questions asked to participants

Interview Topic Guide (Study 1 – Care homes with experience of Deaf BSL people with dementia)

Thank you for agreeing to take part in this project. Do you have any questions for me before we move on with these questions? I believe you may have seen a copy of the interview topic guide.

I expect this interview will take about 90 minutes. It is being video recorded on Zoom. That is for data analysis purposes only and everything will be deleted when the analysis is complete as set out in the participant information sheet you have already read.

Based on the nature of your profession, I am sure you can appreciate how valuable it is for me to have discussions with people like yourself who have experience in this field. This will include your thoughts and views about the services which are available for Deaf BSL users with dementia.

[Participants will be reminded they are answering on behalf of their organisation as well as drawing on their own professional experience]

May I start by asking a few questions about your job and the provision within the care home....

Questions may include:

Within the care home

- Q. Can you confirm what your job role is in the care home?
- Q. How long have you been working in this role?
- Q. What facilities/activities are provided in the care home?
- Q. How many Deaf residents do you have currently [that means Deaf sign language users] and how many in the past?
- Q. How many of these have dementia? Which type? [may be suspected or diagnosed]
- Q. Do staff find it easy or challenging to communicate with Deaf residents with dementia? [please explain]
- Q. Has any special training been provided to staff working with Deaf residents with dementia? [If so, what? If not, why not?]
- Q. What equipment is being provided/what adaptations have been made specifically for Deaf residents?



Appendix 2

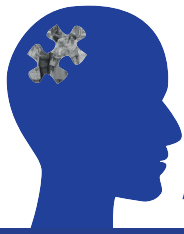
- Q. What do you think day-to-day life in a residential care home is like for Deaf residents?
- Q. What do you think the key challenges are in planning and delivering residential care services for Deaf residents?
- Q. Currently, what works well in residential care for Deaf residents? [Do you have any good practice examples?]
- Q. With specific respect to Deaf BSL users with dementia, are there any resources you or Deaf residents have found helpful/beneficial?
- Q. How important do you think it would be to the Deaf resident to be able to keep their links to the local Deaf community? Do they keep their links?
- Q. In what ways do you find it easy or difficult to meet Deaf residents' cultural needs? [Check what they know about Deaf culture]
- Q. Have you considered bringing in a befriender/volunteer for Deaf residents?
- Q. What solutions would you come with to avoid/reduce any isolation or loneliness for Deaf residents?

Services outside the care home

- Q. Do you think the home received sufficient information about the care needs and preferences of Deaf residents with dementia in comparison with other residents? [for example, assessments, biographical details, communication needs, by whom for dementia assessment]
- Q. If you had the chance to talk to a family member/nominated person about the home they were considering for the Deaf person with dementia in the future, what questions would you ask them?
- Q. In your experience, do you think Deaf people were aware of the range of care choices available to them?
- Q. Are you aware of any services that are available in Scotland (or beyond) for Deaf people with dementia?

Future development

- Q. Based on your experience, is there anything you would like to see be developed for:
 - Deaf people with dementia who are living in care homes
 - Deaf people with dementia not currently living in care homes which they could access outside the home?
 - the staff in the care sector working with Deaf people with dementia
- Q. Would you consider setting up a unit for Deaf people in the home?
- Q. Are you aware of the BDA Scotland's dementia toolkit? Would you find it useful?



Appendix 2

Are there any other comments you'd like to add before we finish?

Thank you for your time and your input is much appreciated

.....

Interview Topic Guide (Study 2 – care homes for people with dementia who have no previous or current experience of caring for a resident who is a BSL user and has dementia)

Thank you for agreeing to take part in this project. Do you have any questions for me before we move on with these questions?

I expect this interview will take 90 minutes. It is being video recorded on Zoom. That is for data analysis purposes only and everything will be deleted when the analysis is complete as set out in the participant information sheet you have already read.

Based on the nature of your profession, I am sure you can appreciate how valuable it is for me to have discussions with people like yourself who have experience in this field. This will include your thoughts and views about what services could be made available for Deaf BSL users with dementia if they came to live in the care home.

[Participants will be reminded they are answering on behalf of their organisation as well as drawing on their own professional experience]

May I start by asking a few questions about your job and the provision within the care home....

Questions may include:

Within the care home

- Q.** Can you confirm what your job role is in the care home?
- Q.** How long have you been working in this role?
- Q.** What facilities/activities are provided in the care home?

I understand you may have no direct experience of working with Deaf BSL users with dementia in the care sector. I have prepared a scenario based on a mix of elements from real-life case examples in previous studies which have been disguised, relating to a Deaf BSL user with dementia living in the care home.



Appendix 2

Case scenario;

Brian is a 76 year old man and has recently become a widower. He is Deaf and has used British Sign Language (BSL) all his life. He currently lives on his own in the family home and neither of his daughters live locally. He was diagnosed as having an early onset dementia about 2 years ago and his wife used to take care of things at home. Since she passed away in recent weeks, he hasn't paid any of the bills and hardly any food was found in the house. It has been agreed with his family that he needs full-time care in a home specifically for people with dementia.

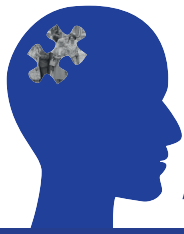
- Q. What communication strategies would the home consider putting in place for someone like Brian?
- Q. What training do you think would benefit staff who are working with him?
- Q. What equipment/adaptions do you think should be provided for him?
- Q. What do you think the key challenges would be in planning and delivering residential care services for him?
- Q. What preparation would you undertake prior to Brian arriving (e.g. room, staff)?
- Q. Who do you think you would contact in the first instance for advice/guidance? (Deaf organisation e.g. BDA Scotland)
- Q. Do you know how to book a sign language interpreter?
- Q. Are you aware of the BDA Scotland's dementia toolkit? Would you find it useful?
- Q. Is there anything else that you would do differently in comparison with how you usually care for residents in the home?

Based on your experiences in dementia care,

- Q. In your experience, how do you think Deaf residents with dementia can be fully informed about the choices/activities available to them?
- Q. With specific respect to Deaf BSL users with dementia, do you know of any resources that could benefit either them or the staff who are caring for them?
- Q. How important do you think it would be for them to be able to keep their links to the local Deaf community?
- Q. In what ways would you find it easy or difficult to meet Deaf residents' cultural needs? [Check what they know about Deaf culture]
- Q. Would you consider bringing in a befriender/volunteer for Deaf residents?
- Q. What solutions would you come with to avoid/reduce any isolation or loneliness for Deaf residents?

Services outside the care home

- Q. What information do you think should be provided to care homes prior to their entry?



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Q. Are you aware of any services available in Scotland (or beyond) for Deaf people with dementia?

Q. Are you aware of the BDA Scotland's dementia toolkit? Would you find it useful?

Future development

Q. Based on your experience of dementia care, is there anything you would like to see be developed for:

- Deaf people with dementia living in care homes
- Deaf people with dementia not currently living in care homes which they could access outside the home?
- staff in the care sector working with Deaf people with dementia?

Q. Would you consider setting up a unit for Deaf people in the home?

Are there any other comments you'd like to add before we finish?

Thank you for your time and your input is much appreciated

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Focus Group Script for the interviewer (Study 3 – Deaf carers of Deaf people with dementia based in Scotland)

Thank you for agreeing to take part in this project. Do you have any questions for me before we move on with the focus group questions?

I expect this discussion will take about 1½ to 2 hours, and it will be video-recorded on Zoom. The recordings are for data analysis purposes only and the video recording will be deleted after the analysis is complete, as set out in the participant information sheet which was provided to you before you agreed to participate.

I am sure you can appreciate how valuable it is for me to have discussions with people like this group. The aim is to gather information from you based on your experience as a carer to a Deaf person who has dementia, either currently or formerly – this could be in residential, domiciliary or respite care. This discussion will include your thoughts and views about what current services are like and what care services could be made available for Deaf BSL users with dementia in Scotland. May I start by asking a few questions about your role and the provision within the dementia care services



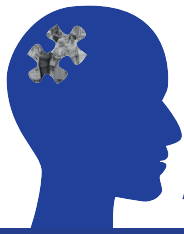
Appendix 2

Questions may include:

- Q.** What does your carer role involve/did involve? [prompts: is it a family/family friend care relationship? Or a professional carer job? Double check that the person is referring to experience with a deaf person with dementia; are they drawing on past experience or current experience or both]
- Q.** Do you use any communication strategies other than BSL with them? [Prompt: dementia might mean they communicate differently, or find it more difficult to understand in comparison with before]
- Q.** What training has been provided to you as a carer? [Prompt: if yes – what was it? How useful was it? If no – what would have you liked or do you want now?]
- Q.** What do you think day-to-day life being cared for, is like for Deaf person?
- Q.** What kind of help and support are you receiving/have received in your carer role? [Prompt: if none what would you have liked/wanted to have]
- Q.** Currently or formerly, what works well in care services for them? [Do you have any good practice examples?]
- Q.** What do you think the key challenges are in planning and delivering residential care services for Deaf people with dementia are? [Prompt: do you have direct experience of this now or in the past]
- Q.** What has the person you have cared for found helpful? [Prompt: activities, resources, support]
- Q.** How have the Deaf community and Deaf family and friends reacted to their dementia? [Prompts: supportive? Difficult reactions?]
- Q.** As a Deaf carer what support, information or advice have you found useful? [prompt: specific examples e.g. carer groups or Alzheimer Scotland?]
- Q.** As a Deaf carer – what do you wish was available to support you?
- Q.** If the person you care for had to go into residential care (or is currently in residential care) how important do you think it would be them to be able to keep their links to the local Deaf community? Do they?
- Q.** Are you aware of any services that are available in Scotland (or beyond) for Deaf people with dementia?

Future development

- Q.** Based on your experience, is there anything you would like to see be developed for:
 - Deaf people with dementia who are living at home
 - Deaf people with dementia who are living in care homes
 - the staff in the care sector working with Deaf people with dementia



Appendix 2

Are there any other comments you'd like to add before we finish?

Thank you for your time and your input is much appreciated

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Focus Group Script for the interviewer (Study 4 – Deaf community on dementia care in Scotland)

Thank you for agreeing to take part in this project. Do you have any questions for me before we move on with the focus group questions?

I expect this discussion will take about 1½ to 2 hours, and it will be video-recorded on Zoom. The recordings are for data analysis purposes only and the video recording will be deleted after the analysis is complete, as set out in the participant information sheet which was provided to you before you agreed to participate.

I am sure you can appreciate how valuable it is for me to have discussions with people like this group. The aim is to talk about residential, domiciliary, day care and respite care services in Scotland for Deaf people with dementia. As a Deaf person, you may wish to share your thoughts and views on current services and what care services could be made available for Deaf BSL users with dementia in Scotland – think about if you or someone you cared for developed dementia and had to make use of them. You might have a Deaf relative or friend who has needed to use dementia services, either now or in the past.

May I start by asking a few questions about your experiences and what you think of the current services?

Questions may include:

- Q.** Who do you know that is Deaf and has dementia e.g. a family member or a friend and where do you know them from?
- Q.** What is your relationship with them like?
- Q.** Do you use any communication strategies other than BSL with them?
- Q.** Are you aware of any social care services available in Scotland (or beyond) for Deaf people with dementia? Are there any useful resources?
- Q.** In your experience, how do you think Deaf people with dementia can be fully informed about the choices available to them of social care services?
[prompt: domiciliary services, residential services, care packages, means test, Power of Attorney]



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- Q. What do you think the key challenges are/would be in planning and delivering social care services for Deaf people with dementia?
- Q. What do you think day-to-day life being cared for, is like for Deaf people with dementia?
- Q. What training do you think would benefit care staff or members of the community who come into contact with Deaf people with dementia?
- Q. If a Deaf person with dementia enters residential care – how important do you think it would be for them to be able to keep their links to the local Deaf community? Why?
- Q. Based on your experience, is there anything you would like to see be developed in the future for Deaf people with dementia?
- Q. Do you think Deaf carers of Deaf people with dementia have enough information and support? If yes why? If no, why not?
- Q. Do you have any concerns for Deaf people with dementia when they consider moving into residential care?

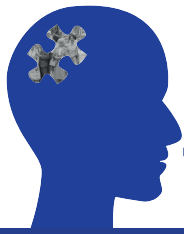
Group activity

I have a list of options for you to consider. Which ones do you think are most important to Deaf people with dementia? (put them in order?)

- ☛ to live in a residential home near family/friends
 - ☛ to live in a residential home near the local Deaf community
 - ☛ to live in a residential home with other Deaf people
 - ☛ to live in a residential home where the staff are BSL aware, can sign and there are specialised Deaf equipment and facilities available
 - ☛ to live in a residential home with a high standard of (dementia) care
 - ☛ to live in a residential home with low fees
 - ☛ to remain at home with domiciliary care from staff with fluent BSL skills
- Q. Why have you chosen this option over that option?
 - Q. Would you consider going into residential care if there was a dementia unit for Deaf people? Why yes or no?

Are there any other comments you'd like to add before we finish?

Thank you for your time and your input is much appreciated



The British Deaf Association

The BDA stands for **Deaf Equality, Access and Freedom of choice**

Vision

Our vision is Deaf people fully participating and contributing as equal and valued citizens in wider society.

Mission

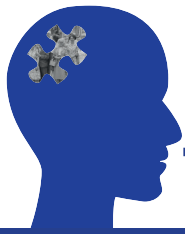
Our Mission is to ensure a world in which the language, culture, community, diversity and heritage of Deaf people in the UK is respected and fully protected, ensuring that Deaf people can participate and contribute as equal and valued citizens in the wider society. This will be achieved through:

- Improving the quality of life by empowering Deaf individuals and groups;
- Enhancing freedom, equality and diversity;
- Protecting and promoting BSL and ISL.

Values

The BDA is a Deaf people's organisation representing a diverse, vibrant and ever-changing community of Deaf people. Our activities, promotions, and partnerships with other organisations aim to empower our community towards full participation and contribution as equal and valued citizens in the wider society. We also aim to act as guardians of BSL and ISL.

1. **Protecting our Deaf culture and Identity** – we value Deaf peoples' sense of Deaf culture and identity derived from belonging to a cultural and linguistic group, sharing similar beliefs and experiences with a sense of belonging.
2. **Asserting our linguistic rights** – we value the use of BSL and ISL as a human right. As such, BSL and ISL must be preserved, protected and promoted because we also value the right of Deaf people to use their first or preferred language.
3. **Fostering our community** – we value Deaf people with diverse perspectives, experiences and abilities. We are committed to equality and the elimination of all forms of discrimination with a special focus on those affecting Deaf people and their language.
4. **Achieving equality in legal, civil and human rights** – we value universal human rights such as the right to receive education and access to information in sign language, and freedom from political restrictions on our opportunities to become full citizens.
5. **Developing our alliance** – we value those who support us and are our allies because they share our vision and mission, and support our BSL and ISL community.



About the British Deaf Association

Founded in 1890, the British Deaf Association (BDA) is a national Deaf-led organisation that works directly with Deaf people who use British Sign Language (BSL) and Irish Sign Language (ISL). Our work concentrates on campaigning for equal rights on a national level and working at a local level empowering Deaf people to achieve access to their local public services. This is carried out through projects delivering individual and community advocacy.

We also work to ensure BSL/ISL is included by public bodies by delivering a public commitment through signing the BSL and ISL Charter.

Our Board of Trustees are all Deaf (we use the capitalised 'D' to denote the fact that we have a separate language and culture), and, 80% of our staff are Deaf.

Many Deaf people who use BSL/ISL lack access to education, health services, employment and other public services. Our work is designed to empower Deaf people and to improve access to general information and public services. We seek to achieve this by working with Deaf people at the local level through setting up forums to lobby public bodies and supporting Deaf people individually.

This is in line with the overall BDA objectives, which are: **D**eaf **E**quality, **A**ccess and **F**reedom of choice.

For a list of signatories to our BSL and ISL Charter, FAQs, and other information, including what the BDA can do for your organisation, please look at our website: www.bda.org.uk

