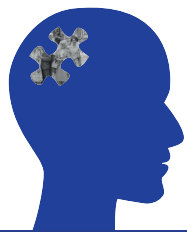




Deaf people with dementia and care homes in Scotland

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

March 2022



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

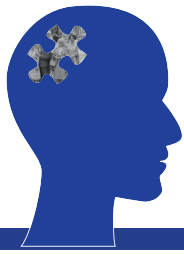
Deaf perspectives and Care Home perspectives are quite different. Sometimes Deaf people and care home staff identified the same problem, but thought about it in different ways. Sometimes the priorities of Deaf people were very different from those of care homes. We have compared and contrasted these 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.

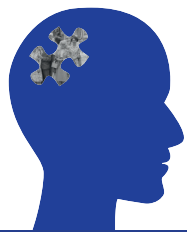
Social workers are an important part of assessment and information to support a Deaf person moving into residential care and specifying their needs and preferences. However, there is a big difference between the information provided by social workers in general and information provided from an assessment 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.

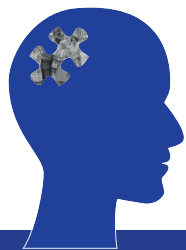
Care home managers and staff are open to the idea of specialised Deaf units. However, they are concerned with inflexible old buildings that do not allow such space, and with segregating Deaf residents. Members of the Deaf community are interested in the idea of establishing specialised Deaf units. However, 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 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**.

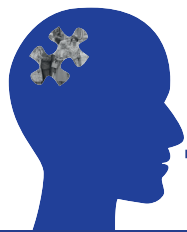
Provide simple '**how to**' **guides** for care home staff including e.g. how to book an interpreter, how to set up remote videocalls for a resident in BSL with Deaf family and friends.

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.



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

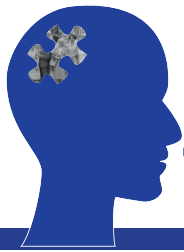
Our Mission is to ensure a world in which the language, culture, community, diversity and heritage of Deaf people in the UK is respected and fully protected, ensuring that Deaf people can participate and contribute as equal and valued citizens in the wider society. This will be achieved through:

- 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

