

# DEMENTIA FRIENDLY COMMUNITIES: SUPPORTED LEARNING AND OUTREACH WITH THE DEAF COMMUNITY

From January 2014 until July 2015, a programme of dementia awareness for Deaf people, including bespoke resources for the Deaf community, was developed and delivered collaboratively by Alzheimer's Society in Northern Ireland and British Deaf Association (BDA).

## What's the issue?

There is strong evidence of a link between hearing loss and dementia. People with mild hearing loss have nearly twice the chance of going on to develop dementia as people without any hearing loss. The risk increases threefold for those with moderate hearing loss and fivefold for those with severe hearing loss (Lin et al., 2011). Research from the Deaf with Dementia project suggests that awareness of dementia in the Deaf community is low, as is the uptake of dementia support. There are barriers to accessing traditional means of information and support, and currently there is no dementia-specific support for the Deaf community.

## Ways forward

- Face-to-face dementia awareness initiatives, delivered in British or Irish Sign Language (BSL/ISL) and in partnership with an organisation trusted by the Deaf community, are highly successful in engaging Deaf people, Deaf people with dementia, Deaf carers and carers of Deaf people.
- National and local organisations working with people with dementia or providing information and resources about dementia, need to ensure that they involve Deaf people, and organisations working with Deaf people, in the design and delivery of dementia awareness and dementia services for Deaf people.
- Film resources must include BSL/ISL, subtitles and voiceover.
- Deaf people need support services that are provided by, and for, Deaf people or by people with use of BSL/ ISL. Access to services provided for hearing people is not sufficient to meet their needs.
- With an ageing Deaf population, Deaf organisations must make dementia awareness a priority.
- Governments and Departments of Health should ensure that national strategies and policy initiatives provide better dementia diagnostic tools for Deaf people, as well as funding for access to work programmes and interpreters to support Deaf people.

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# BACKGROUND

The UK is facing the greatest health crisis of our century. Greater numbers of people are developing dementia than ever before: 225,000 people every year in the UK, which equates to roughly one person every three minutes. While diagnosis rates are improving across the UK, the average stands at less than 60 per cent. People with severe hearing loss are up to five times more likely to have dementia (Action on Hearing Loss, 2014).

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This report aims to inform the development of policy and practice in relation to dementia awareness and information models in the Deaf community and with people with hearing loss. These approaches challenge misconceptions and provide signposting for appropriate information and support. The report considers and provides next steps on best practice models based on a pilot project with Alzheimer's Society and BDA.

The term Deaf is predominantly used throughout this paper. Deaf people use 'Deaf' to describe themselves and identify themselves as having a strong cultural affinity with other Deaf people whose first or preferred language is British or Irish Sign Language (BSL/ISL). The word 'deaf' without a capital 'd' is used to describe those who do not have BSL/ISL – an example of this is a deaf child in a hearing family that does not use BSL.

## Dementia in Northern Ireland

Dementia friendly communities, awareness-raising and improved diagnosis rates for over-65s are all key commitments of the UK Prime Minister's *Challenge on Dementia 2020* (Department of Health, 2015). In Northern Ireland, Alzheimer's Society and The Atlantic Philanthropies have funded a Dementia Friendly Communities programme from 2013–2017. In addition, a regional dementia strategy, *Improving Dementia Services in Northern Ireland* was launched in 2011 (Department of Health, Social Services and Public Safety Northern Ireland, 2011). Increased access to dementia awareness, information and support – including improved access for minority communities – are key aims of these initiatives.

An estimated 19,765 people are currently living with dementia in Northern Ireland and this figure is expected to rise to over 60,000 by 2051. Currently around 7,000 people are living without a diagnosis (Alzheimer's Society, 2014). There are a number of pertinent reasons for this: other health issues masking dementia; a lack of information and awareness among the general public; stigma and discrimination associated with the condition; lack of understanding on how to obtain a diagnosis, and a lack of awareness of dementia and training for health professionals about the condition to support them to make confident and timely diagnoses.

There are approximately 300,000 people who are deaf, or have hearing loss or tinnitus in Northern Ireland. As with dementia, the proportion of deaf people starts to increase significantly with age – 71 per cent of the over 70 population are deaf or have significant hearing loss in the UK, compared to one in three people over the age of 65 living with dementia. However, for people who are Deaf and living with dementia there are additional complexities that make gaining a diagnosis of dementia even harder. Research has shown that current diagnostic tools are often not appropriate for a Deaf person due to different cultural references and no baselines available of what could be correct for a Deaf user (Deaf with Dementia Project, 2014). Deaf people and people with hearing loss with dementia often find it difficult to obtain adequate referrals, information, support and services that are suited to their complex needs. They need all of these things provided in a way that reflects their own use of language – BSL and ISL – and Deaf culture.

## Diagnosis

Research demonstrates how getting a timely diagnosis of dementia can bring a whole raft of benefits to patients and their carers (Age Trust, 2013). The report found that people living with dementia say

that a diagnosis can reduce anxiety, help them plan for the future, allow them to access local support and give them the tools they need to explain their condition to friends and family.

In the Deaf community, there are currently barriers to diagnosis and lack of dementia awareness and information. These lead to increased stigma and misconceptions about dementia.

For the general population, a diagnosis of dementia averages 60 per cent. However, for Deaf people with dementia, there are additional complexities that make gaining a diagnosis of dementia even harder. Deaf people with dementia find it difficult to obtain adequate referrals, information, support and services that are suited to their complex needs. They need all of these things provided in a way that reflects Deaf culture and their own use of language – using BSL and ISL. Developed for hearing people, current diagnostic tools are often not suitable for Deaf people (University of Manchester, 2014).

The Dementia Friendly Communities for Deaf programme (DFCD) agreed to help raise awareness of these research findings among Deaf people in Northern Ireland as part of dementia awareness raising.

In addition, the programme raised awareness of a new dementia diagnostic option for Deaf people worried about dementia. The Deaf with Dementia Project team have developed the first norms for older Deaf BSL signers anywhere in the world, which can be used in diagnostic clinics. The test is sensitive to dementia and mild cognitive impairment. A new clinic for Deaf patients has also been established within the Cognitive Disorders Clinic at National Hospital for Neurology and Neuropsychology (NHNN), Queen Square, London.

### Deaf with Dementia Project

The Deaf with Dementia Project is a three year research project looking at:

- 1** Characteristics of normal ageing in the Deaf community:
  - creating a cognitive and language screening tool in BSL with a standardised video format;
  - sampling memory, visuospatial, language and executive function abilities, as well as orientation to time and space.
- 2** The experiences of Deaf people with dementia:
  - Signers living with dementia and their carers have been interviewed and first-hand experiences analysed, including how being a BSL user can have an impact on early diagnosis and experiences of services.
- 3** Deaf community focus groups:
  - were asked about their knowledge of dementia and where they would go for support or information;
  - were also asked to review current service provision, in order to report preferences back to services, and to create accessible information materials for Deaf people.

### Awareness and support

People living with dementia and their carers tell us that, as cognitive ability declines, it becomes harder to undertake day-to-day activities without their local community's support. The lack of awareness within the community about dementia and the impact of this on an individual are significant (Alzheimer's Society, 2011).

This in turn increases social isolation, as networks that people belonged to prior to diagnosis gradually withdraw. Friends and colleagues struggle to understand the condition and are unsure of how to communicate with and/or support someone with dementia. As a result, people with dementia may feel frustrated, lonely and socially excluded.

Two thirds of people with dementia currently live in the community. According to Alzheimer's Society (2011), carers said that they wish to care for their loved one at home, but to do so they require the appropriate support and information which is not readily available at the moment. Most people living with dementia require assistance and support to live as independently as possible within their

community, but these support functions currently do not meet people's needs. Additionally, greater community awareness and understanding of dementia is required so people can live well with dementia.

Deaf people and Deaf carers have reported that this stigma may result in them feeling excluded from Deaf clubs and the Deaf community.

Since 2012, BDA advocacy team have been signposting Deaf people with dementia to the Alzheimer's Society's advocacy team. This has highlighted these difficulties and demonstrated that often Deaf people are only accessing information, support and diagnosis when they are at, or are reaching, crisis point. The advocacy work has helped to inform the need for outreach to this particular group of people. It echoes research findings that show Deaf people have not benefitted from access to dementia awareness, that dementia is not readily identified and that there are considerable misconceptions and stigma about dementia (University of Manchester, 2014).

### Dementia friendly communities

In response to the evidence above, Alzheimer's Society, in collaboration with other private sector and third sector organisations, has been facilitating the creation of dementia friendly communities (DFCs) so that people with dementia can lead the lives they want and play a full role in our society. DFCs should be places where there is increased awareness of dementia. Greater awareness will, in turn, support better diagnosis rates and joined up working by health and social care providers. In the long term, a DFC will be a place where people with dementia and their carers are given assistance at home earlier, reducing the risks of comorbidities or falls, fractures and infections, and helping to reduce stress and fatigue in their carers. This will mean that the person with dementia could require fewer hospitalisations and remain in their home for longer (Alzheimer's Society, 2013).

This initiative has been developing in villages, towns, and cities across Northern Ireland since April 2013.

### Availability of dementia resources for Deaf people

In December 2013, DFCD reviewed the availability of dementia information resources nationally and locally, and their accessibility or non-accessibility to people who are Deaf and primarily users of BSL/ISL. It was found that resources aimed at a Deaf audience were very limited and that most information was reliant on the use of the written word.

Research by Conrad in 'The Deaf School Child' (1979) showed that deaf school leavers had an average reading age of 8–9 years and nearly 20 per cent of a cohort of deaf young people who had a normal IQ score were unable to complete an interview in either speech or sign. These alarming statistics have not significantly improved in the intervening years as more recent government statistics from national curriculum tests show that education provision is clearly failing many deaf children.

National curriculum tests are a measurement of achievement against the precise attainment targets of the national curriculum rather than any generalised concept of ability in any of the subject areas. The national curriculum standards have been designed so that most pupils will progress by approximately one level every two years. This means that by the end of key stage 2 (age 11), pupils are expected to achieve level 4. In 2011, UK Government data shows the percentage of pupils achieving the expected level (level 4 or above) in the 2011 key stage 2 tests in both English and mathematics was 74 per cent, with 80 per cent achieving the expected level for reading, writing and arithmetic (Department for Education National Curriculum assessments statistical release, 15 December 2011).

This contrasts sharply with the figures for deaf children. UK Government data shows that in 2011, some 45 per cent of deaf children at key stage 2 achieved the expected level for English and mathematics, and only 36 per cent achieved the expected level for reading, writing and arithmetic at key stage 2 (NDCS note on Department for Education figures on attainment for deaf children in 2011, England).

The use of plain English that is clear, concise and jargon free can be a particularly helpful tool for Deaf people when information is presented in written English. Although plain English was evident in many of

the resources reviewed, their efficacy was limited due to lack of visuals that would aid a Deaf audience. Information available in booklets, leaflets and on websites often had limited, and in some cases no usefulness for a Deaf audience.

A number of organisations, including Alzheimer's Society, had provided subtitled films – but again efficacy was limited due to a current general lack of understanding among organisations of the needs of Deaf people. These films could have been made accessible with the provision of BSL/ISL versions and/or subtitles in plain English which changed colour with the speaker – plus a voiceover so that family and friends could support with learning.

Alzheimer's Society and others generally provide a textphone service. However Deaf people reported that this would often only be useful to an older Deaf person due to technological advances. The DFCD team found that most Deaf adults prefer to use FaceTime and ooVoo (free video chat and instant messaging) as these better support communication through sign language.

## Programme overview and outputs

The new joint Alzheimer's Society/BDA initiative aimed to provide a hard to reach group with vital information about dementia, helping to break down barriers that are preventing people from the Deaf community, and those with hearing loss, to access the support they need to improve their quality of life. It would also help to dispel the stigma and discrimination often experienced within communities, which is made more complex by additional health and care needs.

Alzheimer's Society and BDA agreed to create a bespoke dementia awareness workshop, based on the DFC awareness workshop delivered in Northern Ireland, to raise awareness of dementia among Deaf people. A bespoke information and signposting leaflet was also created.

### Awareness workshops

The DFC workshop has three main aims:

- to develop participants' knowledge of dementia;
- to increase their confidence and skills to help them relate to, communicate with and support someone with dementia;
- to enable them to become a Dementia Friend.

The DFC workshop was reviewed by Deaf people, Deaf people living with dementia, carers of Deaf people with dementia and BDA staff members, against the research findings from the Deaf with Dementia Project. As a result of this consultative process, it was agreed that each of the three main aims identified above would remain and that tackling myths and misconceptions about dementia would be key. It was agreed with the project team that research findings about how Deaf people live with dementia would be included, as would information on research relating to diagnosis.

The starting point was to work with Deaf people to ensure that the workshop presentation was in plain English, incorporated the points above, had visuals added to aid a Deaf audience, and included statistics relevant to people with hearing loss.

In order to ensure effective delivery of the workshop, four interpreters were identified – two who use BSL and two who use ISL. The workshop was provided to them in advance so that they were familiar with it and could tease out any potential issues.

The first issue that arose was agreeing a term for dementia. The sign commonly used in BSL can also mean madness, which itself had the potential to create misconceptions. It was agreed the term dementia would use the sign for the brain, and then be finger spelt in the same way as it is for ISL. This proved challenging when considering different types of dementia, including Alzheimer's, and extra time was allocated to explain the terms.

Secondly, a sign had to be agreed for the term Dementia Friendly Communities. The agreed best sign by Deaf people was a combination of the sign for brain, the sign for friend, and the sign for community.

Thirdly, timing and rest periods had to be planned in advance, and awareness training provided to Alzheimer’s Society staff who would be involved in the project. This involved Alzheimer’s Society staff meeting with BDA staff and the interpreters to learn more about the needs of Deaf people when communicating, the needs of the interpreter when working together, how to effectively communicate one-to-one using an interpreter and in groups with Deaf people, and further awareness around acceptable language and commonly used terms.

DFC workshops aim to be as interactive as possible and to allow audience participation, sharing of experiences and case studies to enable enhanced learning.

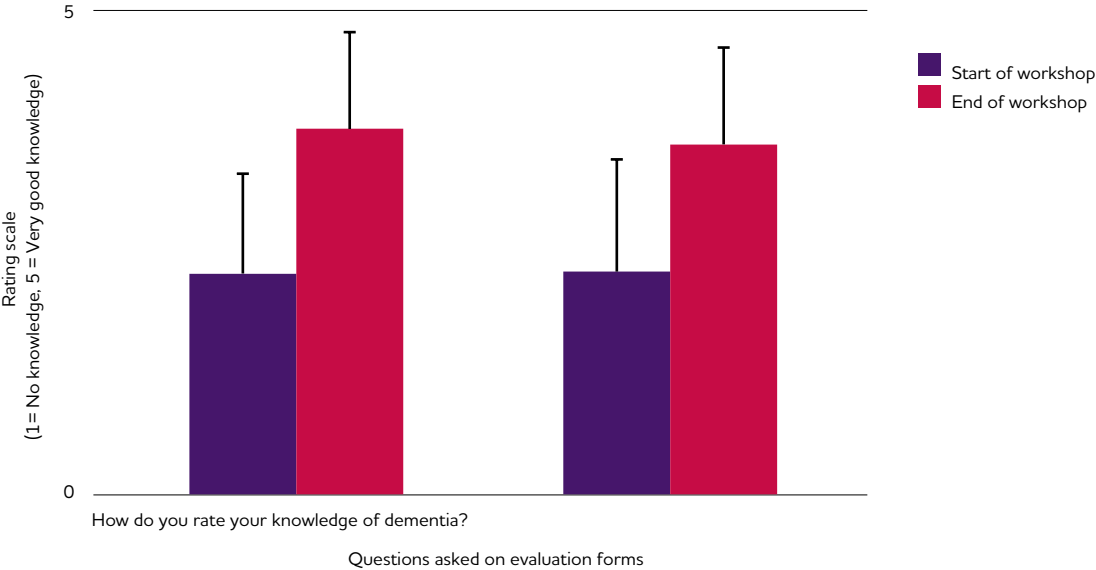
In order to accommodate a Deaf group and people with hearing loss, it was agreed that the workshops would last three hours, one hour longer than those available for hearing people. This was to allow more frequent breaks, as the amount of concentration required can be tiring for Deaf people and people with hearing loss, especially if it is moderate to severe. Time was also allowed for the opportunity for discussions with each other and staff from BDA and Alzheimer’s Society over lunch or refreshments.

The workshops were delivered at 16 locations across NI to cover as large a geographical spread as possible, including Newry, Fermanagh, Derry-Londonderry and Belfast. They were promoted by BDA through their networks, including the In-Touch Team leader at Action on Hearing Loss, and through two workshops at Action on Hearing Loss offices in Northern Ireland.

The programme reached 300 participants, 245 of whom are Deaf, including Deaf carers of people with dementia, and eight healthcare professionals working with Deaf people. In addition, some 50 Action on Hearing Loss staff (including five Deaf staff members), volunteers and service users received the bespoke workshop. This included staff and volunteers working on the In-Touch programme, a befriending service for people who are Deaf or hard of hearing both in the community and in residential homes across Northern Ireland.

### Evaluation of workshops

**Figure 1: Responses to questions asked before and after DFCDAs workshops**



The statistics displayed in Figure 1 confirmed our hypothesis that the delivery of Dementia Friendly Communities for Deaf Awareness (DFCDA) workshops to members and staff associated with BDA increased their knowledge of dementia, as well as improving their confidence and skills to enable them to relate to, communicate with and support someone with dementia.

**“It is good to listen to the talk, it helps us to understand what it [dementia] is all about.”**

Deaf participant

In response to the question, ‘How do you rate your knowledge of dementia?’ rated on a scale from ‘1= No knowledge’ to ‘5= Very good knowledge’, participants ratings increased from an average score of 2.28 at the start of the workshop, to an average score of 3.77 at the end of the workshop. Additionally, when faced with the question, ‘How do you rate your confidence and skills to enable you to relate to, communicate with and support someone with dementia?’, answered using the same rating scale of ‘1= No knowledge’ to ‘5= Very good knowledge’, participants showed improvement, from an average score of 2.30 at the start of the workshop, to an average score of 3.61 at the end of the workshop.

**“This gives me a better understanding and increases my confidence meeting people with dementia. Also my attitude is now changed after I realise what dementia actually is.”**

Deaf participant

Of the 50 participants in DFCDA randomly selected for analysis, 100 per cent answered ‘Yes’ on their evaluation forms when asked; 1) if they found the presentation useful, and 2) if they would recommend that other people attend the workshop. With regards to the timing of the workshops, four participants indicated that the timing was inappropriate, all stating that ‘so many interruptions resulted in the end of the presentation being rushed’. This is something which will be taken into consideration when selecting suitable venues for future delivery of awareness workshops to BDA and other organisations.

Finally, a huge positive outcome of the delivery of workshops to BDA was the interest of six out of the 50 randomly selected participants (12 per cent) in becoming Dementia Friendly Community Champions – all of whom indicated they would like to be contacted by text or letter to accommodate their loss of hearing.

For the evaluation, hard-copy evaluation forms were provided, and staff and volunteers from BDA supported with BSL/ISL signing to facilitate the completion of these. However 10 per cent of forms from all participants were not completed due to lack of time/support with completion. BDA have recommended filming feedback for future awareness sessions so that it can be provided directly from participants in BSL/ ISL.

**“[It is] good to see a shared partnership between Alzheimer’s Society and BDA addressing the needs of the Deaf community.”**

Deaf participant

### **Signposting and support**

Signposting attendees for further information and support where required is also a key output of the DFCDA workshops. People with mild to moderate hearing loss were signposted to the local Alzheimer’s Society dementia support service, or their local GP if they were worried about potential signs or symptoms of dementia. Action on Hearing Loss staff and volunteers were informed of local support services and their local Dementia Support Worker to whom they could make direct referrals. Alzheimer’s Society Dementia Support Workers in Northern Ireland were also informed of Action on Hearing Loss services to which they could make referrals or signpost people.

Alzheimer’s Society outreach activity with BDA in 2012 had already highlighted that Deaf people reported difficulties in accessing the local dementia support service, due to communication barriers



and need for interpreters. Deaf people normally access interpreters through Deaf organisations or government run initiatives. However, access to interpreters was reported to be underfunded or limited.

As a temporary measure, it was agreed that Deaf people could be supported to access Alzheimer's Society's dementia support services in NI through the BDA advocacy service and staff members. It was agreed by all involved that this was a compromise that would ensure that some level of support could be provided.

In addition to Alzheimer's Society dementia support service leaflets being available at all workshops, a bespoke plain English leaflet was created. This uses both the BDA and Alzheimer's Society logos and spells out clearly that Deaf people can also access Alzheimer's Society services in partnership with the BDA advocacy service.

The bespoke leaflet provides contact details for the two BDA Community Advocacy Officers, with SMS/FaceTime contact numbers, email addresses and OoVoo details. It also provides a brief overview of Alzheimer's Society services, alongside information about the National Dementia Helpline including email address, textphone number and times for online live chat plus signposting to the Alzheimer's Society website.

### Dementia awareness DVD

Deaf organisations, including BDA, often support Deaf people by providing information on film, with BSL/ISL as a well-recognised Deaf accessible format. This is a trusted means of communication within the Deaf community and one that enables people to review information conveniently in a BSL/ISL format. In addition, the films BDA produces are subtitled and have voiceover to enable the sharing of information with hearing family and friends.

In reviewing dementia films available for Deaf people, it became evident that Deaf people had limited access. Dementia awareness films by non-Deaf organisations had not been produced with Deaf people or Deaf organisations and, though often subtitled, did not provide a voiceover or BSL/ISL. In the experience of BDA, most providers do not understand that written English is often a secondary language for Deaf people and that BSL/ISL should be recognised as the primary language for films.

There were also limited films about dementia available from Deaf organisations. Those that were available provided out of date information and had not been produced with an organisation specialising in dementia.

DFCD developed a DVD to support delivery of dementia awareness raising. The steering group for delivery of the DFCD film included Deaf people, Deaf carers of people with dementia and hearing carers of Deaf people with dementia. The film provides information on what dementia is, signs and symptoms, plus case studies from Deaf people living with dementia. 500 hard copies of the DVD were produced and it is also available online at: <https://www.bda.org.uk/health-dementia-ni>

The DFCD DVD was launched at the World Congress Mental Health and Deafness at Riddell Hall, Queen's University Belfast in September 2014. Alice Johnston from BDA and Heather Lundy from Alzheimer's Society presented on this project and partnership. The DVD was also promoted at the DFC conference in September 2014 and at BDA's Annual conference in November 2014. Copies have also been provided to colleagues in Scotland, London and the Midlands. BDA provided free copies to all of the Deaf clubs in Northern Ireland and, through their networks, to the Sensory Social Work Teams, Mental Health and Deafness teams and other stakeholder organisations including Action on Hearing Loss.

The DVD has been very well received and Deaf participants have fed back that they are very happy with the results. In addition it has been well received by sensory team social workers who have been sharing it through their services and Deaf clubs.



## Summary of programme outputs

- Involvement of people affected by dementia who are Deaf or have hearing loss, in the design of the DFC workshops.
- Creation of an innovative dementia awareness raising DVD that is BSL/ISL, voiced-over and subtitled.
- Recruitment of four fully qualified BSL/ISL interpreters by the BDA to provide translation at the 12 DFC workshops.
- Delivery of 12 DFC awareness raising workshops jointly by Alzheimer's Society and the BDA to people who are Deaf or have hearing loss across various locations in NI.
- Participation of some 300 people in the DFC workshops.
- Feedback from Deaf people on how a dementia support service should best meet their needs, including need for support to access healthcare professionals.

## Programme outcomes

Research has shown that if people with dementia are given the opportunity to live independently in their own community, they can improve their quality and enjoyment of life whilst living with dementia (Alzheimer's Society, 2009). Raising awareness of what dementia is and the challenges it brings through the actions outlined in this project is one of the most significant ways to inform and educate communities.

This programme used a combination of targeted information and dissemination of materials, including presentations about the programme and launch of the DVD at the World Congress on Mental Health and Deafness 2014. The programme identified that general awareness raising, accessible support and advice, and influencing policy will have the greatest impact for people affected by dementia, particularly those from the Deaf community or with hearing loss.

Small and simple changes in the way people think about dementia, and recognition of how they can continue to involve and support people with dementia will have a huge and significant impact.

This project challenged the stigma of dementia and helped to create an attitudinal change which will make dementia more accepted within the Deaf community. Around 300 Deaf people were reached, some of whom shared their own experiences of dementia at the workshops and voiced recognition of signs and symptoms being experienced by themselves or a family member. Deaf people reported an increased understanding of dementia and an increased confidence in their ability to relate to, communicate with, and support someone with dementia.

Providing information from a trusted dementia organisation (Alzheimer's Society) in partnership with an organisation trusted by the Deaf community (BDA) greatly increased the project's reach. Widespread coverage of the Deaf community has been achieved through the DFCD programme, and dissemination of accurate information and resources in print and DVD will increase awareness and lessen the fear associated with dementia.

## Next steps

The vision underpinning DFCs is that they are a place where people with dementia are understood and can live well. In order for Deaf people to live well with dementia within the Deaf community, they require bespoke information and awareness programmes, Deaf accessible support services, and support to access healthcare professionals through, for example, BSL/ISL interpreters and support workers.

Through this programme, Alzheimer's Society and BDA have talked to some 300 Deaf people and Deaf carers, plus sensory social work staff and other key stakeholders. Deaf people have identified that they would get better outcomes from a dementia support service that is by Deaf people and for Deaf people than from accessing dementia information and support services with interpreters. Hearing carers of people who are Deaf have said they would best benefit from access to support of people in a similar position.

Alzheimer's Society's Innovation Fund has agreed to fund a two-year pilot dementia support and information service specifically for Deaf people or those who are hard of hearing who are affected by dementia. This will start in January 2016.

The programme will require the recruitment of a dementia support worker who will be based at the Belfast BDA Northern Ireland office and who will be able to competently communicate with the target group via BSL/ISL so that they can easily connect and integrate with the target group.

The Dementia support service for Deaf is designed in collaboration with Alzheimer's Society, BDA and the Deaf with Dementia Project Team and implemented in partnership with Alzheimer's Society and the BDA. This innovative dementia support service will be based on the Alzheimer's Society's core service model for Dementia Support and aims to provide dementia awareness for Deaf people, one-to-one information and support, a dementia information programme for people with a diagnosis, a friendship group for Deaf people with dementia, a carer support group for Deaf carers and hearing carers of Deaf people with dementia, and an education programme for healthcare professionals.

This new initiative will provide a hard to reach group with vital information about dementia, helping to break down barriers that are preventing people from the Deaf community and those with hearing loss to access the support that could help them to improve their quality of life. It will also help to dispel the stigma and discrimination often associated with dementia.

## **Conclusion and recommendations**

On the basis of learning from the DFCD programme, a number of recommendations can be made for groups, projects, organisations and government to ensure that Deaf people have access to dementia awareness, diagnosis, support and the opportunity to plan for the future.

Governments and health services need to be aware that people with mild to severe hearing loss are two to five times more likely to develop dementia. People with severe hearing loss, including people who are Deaf, face increased barriers to diagnosis, information and support.

Dementia awareness programmes and provision of information, support services and support with healthcare appointments need to include provision of interpreter services and should be provided in collaboration with organisations that have expert knowledge of dementia and the needs of Deaf people. The success of future dementia awareness raising initiatives and access to diagnosis, information and support services by Deaf people depends on engagement and involvement of the Deaf community. In particular, consideration needs to be given to the needs of carers of Deaf people with dementia who have limited access to peer support programmes.

These are the specific recommendations for groups, projects and organisations seeking to provide dementia awareness, support services and information to the Deaf community and with Deaf people with dementia:

- Work with an organisation trusted by Deaf people and people with hearing loss.
- Involve Deaf people in the creation and review of awareness programmes and resources.
- Provide Deaf awareness training to staff involved in the programme.
- Provide dementia awareness training to Deaf staff involved in the programme.

- Consider the communication needs of Deaf people using BSL/ISL.
- Use plain English, remove all unnecessary text and use lots of visual aids.
- Practice delivering the workshop and film resources developed with interpreters and Deaf people to agree sign terms and break points.
- Ensure venues used for delivering workshops to Deaf and people with hearing loss have access to working loop systems.
- Consider venue lighting for Deaf people to minimise glare.
- Consider visibility of, and space required for, interpreters.
- Welcome Deaf people and learn some basic signs in BSL/ISL to say 'hello', 'welcome' and 'thank you'.
- When using an interpreter, it is important to always look at the Deaf person.

Providers of support services should incorporate all of the above recommendations plus:

- Give Deaf people better and more consistent access to interpreters to meet their healthcare needs, including GP and hospitals appointments.
- Be aware that access to services for hearing people through interpreters is often not appropriate.
- Provide awareness, information and support to Deaf people and Deaf people with dementia in a peer environment, with Deaf people and users of BSL/ISL.

Alzheimer's Society and BDA will pilot a dementia support service for Deaf people from January 2016 to evidence learning towards a model of best practice.

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## About this paper

The purpose of this paper is to describe the Dementia Friendly Communities and Deaf project (DFCD). DFCD was a 20-month project that ran from January 2014 – July 2015. It aimed to provide access to bespoke dementia awareness and information for Deaf people and those with hearing loss. DFCD wanted to challenge misconceptions and stigma within the Deaf community caused by years of limited access to information about dementia in British or Irish Sign Language. The paper summarises key findings on existing provision, a project overview and project outcomes. It makes a number of recommendations for supporting and engaging Deaf people in dementia services.

## FOR FURTHER INFORMATION

This summary is part of JRF's research and development programme. The views are those of the authors and not necessarily those of the JRF.

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