



### **Lay summary of project and outcomes**

**The Deaf community:** There are around 100,000 Deaf people living in the United Kingdom (UK) who use British Sign Language (BSL) as their language and everyday means of communication. Here, the use of Deaf with a capital D identifies the person as someone who is part of the BSL community and not someone who has lost their hearing owing to the effects of growing older, for example. BSL is an entirely visual language, not connected with English. There is a rich tradition of Deaf culture in the UK with key people, places and events that have shaped Deaf heritage and contributed to community identity. This was the first multi-site study that attempted to understand how dementia impacts on someone who communicates through BSL rather than through speech, as in the hearing community.

**Working Together:** The study was primarily targeted at the early identification and awareness of dementia in the Deaf community. This was deliberate and matched a key concern of the National Dementia Strategy in England, as well as many other Dementia Strategies around the UK and the world, in that an early and timely diagnosis of dementia will enable the person and their family to be helped as much as possible and give time for future informed choices to be made. For Deaf people with dementia however, we did not know how this took place and what the Deaf community knew about dementia. Cognitive screening tools in BSL did not exist. Therefore, our project was multi-site and multi-professional involving the University of Manchester (Social Research with Deaf people programme and the Dementia and Ageing Research Theme), City University, London, Deafness Cognition and Language (DCAL) Research Centre, based at University College London, the Royal Association for Deaf People and contributions from Deaf carers of partners and parents with Dementia.

**What We Found:** A lot of data were collected during the lifetime of the project and analysis of some of this data remains on-going. However, there have been some key achievements. We were able to pilot and develop the first BSL Cognitive Screening Test (BSL-CST) that screens for orientation, memory, executive function, sign language and visuospatial impairment in older Deaf signers. The BSL-CST is designed to detect acquired cognitive impairment caused by neurodegenerative conditions such as dementia and was based on some well-known existing screening tools for the hearing community, but with some new and adapted items. The BSL-CST has its origins entirely in signed language with no English language requirements and includes items specifically assessing integrity of language function in BSL. We also created a new BSL test of Verbal Memory and Learning (BSL-VMLT) which provides a more specific measure of verbal memory and forgetting patterns. There are no other similar tests in any signed language around the world. The development of the BSL-CST has led to the first diagnostic clinic for Deaf people with suspected dementia being set up in London. To date, 19 Deaf patients have benefitted from detailed assessment and diagnosis and staff at DCAL have helped to deliver this new service.

Another notable finding is that we can report that Deaf people living with dementia have self-awareness about their condition and share similar experiences to the hearing community in how this is manifest, for example through forgetting, making mistakes and a loss of orientation. However, from a cultural point of view there are two additional features that we have identified so far. Dementia is seen as taking away the person's status in the Deaf community, sometimes expressed as loss of a good name, loss of reputation and loss of role. It is also seen as taking away a specific language i.e. sign language. Both are important to a Deaf person's identity because this is forged through relationships made in the Deaf community with other sign language users. Therefore the impact is great. As a way of assisting this situation, more information and education about what is, and what is not, dementia is required by the Deaf community. This information provision should be inter-generational and available across the life span. We found that translation of information into BSL is not enough. Access to knowledge has to happen through ways that are culturally meaningful e.g. discussion groups rather than watching DVDs in BSL.

**Being Deaf with Dementia:** From first-hand accounts of Deaf people living with dementia and their family members, we also learned what it was like to live with dementia and how dementia in Deaf people may first appear. These issues included: the use of older signs that have fallen out of currency for most Deaf signers in recent years; a restricted facial expression which has grammatical implications when attempting to 'read' what another person is trying to communicate; small and restricted signing space; a lessened ability to respond to visual cues and to be aware of communication happening in the wider environment/visual field; placing the hands in the 'wrong' signing position. We found that Deaf carers were very skilled at supporting Deaf people with dementia to remain contributors to conversations by using the resources of a language that is entirely visual e.g. directing eye contact, non-verbally cueing a person into conversations, showing pauses in conversation with specific body language. Carers found themselves having to explain culturally normal behaviours to professionals in order to stop inaccurate conclusions being reached about Deaf people with dementia. Very few support services were accessible or appropriate for Deaf people with dementia. Deaf people with dementia living in mainstream (hearing) care facilities were especially isolated.

**Taking Stock and Going Forward:** This study provides a solid platform for additional work and signposts new research, policy, education and service directions for the Deaf community. As an illustration, the Deaf with Dementia project has so far contributed to UK government policy through its lobbying channels and 'Deaf with dementia' is now part of the SCIE dementia gateway to further education and understanding across the whole system of support. The Deaf with dementia project is also written into the 'Dementia Pledge Exemplars' that support the implementation of the English National Dementia Strategy. The assessment and diagnostic clinic for Deaf people with suspected dementia is groundbreaking. The international application of the tools created to assess cognition and language in this group is clear; they are, to the best of our knowledge, the first tools of their type in the world. The challenge is to build on the interconnected parts of this study to create a complete care pathway for Deaf people with dementia and their families and supports the future needs of the Deaf community.