

<b>Institution:</b> University College London
<b>Unit of Assessment:</b> 4 - Psychology, Psychiatry and Neuroscience
<b>Title of case study:</b> The creation of neuropsychological assessments and services for Deaf patients with neurological impairments
<p><b>1. Summary of the impact</b></p> <p>As a direct result of research conducted by Professor Bencie Woll at the Deafness Cognition and Language Research Centre (DCAL), UCL, the NHS has established the first neuropsychology clinic for Deaf patients who use British Sign Language within the Cognitive Disorders clinic at the National Hospital for Neurology and Neurosurgery (NHNN). By developing services for this under-researched group, NHS provision has become accessible for the first time, benefiting both patients and service providers. We have disseminated our resources around the world, and have highlighted them to the Deaf community through a unique programme of public engagement. Our research has also influenced UK government policy on Deafness.</p>
<p><b>2. Underpinning research</b></p> <p>Early identification, accessible information and ‘living well with dementia’ are key aims of the Government’s dementia strategy but previously, cognitive assessments in British Sign Language (BSL) did not exist, and so these aims went unmet for deaf people. Because BSL is unrelated to spoken English, linguistic, cultural and educational differences mean that the use of interpreters or written English formats is unreliable and error prone, particularly as communication itself is part of the assessment. Diagnosis of deaf patients is typically late with adverse consequences for access to medication, rehabilitation and care planning.</p> <p>Deaf people do not have equal access to NHS neurology services. In an earlier survey of NHS neurological services we had identified that Deaf people were referred to speech and language therapy services following stroke at about 20% of the rate of referrals for hearing patients. It is likely that the situation is similar for those affected by other acquired neurological and neuropsychiatric conditions, such as head injury, progressive neurological diseases, and schizophrenia.</p> <p>The underpinning approach to our research is to use sign language as a model system for studying language more generally, by enabling separate consideration of speech and language. Within the area of acquired neurological and neuropsychiatric impairment, we have undertaken several studies. Following our earlier studies at City University, which explored aphasia and apraxia in signers with stroke, we have undertaken a series of case studies from 2005 onwards of motor impairments in signers [1, 2]. For example, we have shown through a case study of a signer with progressive supranuclear palsy that the characteristic feature of palilalia is found in sign language, indicating that theories of palilalia which relate it specifically to speech are incorrect [2].</p> <p>We have also explored the manifestations of voice hallucinations in deaf people with schizophrenia, providing novel insights into the nature of subvocal thought and sensory feedback loops [3, 4]. We have continued to maintain an information and advice service for clinicians and have undertaken opportunistic collection of data as and when cases present.</p> <p>In 2010 we began a joint project with the University of Manchester, City University London and Royal Association for Deaf People (RAD). This project, funded by the Alzheimer’s Society, aims to improve early diagnosis and management among Deaf people who use BSL. The DCAL/UCL team was primarily responsible for Study 1 which focused on the Older Healthy Deaf Brain. Diagnosis of dementia in the Deaf community is considerably delayed because of limited recognition of the nature of their impairments, the absence of appropriate assessment tools, and poor communication between clinical staff, patients and carers [5]. This study included developing a profile of normal ageing within the Deaf Community from a cognitive perspective. This was used to</p>

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develop a screening instrument for dementia in BSL that is linguistically and culturally appropriate and that is normed for the Deaf population [6].

The underpinning research was undertaken by Professor Bencie Woll, Director of DCAL, Dr Joanna Atkinson, Research Fellow, and Dr Tanya Denmark, Post-doctoral Researcher.

### 3. References to the research

- [1] Tyrone ME, Woll B. Palilalia in sign language. *Neurology*. 2008 Jan 8;70(2):155-6.  
<http://dx.doi.org/10.1212/01.wnl.0000279378.09844.89>.
- [2] Tyrone ME, Atkinson JR, Marshall J, Woll B. The effects of cerebellar ataxia on sign language production: a case study. *Neurocase*. 2009 Oct;15(5):419-26.  
<http://dx.doi.org/10.1080/13554790902893097>
- [3] Atkinson JR, Gleeson K, Cromwell J, O'Rourke S. Exploring the perceptual characteristics of voice-hallucinations in deaf people. *Cogn Neuropsychiatry*. 2007 Jul;12(4):339-61.  
<http://dx.doi.org/10.1080/13546800701238229>
- [4] Atkinson JR. The perceptual characteristics of voice-hallucinations in deaf people: insights into the nature of subvocal thought and sensory feedback loops. *Schizophr Bull*. 2006 Oct;32(4):701-8. <http://dx.doi.org/10.1093/schbul/sbj063>
- [5] Atkinson J, Denmark T, Woll B, Ferguson-Coleman E, Rogers K, Young A, Keady J, Burns A, Geall R, Marshall J. Deaf with dementia: towards better recognition and services. *Journal of Dementia Care*. 2011;19(3):38-9.  
<http://www.nursing.manchester.ac.uk/images/File/DWD%20poster/DWD%20draft%20article%20for%20JoDC%20with%20revisions%20FINAL.pdf>
- [6] Denmark T, Atkinson J, Woll B, Marshall J. Identifying dementia in deaf sign language users. *Alzheimer's & Dementia*. 2012 8(4) Supplement P556  
<http://dx.doi.org/10.1016/j.jalz.2012.05.1498>

Details of peer reviewed grants and fellowships that supported this work:

2011-16. Deafness, Cognition and Language Research Centre (DCAL). ESRC. £5.5m

2006-10. Deafness, Cognition and Language Research Centre (DCAL). ESRC. £3.6m

2010-13. Overcoming obstacles to the early identification of dementia in the signing Deaf community. Alzheimer's Society. £250,452

1999-2003. Aphasia and Apraxia following CVA in BSL users: a preliminary study. Wellcome Trust. £244,700

### 4. Details of the impact

The programme of research described above has had impacts on clinical services for deaf patients, and on wider government policy in this area.

As part of our initial studies of signers with stroke and signers with dementia, we developed the first ever standardised cognitive and language screening tests designed for signers with acquired neurological impairments [a]. We have disseminated this work to professionals (speech and language therapists, psychologists, physicians, social workers, etc.) through publications and invitations to present our work, for example, to the German Federal Ministry of Family Affairs, Senior Citizens, Women and Youth (March 2013) and at the Alzheimer Association International Conference (July 2013) and have made assessment tools available to clinicians and researchers working with a variety of signers with developmental and acquired impairments in their language.

The Cognitive Screening Test is currently undergoing evaluation at the University of Cologne for use in Germany and at the Sourds et Santé - Nord Pas de Calais network based at the Groupe Hospitalier de l'Institut Catholique de Lille for use in France. We are also in discussion with colleagues in Austria, the Netherlands and Sweden about possible adaptations. We receive around 50 enquiries a month requesting information and services.

The research team met with staff from the Specialist Cognitive Disorders clinic at the National Hospital for Neurology and Neurosurgery in Queens Square in February 2011 and it was agreed to establish the first ever monthly neurological clinic for signers [b]. Patients are referred to the clinic for assessment of dementia or other neurodegenerative disorders; they are Deaf BSL users presenting with acquired cognitive difficulties from all parts of the UK. By early 2013, 18 deaf patients had benefitted from detailed assessment and diagnosis. This is the first service of its kind anywhere in the world. It was promoted by the Royal Association for Deaf People [c] and in an article in the Alzheimer's Society's Living with Dementia magazine in May 2012 which reported that the research described above "*is already benefiting Deaf people through a new clinic service*" [d]. NHS Clinical services can now offer assessment leading to appropriate interventions and services. Patients, families of patients and carers, and the NHS have benefitted from the establishment of interventions and services for this population. Before the establishment of the clinic, deaf patients experienced delays in assessment: some patients had been passed around between services for three years or more without a diagnosis because cognitive tests used in mainstream clinics are unsuitable [e].

Patients are typically seen in the early to mid stages of dementia. The tests give a clear indication of cognitive impairment and allow confident diagnosis in conjunction with brain scans, at an early stage of cognitive impairment, thus allowing speedier and more accurate diagnosis of dementia and other acquired neurological impairments in Deaf people, enabling access to services which should in turn lead to better health outcomes and reduced costs to the NHS and local authority care services. The clinic thus represents a significant step towards reducing wider healthcare inequalities for deaf people in the UK. Improved diagnostic tools should demonstrate health needs in the deaf population, thus enabling clinical leads to plan appropriate provision. Meeting clinical needs earlier should allow for more timely, sensitive and efficient management of individual cases [f].

We have also highlighted our work directly to the Deaf community through our unique programme of public engagement work, which has included the "DCAL Roadshow", presenting our research at Deaf Community Centres in different regions of Great Britain and Northern Ireland, and annual visits and presentations at the English Deaf Darby and Joan Club holiday weeks, attended by over 1000 Deaf people aged 50-90. The research and the clinic have featured on BBC *See Hear* (2010, 2012) and in the British Sign Language Broadcasting Trust's film *Living with Parkinson's* on Film4 (2012) [g].

In relation to policy, both the research and the data obtained through the clinic have served as a springboard for policy development. The Deaf with Dementia team were asked to prepare briefing documents for the government, so that Deaf people with dementia could be included in the development of the equalities action plan with respect to the National Dementia Strategy (Deaf People with Dementia, Dec 2010) [h]; and briefing notes prepared for Paul Burstow, Minister of State for Care Services, at his request (Deaf people and Dementia, Oct 2011). The All Party Parliamentary Group (APPG) in Deafness have agreed to support joint proposals on health and social care developed by DCAL in collaboration with Action on Hearing Loss (AoHL); we launched our joint report in March 2013 in conjunction with the APPG to press for the creation of permanent services for this population [i].

## 5. Sources to corroborate the impact

[a] <http://www.ucl.ac.uk/dcal/documents/poster> (PPT)

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- [b] <http://www.nursing.manchester.ac.uk/deafwithdementia/clinicinfo/>
- [c] Press release from the Royal Association for Deaf People about the Deaf with Dementia project: [http://royaldeaf.org.uk/newsid\\_60/Hope\\_for\\_Deaf\\_people\\_with\\_dementia](http://royaldeaf.org.uk/newsid_60/Hope_for_Deaf_people_with_dementia)
- [d] [http://www.alzheimers.org.uk/site/scripts/documents\\_info.php?documentID=1867&pageNumber=4](http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=1867&pageNumber=4)
- [e] Details can be corroborated by National Hospital for Neurology and Neurosurgery, Queens Square. Contact details provided.
- [f] Corroboration of the impact of the research and clinic on Deaf people's health can be provided by the following organisations/individuals. Contact details provided.
- Medical Director, Sign Health
  - General Secretary, British Society for Mental Health and Deafness
  - Deputy Director of the Centre for Stroke and Dementia, St George's Hospital, London
  - Specialist Clinical Psychologist, Nottinghamshire Healthcare NHS Trust
- [g] *Living with Parkinson's* <http://www.bslzone.co.uk/bsl-zone/living-with-parkinsons/?subs=subs>  
BBC See Hear, Series 30, Episode 23 <http://www.bbc.co.uk/programmes/p00c7h33>  
Extended feature on BBC See Hear, Series 32, Episode 18 (November 2012)  
<http://www.bbc.co.uk/programmes/b01nj0mf>
- [h] See *The National Dementia Strategy Equalities Action Plan* which refers to the Deaf with Dementia project. <https://www.gov.uk/government/publications/national-dementia-strategy-equalities-action-plan>
- [i] DCAL/AoHL Long Term Conditions Review, March 2013  
<http://www.actiononhearingloss.org.uk/joiningup.aspx>