

The **ESRC** Deafness Cognition and Language research centre (**DCAL**) brings together leading Deaf and hearing researchers in the fields of sign linguistics, psychology, and neuroscience.
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DCAL Briefing: The need for a specialist national neurology service for deaf people

What currently happens when deaf people acquire a neurological disability as a result of stroke, head injury, tumour or neurodegenerative diseases such as dementia or Parkinson's disease? Our research suggests that they are often subject to under-diagnosis, late-diagnosis or misdiagnosis. The consequences of this can be distressing for patient and family and leads to poor health outcomes and inefficient use of valuable NHS resources.

Why is assessment and diagnosis so poor for deaf patients?

- Symptoms are often attributed to impoverished communication or missed by professionals without expertise in British Sign Language (BSL)
- Assessment and diagnosis cannot proceed because communication between healthcare professionals and deaf service-users is poor or absent
- There are few suitable clinical assessment tools or outcome measures that have been developed for use specifically with the deaf population
- There is no research-led system for assessment, intervention or evaluation of treatment outcome

What can be done to improve diagnosis and treatment for deaf patients?

- It is vitally important that a permanent national service for referral of Deaf people with suspected neurological and neuropsychiatric conditions is established. This should give deaf patients access to a specialised multidisciplinary team with expertise in neurology, neuropsychology, psychiatry, deafness and BSL
- Effective and reliable diagnostic, assessment, intervention and evaluation tools using BSL
- Use of technology to enable remote provision to distant and rural communities
- Involving and training professionals in the health service and sign language interpreters
- Developing an advisory service to facilitate the appropriate treatment and increased access to services of deaf patients, where treatment occurs within mainstream NHS services
- Monitoring of referral, assessment, intervention and outcome
- Making support services accessible to Deaf patients and carers

Currently there is no permanent specialist provision. DCAL are however working with National Hospital for Neurology and Neurosurgery to pilot access for deaf patients to their diagnostic Cognitive Disorders Clinic. Newly developed cognition and memory tests for signers are used to support accurate diagnosis within the clinic. It is vital that this clinic is established on a permanent basis to ensure that deaf patients receive appropriate assessment and diagnosis. **Intervention and community based provision is also desperately needed.**



Case Studies: The following are real examples of how deaf people have not received the right assessment or diagnosis:

A deaf person who received an assessment suitable for a hearing person

My mother has dementia. It took a long time to get a diagnosis because the professionals did not really know what they were looking at and they could not sign. A person came and did an assessment which was for hearing people. It was not suitable for my mother, the questions just weren't relevant. The sign language interpreter used wasn't trained in working with people with dementia so I had to act as a relay so my mum could understand. By the time she was finally diagnosed, her dementia was obvious to everyone. It's sad she was not diagnosed when we first raised our concerns so we could have had more time with her while she was clearer headed.

A deaf person with missed diagnosis because doctors couldn't communicate with him

When my father had the stroke things were terrible for him in hospital because the doctors couldn't communicate with him. He stayed in hospital for 4 months, much longer than necessary. The doctors struggled to diagnose changes in his medical condition. They would ask my father a question about his medical needs and he would nod his head having not really understood and they assumed that he was cognitively alert when this was not the case. I had to challenge this when I noticed he was signing things that didn't make sense and was in a state of confusion. I have since worked out myself that he has aphasia after his stroke but the hospital did not even pick this up!

A deaf person who finally received the right diagnosis

After decades of frustrating experiences with the NHS but just two appointments at a specialist deaf cognitive disorders clinic my mother finally received a diagnosis that explains her perplexing health problems. No one could explain why she experienced pain, fatigue, reading and memory issues, bizarre visual problems, obsessions and emotional detachment. She had myriad investigations with consultants, neurologists, psychiatrists and support services, resulting in treatments which either made no difference or things worse. A BSL interpreter was needed each time. Half of the appointments were cancelled on arrival because there was no interpreter. The cost to the NHS is unimaginable.

No diagnosis was ever reached. Most professionals had no understanding of deafness or BSL, and each time I would have to explain that my mother was a bright, articulate person rather than someone with learning difficulties as would normally be assumed. I would have to challenge the psychology tests used, because the questions were irrelevant for a deaf person or her scores were being judged against those for hearing people rendering them meaningless.

The clinic was a remarkably different experience for us. The team were fully Deaf aware. Not just at a surface level, but they had deep understanding of what is normal and abnormal for a deaf person. The service was fully accessible, building a relationship, providing assessments and diagnostic support in BSL, my mother's first language. At last we were provided with an accurate neurological diagnosis which made sense of all her symptoms. The results of a MRI scan, showed brain damage to Mum's right temporal lobe. It was the missing piece of the jigsaw, all her behaviours suddenly made sense.