

# Specialist neurological clinic for deaf people cost benefit model

## Background

This cost benefits model sets out the information that is required by NHS England to establish a nationally commissioned service for Deaf people with neurological conditions.

The assessment and diagnosis of neurological conditions is uniquely dependent on effective communication with the patient. Deaf people who use BSL are at significant risk of misdiagnosis if the assessment process is not sufficiently calibrated to working with people who use a visual language.

Currently there is no permanent specialist neurology provision to properly assess and diagnose Deaf patients who present with acquired neurological symptoms. DCAL<sup>1</sup> has been working with the National Hospital for Neurology and Neurosurgery to pilot access for Deaf patients via a specialist diagnostic Cognitive Disorders Clinic. Dealing with up to 24 patients per year this pilot has demonstrated the operational and clinic feasibility of hosting a specialist clinic for Deaf people within an NHS service. It has also provided the cost benefit modelling that demonstrates that a national clinic covering a wider range of conditions would be financially sustainable and offer significant financial benefits to commissioners.

## Four tests

Within the current operating model of the NHS in England there is an acceptance that some services are so specialised they need to be commissioned nationally. These services are high cost, low volume interventions and treatments and include 'long-term' as well as episodic conditions. The number of patients accessing these services is small, and a critical mass of patients is needed in each treatment centre in order to achieve the best outcomes and maintain the clinical competence of NHS staff.

These services tend to be located in specialist hospital trusts in major towns and cities. Concentrating services in this way ensures that specialist staff can be more easily recruited and their training maintained. It is also more cost-effective and makes the best use of resources such as high-tech equipment and staff expertise.

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<sup>1</sup> Deafness, Cognition and Language Research Centre, funded by the Economic and Social Research Council. DCAL brings together leading researchers in the fields of sign language, psychology and neuroscience and is the largest research centre in this field in Europe with nearly 30 staff and research students, about one quarter of whom are deaf.

The Department of Health has set out 4 tests which it considers in relation to specialist services commissioning nationally through NHS England

- the cost of providing the service or facility
- the number of persons able to provide the service or facility
- the financial implications for Clinical Commissioning Groups (CCGs) if they were required to arrange for the provision of the service or facility themselves
- the number of individuals who require provision of a service

## Cost of providing the service

The upfront cost of developing a specialist neurological clinic for deaf people would not involve significant investment as the proposal would involve a specialist service being hosted within an existing service.

The additional cost of treating a Deaf patient with dementia has been identified by the National Hospital for Neurology and Neurosurgery as £606 per patient. This is the premium for a BSL assessment process involving clinical specialists with a track record of working with Deaf people. The per patient cost is just for the initial assessment phase. It does not include monitoring and intervention costs or the cost of psychological and nursing interventions for patients following diagnosis.

Although costs would vary slightly for different conditions, we have identified that the cost of treating new cases of the main neurological conditions service would be £180,000 per year. These costs are based on providing the service at a single national location.

The costs of providing ongoing services would be significantly reduced by an accurate and timely assessment. However a figure of £200 outpatient costs per patient has been identified as a reasonable assumption for 75% of the 1900 Deaf people likely to be diagnosed. This equates to an ongoing support and assessment cost of £280,000.

Given however that many of the conditions may prevent the patient travelling, an additional cost would be required to provide a remote facility using telemedicine through regional clinics. The cost of providing such specialist satellite service would be £120,000 per year.

SERVICE	COST PER ANNUM £
Assessment	180,000
Monitoring and intervention	280,000
Remote services	120,000
<b>Total</b>	<b>580,000</b>

## The number of persons able to provide the service or facility

Currently there a small number of clinicians with the required experience and skills to provide this specialist service. Due to the specialist nature of the service it is likely that the best means of delivery would be with a specialist clinic at a single location, the National Hospital for Neurology and Neurosurgery, supplemented by remote services provided to local and regional centres.

## Financial implications to CCGs and hospital trusts

CCGs have not been able to commission specialist services of this sort because they have not previously been available.

The cost of misdiagnosis, late diagnosis and avoidable hospital admissions are however current met by CCGs. DCAL has identified significant numbers of people who have for example been admitted to high cost mental health settings who could have been supported with lower levels of intervention if the initial assessment had been accurate. DCAL has worked with Action on Hearing Loss to identify the cost of not treating neurological conditions in the deaf community in a timely and accurate manner. Using a recognised health social care pathway we have identified the additional cost resulting from non-provision of appropriate assessment as up to £140,000 per patient over a 3 year period<sup>2</sup>.

The additional cost of providing an initial non-specialist service for deaf patients using interpreters is an additional £1500 per patient<sup>3</sup>. This is based on the costs of BSL interpreters for clinical consultation, assessment and follow up. This cost is incurred by hospital trusts. The cost to the NHS of this based on incidence of neurological disorders amongst the Deaf population per year is £459,000. It should be noted however that these interpreters do not have the specialist knowledge to support consultations with patients who have neurological conditions.

## The number of individuals who require provision of a service

The numbers of Deaf people who require the service is small in the total population.

**Around 350 Deaf people every year develop a neurological condition needing assessment and diagnosis.**

**1900 Deaf people are living with neurological conditions**

Condition	UK Incidence (new cases per 100,000 population)	UK Prevalence (existing cases per 100,000)	Approximate Total Numbers	Incidence in Deaf BSL-using community of 50,000	Prevalence in Deaf BSL community of 50,000
Stroke	204	800	300,000	102	400
Alzheimer's disease	184	25,000 in over 65s, 1,000 in general population	700,000	92	500
Traumatic Brain injury leading to long term problems	175 requiring hospital admission	1200 with long term problems	420,000 up to 65 years	87	600
Multiple sclerosis		100-120	52,000-62,000	10-20	50-60

<sup>2</sup> This financial analysis was published in the *Joined Up* report

<sup>3</sup>Figure provided by University College London Hospitals NHS Foundation Trust finance team.

<b>Parkinson's disease</b>	17	200	120,000	9	100
<b>Epilepsy</b>	24-58	430-1,000	182,750-425,000	12-29	215-500

Incidence and prevalence estimates for neurological conditions in Deaf people are extrapolated from estimates for hearing people in the National Service Framework for Long-term Conditions (2007) Department of Health<sup>4</sup>.

There is no evidence to suggest that rates of acquired neurological disease differ from that of the general population. For example, using existing incidence rates (the Stroke Association, 2001) we estimated that at least 100 people from the British Deaf Community have strokes every year, with one third acquiring lasting disabilities. (J. Marshall et al (2003) Is Speech and Language Therapy meeting the needs of language minorities? The case of Deaf people with neurological impairments, *Int J Lang Commun Disord* (2003 Jan-Mar)38(1):85-94)).

Assuming a conservative estimate of a BSL community of 50,000, overall prevalence of deaf BSL users living with a neurological condition is approximately 8000.

## Conclusion

A nationally commissioned service for Deaf people with neurological conditions clearly meets the tests NHS England has set for a national specialist service. The next stage of the process is to initiate discussions with the Department of Health and NHS England to support the creation of a service. We will be doing this in the coming months but are seeking advocates to test and advise our thinking on how to proceed with initial approaches.

## Case Studies

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

### **Case Study 1: A deaf person who received an assessment that was only suitable for a hearing person:**

*"My mother has dementia and has since had a stroke. It took a long time to get a diagnosis of dementia because the professionals did not really know what they were looking for 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 that 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, as we could have had more time with her while she was clearer headed."*

<sup>4</sup> Incidence is number of new cases diagnosed each year. Prevalence is the burden of disease: new cases + old cases

**Case Study 2: A deaf person who was misdiagnosed because doctors could not 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 just nod his head having not really understood what they asked. Consequently 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!”*

In Case Study 3, we see the testimony of a family member whose mother was referred to the pilot clinic. Her case indicates the positive/beneficial outcomes that her loved ones received having journeyed the specialist service pathway:

**Case Study 3: A deaf person who finally received the right diagnosis**

*“After decades of frustrating experiences with the NHS, just two appointments at a specialist deaf cognitive disorders clinic and 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 a myriad of investigations with consultants, neurologists, psychiatrists and support services, resulting in treatments which either made no difference or made 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 was 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 an 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.*