



# The Deaf with Dementia Project



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# The current situation

- The needs of members of the British Deaf community with dementia often not recognised
- Lack of interaction is attributed to communication barriers, not possible cognitive decline.
- Deaf people often live their final years in an environment where nobody signs.

# Before the DwD Project

- No cognitive assessments in BSL
- No culturally or linguistically appropriate clinical services
- No network of support groups for Deaf people with dementia
- Knowledge in the Deaf community about dementia was poor

# Deaf with Dementia project



MANCHESTER  
1824

The University  
of Manchester

- 3 year project funded by Alzheimer's Society
- Manchester University, DCAL UCL, City University, RAD
- Study 1- DCAL's role- test development and normative data collection from healthy deaf older adults aged 50-89 years
- Study 2 & 3-focus groups, qualitative research



ESRC DEAFNESS COGNITION AND LANGUAGE RESEARCH CENTRE



# The 3 Studies: Study 1

- Study 1: characteristics of normal ageing in the Deaf community were identified, creating a cognitive and language screening tool in BSL with a standardized videoformat, in order to sample memory, visuospatial, language and executive function abilities, as well as orientation t time and space

## The 3 studies: Study 2

- Study 2: The experiences of Deaf people with dementia had not been documented before the DwD project began. Signers living with dementia and their carers have been interviewed and first-hand experiences analysed, including how being a BSL user can have impact on early diagnosis and experiences of services

# The 3 studies: Study 3

- Study 3: Deaf community focus groups were asked about their knowledge of dementia and where they would go for support or information. The groups 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

# Deaf cognition

- Normal nonverbal intellectual ability
- Native vs delayed language acquisition
- Organic causes of deafness eg. meningitis, rubella
- Experience with visuomotor language eg. Bias for spatial rather than serial processing
- Auditory deprivation and neural adaptation eg. Broader visual attention
- Subtle patterns of cognitive advantage and disadvantage
- Need to take account of this in testing



# Unequal healthcare





- Dementia diagnosed at mid to late stage when behavioural changes obvious
- Cognitive scores contribute to decisions about medication and services
- Current tests used with hearing people are unreliable in deaf signers (e.g. MMSE, Dean et al, 2009)
- Lack of accurate assessment leads to poorer access to services and treatment outcomes

# Barriers to testing

- Existing tests developed for users of spoken languages are unsuitable
- Not normed or validated with deaf signers
- Cultural and educational differences
- Poor literacy levels mean written instructions cannot be used
- Using interpreters is unreliable and error-prone, especially where communication is part of the assessment



# Developing the test: The British Sign Language Cognitive Screen (BSL-CS)

BRITISH SIGN LANGUAGE COGNITIVE SCREEN Draft Version 4 (2010)						
Participant number: _____			Date of testing: _____			
Checked wearing glasses (if needed): <input type="checkbox"/>			Tester's name: _____			
WELCOME INSTRUCTIONS						
<p> Hello my name is ..... Thank you for volunteering today. Here is a sticky label with your participant number so we can identify you on the video. I will just switch on the camera ok? We will start some tasks now, some are easy and some are harder. Do not worry if you find some hard because everyone finds some of them difficult. Please let me know if you need a break?</p> <p> Switch on camera. Make sure camera has clear view of participant's who is upper body and signing. Make sure plenty of new DV tape in camera.</p> <p> Ask participant to show number sticker to camera and sign the participant's number clearly to the camera.</p>						
VIDEO INSTRUCTIONS						
<p> Watch the video and I will explain and ask you some questions. Please sign clearly back to me so that the camera can see you too. I'll be writing your responses down. OK are you ready to start?</p>						
ORIENTATION						
Write your response given by participant in spaces below						
<ul style="list-style-type: none"> <li>What is the Day</li> <li>Which Building</li> </ul>	Day _____ Building _____	Date _____ Floor _____	Month _____ Town _____	Year _____ County _____	Season _____ County _____	(Score 0-2) DCLL sum to score (Score 0-2)
REGISTRATION						
<ul style="list-style-type: none"> <li>DVD gives 2 signs to repeat and remember. GULL, TREE, PEN.</li> <li>Score only the final trial.</li> <li>Repeat 3 times if necessary. Press <b>0</b> key to repeat item.</li> </ul>	1 <sup>st</sup> Trial GULL _____ (1) TREE _____ (1) PEN _____ (1)	2 <sup>nd</sup> Trial GULL _____ (0) TREE _____ (0) PEN _____ (0)	3 <sup>rd</sup> Trial GULL _____ (0) TREE _____ (0) PEN _____ (0)	(Score 0-3) DCLL sum to check scores (0-3)		
Number of trials (please circle) 1 2 3						
ATTENTION & CONCENTRATION						
Write your response including repeated letters and mistakes						
<ul style="list-style-type: none"> <li>Spell CIIIG forwards</li> <li>Spell CIIIG backwards</li> <li>Spell DCAF forwards</li> <li>Spell DCAF backwards</li> </ul>	Response _____ (0)					
(0-4)						





## BSL-CS

- Standardised video administration on laptop
- Presented by older, native Deaf signer familiar with signing of older generations
- Close monitoring of BSL and neuropsychology aspects during development
- Deaf-led team: all native or near native signers, 3 deaf and 1 hearing

# Cognitive domains

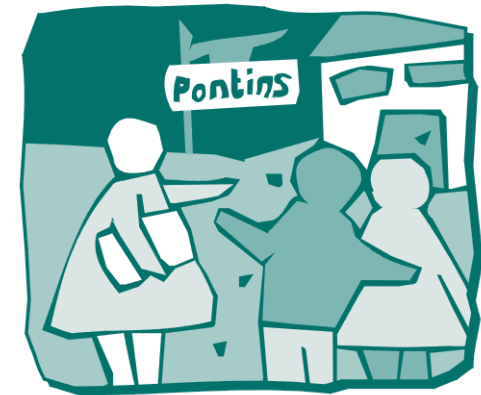


Test includes:

- Memory
- Language
- Visuospatial
- Executive function and attention
- Orientation to time and space

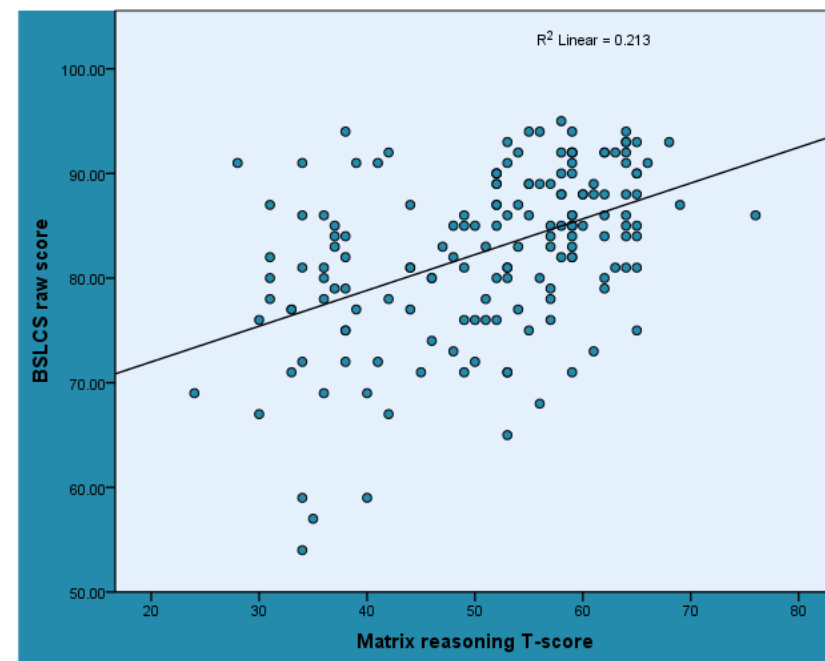
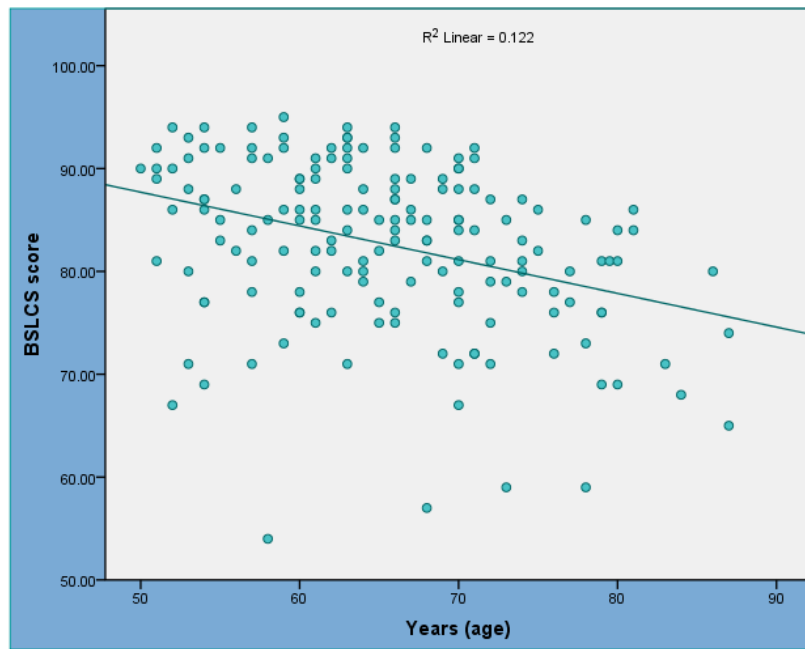
# Collection of normative data

- ◆ Data collected from 226 cognitively healthy deaf adults aged 50-89 yrs attending a holiday camp
- ◆ Health interview screening: no history of neurological disease or injury (except meningitis before aged 10), no mental illness, substance abuse or additional disability
- ◆ WASI Matrix Reasoning was used as control task to check distribution of intellectual ability



# Preliminary Results

Test scores ranged from 54-95 from a possible total of 101. There were no ceiling or floor effects. Scores significantly correlate with age ( $r=.35$ ,  $p<.01$ ) and matrix reasoning ( $r=.46$   $p<.01$ ) showing that the BSLCS is sensitive to both cognitive ageing and intellectual ability.





# What does normal cognitive ageing look like in older deaf signers?

Similar to hearing population, when test is made *culturally and linguistically equivalent*. There is a significant effect of age and general intelligence

# Does cognitive performance differ among signers?

- Significant effect of cause of deafness (genetic vs. organic)
- Significant effect of AoA: native signers outperform non-native signers
- Years of education and occupation classification all positively correlate with BSL-CS scores.

# Study 1 Achievements

- We have the first norms for older deaf signers which can be used in diagnostic clinics
- Test is sensitive to dementia and mild cognitive impairment



- New clinic for Deaf patients within existing Cognitive Disorders Clinic at National Hospital for Neurology and Neuropsychology (NHNN), Queen Square, London

## Study Two: The experience of Deaf people with dementia and their carers

### **Objective:**

- A qualitative study to explore first-hand experiences of Deaf people with dementia and their carers.
  - Recruitment: community-based – word of mouth and group presentations
  - Five Deaf people with dementia and their carers participated in two videoed interviews approx. 4-6 weeks apart with a Deaf researcher.

# Study Two: The experience of Deaf people with dementia and their carers

## **We wanted to know:**

- What BSL users' priorities and values are in terms of care and support;
- The cultural influences on potential recognition of early-stage dementia;
- What daily life is like for a person with dementia who uses BSL;
- About Deaf BSL users' experiences with current service provision

# Study 2 Achievements

## Observations:

- The use of BSL – older generation – language changes?
- The need for self-autonomy within small community
- The use of DVDs not always the best solution
- Access to health services and professional attitudes
- Access to Alzheimer's Society cafe - comments
- Impact of interviews for carers – both on entry and exit

# Study 3: Dementia Awareness and Service Accessibility for Deaf People

## **Objective:**

- To explore the understanding/knowledge of and attitudes towards dementia in the Deaf community (with regard to identification, familial/community support and service need/access)

# Focus groups

- Three focus groups took place with 26 Deaf participants who do NOT have dementia, aged between 21 and 75
- They were facilitated in BSL by a Deaf researcher
- Participants explored together, in BSL:
  - What does dementia mean? Is it a term you understand?
  - If you were concerned that another Deaf person might have dementia, what would alert you? What kinds of things would you notice as a Deaf person?
  - Where would you go for information about dementia and is it accessible?
  - What do Deaf people require in terms of support? Is it the same as everyone else? Or are there additional considerations?
  - How aware are you of existing services? What is the ideal service if you are Deaf?



# Study 3 Achievements

## Early findings indicate:

- Myths or lack of knowledge about dementia are perpetuated through not understanding the condition fully;
- Symptoms of dementia are described as severe mental health problems; rather than descriptions of behavioural changes;
- Frequent mislabelling of other conditions as potential symptoms of dementia;
- Early signs of diagnosis will be identified and supported within the community;
- Lack of awareness/knowledge of 'hearing' services that offer support to people living with dementia;
- Views about the website from the group

# Changing society

- Meeting the needs of Deaf citizens, especially in ensuring full communication access, is a challenge we must meet
- Better understanding will also inform provision for people with hearing loss and other communication impairments