Institution: The University of Manchester

Unit of Assessment: 3 (Allied Health Professions, Dentistry, Nursing and Pharmacy)

Title of case study: Redressing health inequalities through evidence-based health and social care practice with Deaf sign language users

Period when the underpinning research was undertaken: September 2009 - July 2020

Details of staff conducting the underpinning research from the submitting unit:

Name(s):	Role(s) (e.g. job title):	Period(s) employed by submitting HEI:
Alys Young	Professor of Social Work	2005-present
Katherine Rogers	Research Fellow Research Associate Research Assistant	2015-present 2013-2015 2006-2013
Emma Ferguson-Coleman	Research Fellow Research Associate Research Assistant	2019-present 2016-2019 2010-2016
Rosemary Oram	Research Assistant	2012-2016
Claire Dodds	Research Associate	2015-2017
Rachel Belk	Research Associate	2014-2016
Gemma Shields	Lecturer in Healthcare Sciences Research Fellow Hon Senior Lecturer Research Fellow Research Associate	2019-present 2018-2019 2017-2018 2016-2017 2015-2016
John Keady	Professor of Older People's Mental Health	2006-present
Linda Davies	Professor of Health Economics Director of Health Economics Research	2008-present 2004-2008
Karina Lovell	Professor of Mental Health	2004-present

Period when the claimed impact occurred: January 2013 - December 2020

Is this case study continued from a case study submitted in 2014? N

1. Summary of the impact

Deaf signers experience significant health inequalities because health/social care interventions are not designed to respond to their cultural-linguistic needs. Research from SORD (**So**cial **R**esearch with **D**eaf people), the sign-bilingual research group at the University of Manchester, has resulted in more accurate diagnosis and recovery measurement in treating common mental health problems through the adaptation, validation and implementation of health assessment tools in BSL (British Sign Language); improved commissioning guidelines to ensure more targeted and culturally sensitive service provision; the development of new tailored social care interventions for Deaf BSL users with dementia and their carers; and far greater involvement of Deaf people in specifying the key components of effective health and social care for them.

2. Underpinning research

Research evidence demonstrates that Deaf people who use a signed language such as BSL (approximately 100,000 in the UK) experience significant and enduring health inequalities in terms of access to effective service provision and health-related outcomes that are detrimental to socio-economic opportunity and quality of life [1]. Our research has sought to address and change this pattern through four inter-related strands of activity focussing on primary (mental) health and dementia care where the greatest number of Deaf adults are affected. (Note: 'Deaf' refers to sign language users who have a distinct cultural identity, rather than 'deaf' which usually refers to spoken language users).

(i) There was no evidence base concerning the scope and character of unmet need for Deaf signers experiencing dementia. We established a reliable UK estimate for the number of Deaf signers living with dementia and the Deaf community's linguistic/cultural preferences for knowledge exchange about dementia [2] (Alzheimer's Society funded study (2010 - 2013). Three further studies (ESRC/NIHR (2014-2018), Alzheimer's Society (2014-2016; 2017); Alzheimer's Society Junior Fellowship 2020, Ferguson-Coleman) investigated the support needs of Deaf carers of people with dementia.

(ii) Linguistically valid, culturally sensitive research and practice tools in primary mental health care did not exist. We translated, reliability–tested, validated and published a suite of psychometric assessments in BSL including the GAD7 BSL (anxiety), PHQ9 BSL (depression) [1], CORE-OM BSL (primary mental health), WSAS (employment) SWEMWBS BSL (wellbeing) and EQ5D5L BSL (quality of life) [NIHR doctoral fellowship (Rogers 2011-2014), Department of Education (Rogers et al., 2016-2017), NIHR post-doctoral fellowship (Rogers 2020-2025) [2]].

(iii) Deaf signers' mental health is poorer than the general population. We examined the effectiveness of national IAPT (Improving Access to Psychological Therapies) for Deaf signers comparing mainstream access through an interpreter with direct access through a Deaf therapist (NIHR HS&DR Young et al., 2014-2016). It demonstrated the under–determination of health need, severity and recovery when pre- and post-assessment occurred through an interpreter but no significant difference in the cost effectiveness of a directly provided BSL service, despite this being the less preferred route for commissioners on grounds of cost [3]. We identified and published the correct clinical cut-offs to be used with the BSL IAPT assessment instruments for a deaf signing population [4]. We extended our research to investigate for the first time the health state of deaf signers, demonstrating their lower mean health state values than people participating in the 2017 Health Survey for England and that deaf signers with depression (43%) had reduced health states than those without [5].

(iv) We carried out the sign language element of the NHS England funded study (Young et al., 2015 - 2016) into the experiences of patients of interpreter-mediated primary care demonstrating deaf signers' perceptions of adverse effects on health decision making and unreliability of health services' BSL interpreter provision, co-writing the subsequent NHS England commissioning guidance on translation and interpreting in primary care. We extended our research to consider the impact on wellbeing of Deaf people being known 'in translation' by health and other professional groups through two AHRC funded studies (Napier and Young et al. 2015 - 2016; Young and Napier et al. 2016 - 2017) demonstrating primary negative impacts on confidence and secure sense of self [6].

3. References to the research

1. **Young, A.M., Ferguson-Coleman, E., Keady, J.** Understanding dementia: effective information access from the Deaf community's perspective. *Health and Social Care in the Community* 2016; 24(1), 39-47. doi: 10.1111/hsc.12181
2. **Young A., Rogers, K., Davies, L.,** Pilling, M.**, Lovell, K.,** Pilling, S., **Belk, R., Shields, G., Dodds, C.,** Campbell, M., Buck, D., Nassimi-Green, C., **Oram, R.**

Evaluating the effectiveness and cost-effectiveness of British Sign Language Improving Access to Psychological Therapies: an exploratory study. *Health Services and Delivery Research* 2017; (5) 24. doi: 10.3310/hsdr05240

3. **Rogers, K.D., Young, A., Lovell, K.,** Campbell, M., Scott, P.R., Kendal, S. The British Sign Language Versions of the Patient Health Questionnaire, the Generalized Anxiety Disorder 7-Item Scale, and the Work and Social Adjustment Scale, *Journal of Deaf Studies and Deaf Education* 2013; 18 (1): 110-122. doi: 10.1093/deafed/ens040
4. **Belk, R.,** Pilling, M., **Rogers, K., Lovell, K., Young, A.** The theoretical and practical determination of clinical cut-offs for the British Sign Language versions of PHQ-9 and GAD-7. *BMC Psychiatry* 2016; 16:372. doi: 10.1186/s12888-016-1078-0
5. **Shields, G., Rogers, K., Young, A, Davies, L.** Health State Values of Deaf British Sign Language (BSL) Users in the UK: An Application of the BSL Version of the EQ-5D-5L. Applied Health Economics and Health Policy 2020; 18: 547-556. doi: 10.1007/s40258-019-00546-8
6. **Young, A.,** Napier, J., **Oram, R.** "The Translated Deaf Self, Ontological (In)security and Deaf Culture." *The Translator* 2020; 25:4, 349-368. doi: 10.1080/13556509.2020.1734165

4. Details of the impact

Context

Although unequal access to health/social care provision, poor health outcomes and the lack of linguistically and culturally appropriate service provision for Deaf signers were already recognised, the development of evidence-based interventions was hampered by the lack of appropriate clinical research tools, minimal involvement of cultural insiders in research design and service execution, and little data on effectiveness of BSL-specific service provisions. Our work has impacted all of these areas of development.

Pathways to impact - capacity building

Barriers in access to education at all ages through BSL means there is not a readily available Deaf signing academic workforce who are skilled to lead health and social care research within and about their own cultural community. Over 10 years we have built a critical mass of pre- and post- doctoral Deaf (and hearing) signers with specialist cultural-linguistic (BSL) research skills specifically in applied health and social care research which increase the salience and impact of current research and builds future capacity. Awards to SORD's Deaf academics who are BSL users include 3 MRes (ESRC/NIHR); 3 PhD (NIHR and Alzheimer's Society), 2 post-doctoral fellowships (NIHR and Alzheimer's Society) and currently 2 PhDs (ESRC and NIHR) as well as a further 1 MRes (NIHR), 1 MPhil (NIHR), 2 PhDs (ESRC/AHRC) and 3 current PhDs (ESRC and International award) to hearing signers. In 2016 SORD group lead Young won the Times Higher Outstanding Postgraduate Research Supervisor of the Year award for her specific supervisory practice in promoting the achievements of deaf and hearing academics in this specialist field. "*Appointed a fellow of the Academy of Social Sciences in 2015, Professor Young has been described as a 'one-off' whose supervisions, support and research have had a global impact, making her a worthy winner of Times Higher Education's very first award for Outstanding Research Supervisor of the Year.*" [A].

Reach and significance of the impact

(i) Impact on clinical practice

IAPT is the Department of Health's frontline clinical service treating depression/anxiety and serves 1,000,000 people annually. Linguistically and culturally valid standardised self-assessments used within this service are now available for the first time in BSL for use by either Deaf or hearing practitioners delivered in an online format. National IAPT does not collect national data on the language used in assessment/therapy, only the outcome scores. However, SignHealth, who deliver specialist BSL IAPT and use the BSL IAPT tools we

developed and validated, report between 01 January 2011 and 31 December 2019 there were 1,518 Deaf clients who attended where the tools would have been used as per service protocol within a total number of 12,888 sessions within the same period [B]. Additionally, Mayden who administer the online data collection system for IAPT confirm that an additional five NHS service providers have used the BSL versions and recorded data from them into the national database [C]. The EQ5D5L BSL is the first signed language version anywhere in the world to be admitted to the Euroqol Group suite of instruments (the Euroqol Group is an international foundation established to improve decisions about health and health care worldwide by developing, promoting and supporting the use of instruments with the widest possible applicability for the measurement and valuation of health) for assessment of health-related quality of life in clinical practice and is described by the Executive Director of Euroqol as "*a real step forward in health evaluation studies for this minority Deaf population*." [D].

(ii) Impact on health policy and practice guidelines

SORD's evidence of the cost effectiveness of direct IAPT provision through Deaf signing therapists is directly cited within the Royal College of Psychiatry's clinical commissioning guidelines in primary mental health care for deaf people [E]. This is significant because Clinical Commissioning Groups [CCGs] were hitherto reluctant to fund such a specialist therapy assuming that standard therapy with an interpreter was better value for money which had constrained Deaf signers' choices of preferred treatment. We co-wrote the NHS England commissioning guidelines on interpreting and translation in primary care which incorporated in full the 8 quality practice principles we wrote, derived directly from our data analysis. The guidelines, published in September 2018, were distributed directly to all 195 CCGs in England at the time and have been downloaded over 150 times per month up to January 2020 [F, G].

(iii) Impact on inclusion of Deaf signers' needs in social care practice innovations

Innovations in dementia care on an international basis have overlooked deaf signers' specific requirements because they are different from those of older people who have acquired hearing loss. Policy and practice addressing the needs of cultural-linguistic minorities with dementia also usually overlook them, seeing them instead as disabled people. The impact and challenge of our work in spotlighting this neglected group and inspiring new and innovative care practices in many countries has been recognised by the Executive Director of Alzheimer's Europe: "*I was happy to provide these dissemination opportunities to the work carried out by the Social Research with Deaf People Group, as I found their work to have the potential to be truly transformative for a minority population often forgotten or excluded in research and policy developments in the field of dementia*" [H]. Third sector organisations in the UK have used our research evidence to lever social care practice development funds for new bespoke services for deaf BSL users living with dementia, for example the BDA (British Deaf Association) in Scotland "*We greatly value the many years of work that SORD has carried out to make the unique needs of this population (Deaf BSL users with dementia and their care partners) more visible. Their approach to seeking solutions for Deaf people from Deaf people's experience and in BSL has been particularly helpful and matches with our own philosophy*" [I]. SORD is relied upon in the Deaf community to provide evidence-based advice and support for Deaf people living with dementia in the community, as demonstrated through a live-streamed broadcast in BSL "Coronavirus: Supporting elderly and vulnerable people" given on 22 April 2020 during the coronavirus crisis that reached 8,064 people. There were 2,070 engagements and subsequently 1,100 further views since it was uploaded to the broadcaster website [J].

5. Sources to corroborate the impact

A. Times Higher Education Award 2016 "Outstanding Research Supervisor of the Year award", p.35, demonstrating the global impact that Professor Young has had in promoting the achievements of deaf and hearing academics.

B. Letter from SignHealth (dated 28 May 2020) outlining uptake and use of the BSL IAPT instruments within their service over time.

C. Evidence of use by NHS services provided from Mayden (dated 24 April 2020) – a data tracking organisation for data uploads from IAPT services nationally.

D. Letter from Euroqol (dated 1 May 2020) testifying to the Eq5D5L BSL being the first version of their instrument for clinical (and research) practice to be available in any signed language internationally. They have also tweeted and promoted this achievement and its significance: https://euroqol.org/first-euroqol-approved-sign-language-version-of-the-eq-5d-5l-is-now-available/.

E. Royal College of Psychiatry Guidance for Commissioners of Primary Mental Health Care Services for Deaf People, which cites SORD's evidence of the cost effectiveness of direct IAPT provision through Deaf signing therapists.

F. Letter from Translation and Interpreting lead for NHS England (dated 28 February 2020) outlining the direct involvement of SORD in the creation of the guidance and the breadth of the NHS-led dissemination of the guidance.

G. Freedom of information request response from NHS England showing 2,589 downloads in 17 months (over 150 per month) up to January 2020.

H. Letter from the Executive Director of Alzheimer's Europe (dated 17 September 2020) detailing the impact of our work on recognition of the needs of this services group and inspiring new innovations in care.

I. Letter from the British Deaf Association Scotland (dated 2 June 2020) outlining the influence of our research work on the successful funding bid for the development of their services for people with dementia in Scotland.

J. Email from the Digital Editor of the British Sign Language Broadcasting Trust (dated 13 January 2021) confirming that the live stream programme in BSL reached 8,064 people judged by appearances in their Facebook timelines. There were 2,070 engagements. Since uploading to the broadcaster's website it has received 1,100 views since April 2020.