



## Supplementary materials: the Health of Deaf people

Organisation:

University of Manchester

SORD (**S**ocial **R**esearch with **D**eaf people)

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## The SORD research group

<https://sites.manchester.ac.uk/sord>

SORD (**S**ocial **R**esearch with **D**eaf people) is a formal research group within the Division of Nursing Midwifery and Social Work (School of Health Sciences), University of Manchester. We work with the Deaf community and other stakeholders to promote the wellbeing of d/Deaf<sup>1</sup> individuals, families and communities across the life course through high quality, multi-disciplinary applied social research.

As a team of Deaf and hearing researchers, we are committed to creating partnerships that acknowledge and value d/Deaf people's experiences, inform service providers and policy makers, and build bridges between all stakeholders to promote the quality of life and citizenship rights of d/Deaf peoples.

Spanning the lifecourse, our work addresses health inequalities, the impacts of minoritisation, evidence-based service provision and practice with d/Deaf people, the contribution of d/Deaf people to wider society and the richness of Deaf language and culture.

Although we have a specialist focus on signed language and Deaf communities, much of our work contributes to and is relevant to other language groups, processes of marginalisation, social exclusion and best practices in the delivery of health and social care.

We are a sign-bilingual research group comprising of Deaf and hearing people with researchers drawn from a range of professional and academic backgrounds. SORD team members comprise early career interns through to post-doctoral career academics, both Deaf and hearing. We regularly work in partnership across academic disciplines and very closely with service providers in the field and with d/Deaf organisations within the UK and internationally. We are acknowledged as a world class applied social research group in this specialist field.

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<sup>1</sup> We acknowledge that the distinction and terminology between deaf and Deaf is increasingly a contested one. However, we retain the capitalised D to refer to sign language users as distinct from those who would not regard themselves/be regarded as culturally Deaf to clearly differentiate sign language users from the broader issues of those with hearing loss/deafness. We generally refer to children as 'deaf' regardless of language use unless from a Deaf family whereby cultural identity has been established. We are not suggesting that Deaf people are not flexible in their language use by context and interlocutor nor are we ignoring intersectional affiliations that may apply for some individuals and communities.

## **SORD's approach to research in health concerning Deaf people**

A range of the research work of SORD, demonstrates health inequalities experienced by Deaf people, including evidence of disparities in health outcomes in comparison with the general population, specific barriers to access to health services at all stages of the patient journey, systemic inadequacies in the structure and delivery of health services experienced by Deaf people. Our work encompasses not just evidence of the problem but also potential solutions with clear indicators of what might assist in working towards improvements of experience and outcomes for Deaf people. Working from within an understanding of BSL as fundamental to cultural identity, not just diversity of language use, we have traced how services fail to fully account for the language and culture of Deaf people whether in terms of access to services, assessment, under/over diagnosis, equity of treatment options and recording of need/unmet need within the current system. We use 'health' to encompass mental health following the WHO position that there is no health without mental health and consider how issues of rights and marginalisation faced by Deaf people contributes to the poor outcomes experienced. Our work takes a life-span perspective including the health/mental health of children and young people, adults and older people. It is also grounded in notions of intersecting inequalities faced by the diversity of Deaf people and have striven to unpack available data and patient experience to expose this aspect of complexity in understanding inequalities in health faced by Deaf people as it is an area of concern that has been regularly overlooked in research. SORD's research in health is further characterised by our extensive patient and public involvement of Deaf people in research work across all of our studies for which we have won national recognition. All research studies carried out have encompassed teams of Deaf and hearing people working together and in close co-operation with major Deaf organisations who have supported us.

In what follows we demonstrate some of these wider themes within the specifics of our research work and publication outputs including specific practice guidance where we have created these in partnership with deaf organisations and professionals in the field. *[This supplementary material has been edited to ensure a health work focus. It should be read alongside the supplementary materials produced by SORD*

*with respect to social care. Other work by SORD that focusses largely on education and research methodology has been excluded from both documents but is available on our website (<https://sites.manchester.ac.uk/sord>)].*

## Evidence concerning health outcomes

Although internationally there is growing evidence of disparities in morbidity and mortality experienced by Deaf people, the quality of available evidence is a concern. Studies are small, country specific, health condition specific and often with little information about the form of intervention and/or comparative samples used. We seek in our work to ensure that the highest standards of evidence are used to ensure that we can move beyond generalisations about Deaf patients to more targeted and personalised evidence about specific conditions, systems, interventions and outcomes.

<b>Inequalities in health outcomes across lifespan</b>	
<p>Systematic review on health outcomes in Deaf signing populations have been carried out and it was identified that the evidence is lacking. From the available evidence, following the International Classification of Diseases-11 (ICD-11) with respect to health conditions, majority (71%) concerned mental health outcomes. The findings from the studies that looked at a comparison with the general population, including hearing populations, were that Deaf people experienced significantly poorer health and mental health outcomes.</p>	<p>Rogers, KD., Rowlandson, A., Harkness, J., Shields, G., &amp; Young, A. (2024). Health outcomes in Deaf signing populations: a systematic review. PLOS ONE 19(4): e0298479  <a href="https://doi.org/10.1371/journal.pone.0298479">https://doi.org/10.1371/journal.pone.0298479</a></p>
<p>We examined the effectiveness of the national IAPT service (Improving Access to Psychological Therapies) for Deaf signers comparing mainstream access through an interpreter with direct access through a Deaf therapist. 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. This study has highlighted difficulties in obtaining data about Deaf BSL users within secondary datasets from mainstream IAPT services, which has resulted in a lower number of available data about Deaf BSL users.</p>	<p>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: <a href="https://doi.org/10.3310/hsdr05240">10.3310/hsdr05240</a></p> <p>A BSL version of this summary is available at this link: <a href="#">Scientific summary in BSL</a></p>
<p>The study on the positive mental well-being assessment in BSL, highlighted that Deaf peoples' wellbeing is poorer in comparison to the general population. Deaf people who are in employment have better mental well-being scores than those who are not.</p>	<p>Rogers, K., Dodds, C., Campbell, M., &amp; Young, A. (2018). The validation of the Short Warwick-Edinburgh Mental Well-Being Scale (SWEMWBS) with Deaf British sign language users in the UK. Health and Quality of Life Outcomes, 16(1):145. doi: <a href="https://doi.org/10.1186/s12955-018-0976-x">0.1186/s12955-018-0976-x</a></p>

<p>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.</p>	<p>Shields, G., Rogers, K., Young, A., Dedotsi, S., &amp; Davies, L. (2020). Health state values of deaf British sign language (BSL) users in the UK: an application of the BSL version of the EQ-5D-5L. <i>Applied health economics and health policy</i>. 8(4):547-556. doi: <a href="https://doi.org/10.1007/s40258-019-00546-8">10.1007/s40258-019-00546-8</a></p>
<p>At the time of the literature review on the longitudinal studies regarding mental health and deaf children, whether be it prospective or retrospective, showed a lack in evidence as several longitudinal studies involving deaf children concerned the medical aspect of the ear.</p> <p>The findings from the READY study (a prospective longitudinal study) have highlighted that the majority of deaf young people use spoken language, yet their well-being score and health status were significantly lower compared to their hearing counterpart populations.</p>	<p>Rogers, K. D., &amp; Young, A. (2012). Is there an association between deaf children’s mental health difficulties and their adult well-being? The state of the evidence. In Working with the Deaf community Intersource Group (Ireland) Limited.</p> <p>Young, A., Espinoza, F., Dodds, C., Squires, G., Rogers, K., Chilton, H., &amp; O’Neill, R. (2023). Introducing the READY study: DHH young people’s well-being and self-determination. <i>The Journal of Deaf Studies and Deaf Education</i> , 28(3), 267-279. doi: <a href="https://doi.org/10.1093/deafed/enad002">10.1093/deafed/enad002</a>                  URL link BSL summary: <a href="#">Final summary report</a></p>
<p>In partnership with the New Economics Foundation (NEF), commissioned by SignHealth, we produced the first ever model of inequality for deaf people. It was built from literature reviews on inequalities and various aspects of deaf people’s lives, interviews with deaf citizens and key people from deaf organisations across the UK.</p>	<p><a href="https://signhealth.org.uk/campaign/launching-deaf-together/">https://signhealth.org.uk/campaign/launching-deaf-together/</a></p>

## Type and effects of barriers to health services

We have carried out research studies that in different ways demonstrate a range of barriers to effective health services faced by Deaf people and the impact on patients. These encompass:

- i. inaccessible information in BSL whether to support health literacy amongst Deaf people, the self-management of conditions, patient participation in intervention and recovery, or the exercise of choice in patient health decision making.
- ii. systemically, we have highlighted the problems of realising patient-centred outcomes for Deaf people because of a lack of knowledge and understanding of health service providers as well as problems in how health data are recorded in the UK which consistently fails to separate out culturally Deaf BSL users from more general categories of ‘deaf’ people.
- iii. complexities of interpreter-mediated access to diagnosis and treatment.

<b>Barriers to health services</b>	
<p>Research project funded by Alzheimer’s society with several partners including DCAL, City University London and RAD. The findings at the time highlighted that the lack of accessible information and resources in BSL about dementia but also extended this to explore the cultural preferences for the development of knowledge and understanding about dementia. Just because information is in BSL does not mean it is effective for users of that information. This work led also to the development of factsheets and guidance for professionals working with Deaf people and was taken up by Deaf organisations who started to produce accessible information in BSL</p>	<p>Ferguson-Coleman, E., Keady, J., &amp; Young, A. (2014). Dementia and the Deaf community: Knowledge and service access. <i>Aging and Mental Health</i>, 18(6), 674-682. doi: <a href="https://doi.org/10.1080/13607863.2014.880405">10.1080/13607863.2014.880405</a></p> <p>Young, A., Ferguson-Coleman, E., &amp; Keady, J. (2014). Understanding dementia: effective information access from the Deaf community's perspective. <i>Health and Social Care in the Community</i>, 24(1), 39-47. doi: <a href="https://doi.org/10.1111/hsc.12181">10.1111/hsc.12181</a></p> <p>Young, A. &amp; Ferguson-Coleman, E. (2015). Deafness and dementia – a fact sheet. Pennine Care NHS Trust</p>
<p>We have highlighted the challenges of realising patient-centred outcomes for Deaf people who use sign language. For example, Deaf people have often been excluded from the recognition of having a cultural linguistic identity in health care systems, and not been supported in making health related choices in their live because of the lack of awareness from healthcare professionals. We have outlined the key principles for considering better promotion of patient-centred outcomes for Deaf people in the paper.</p> <p>Our major study of IAPT services for Deaf people became the evidence base for the further development and funding of the current SignHealth Psychological Therapy Service, demonstrated the problems arising from failure to adequately categorise Deaf people as BSL users distinct from those with a hearing loss, leading to the lack of accurate data on patient-demand and treatment.</p>	<p>Rogers, K., Ferguson-Coleman, E., &amp; Young, A. (2018). Challenges of Realising Patient-Centred Outcomes for Deaf Patients. <i>The Patient</i>, 9-16. Article 11. doi: <a href="https://doi.org/10.1007/s40271-017-0260-x">10.1007/s40271-017-0260-x</a></p> <p>Young A, Rogers K, Davies L, Pilling M, Lovell K, Pilling S, et al. Evaluating the effectiveness and cost-effectiveness of British Sign Language Improving Access to Psychological Therapies: an exploratory study. <i>Health Serv Deliv Res</i> 2017;5(24). See Chapter 5: Mixed-methods modelling of BSL-IAPT and standard IAPT as accessed by Deaf people (study 3). Available link: <a href="#">Chapter 5</a></p>
<p>We explored the challenges faced by Deaf people when accessing audiology services. Results showed significant barriers stemming from a lack of recognition and appreciation for BSL as a language and for the Deaf person. Service provision demonstrated lack of Deaf awareness among audiology staff, with limited support for BSL access (contacting the clinic and appointments). The onus was always on the Deaf person to communicate with the clinic not the other way round and there were</p>	<p>Hulme, C., Young, A &amp; Munro KJ (2022) Exploring the lived experiences of British Sign Language (BSL) users who access NHS adult hearing aid clinics: an interpretative phenomenological analysis. <i>International Journal of Audiology</i>, 61:9, 744-751. doi: <a href="https://doi.org/10.1080/14992027.2021.1963857">10.1080/14992027.2021.1963857</a></p>



<p>reports of lack of autonomy resulting from the lack of access and being able to communicate in BSL. This is compounded by lack of cultural competency in service design and audiology staff. The insights from this study contributed to the development of a cultural competency model tailored for hearing aid clinics.</p>	
<p>The experiences of patients in interpreter-mediated primary care settings have demonstrated deaf signers' perceptions of adverse effects on health decision making and unreliability of health services' with BSL interpreter provision. We co-wrote the NHS England commissioning guidance on translation and interpreting in primary care.</p> <p>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 demonstrating primary negative impacts on confidence and secure sense of self.</p> <p>The impact of interpreter mediated assessments and outcomes under the Mental Health Act has been a recent major research project, encompassing both spoken and signed language interpreters in their work with AMHPs. [this is fully documented in the accompanying supplementary guidance on social care]</p>	<p>NHS England. (2018). Guidance for commissioners: Interpreting and Translation Services in Primary Care. Available link: <a href="#">Guidance for commissioners</a></p> <p>Young A, Rogers K, Davies L, et al. Evaluating the effectiveness and cost-effectiveness of British Sign Language Improving Access to Psychological Therapies: an exploratory study. Health Serv Deliv Res 2017;5(24). See Chapter 5: Mixed-methods modelling of BSL-IAPT and standard IAPT as accessed by Deaf people (study 3). Available link: <a href="#">Chapter 5</a></p> <p>Young, A., Napier, J., Oram, R. "The Translated Deaf Self, Ontological (In)security and Deaf Culture." The Translator 2020; 25:4, 349-368. doi: <a href="https://doi.org/10.1080/13556509.2020.1734165">10.1080/13556509.2020.1734165</a></p> <p>Ferguson-Coleman, E. and Young, A. (2023), "'What have YOU done in the past few years?'" Deaf BSL users' experiences of caring for people with dementia during COVID-19", Quality in Ageing and Older Adults, 24(4), 139-150. doi: <a href="https://doi.org/10.1108/QAOA-07-2023-0048">10.1108/QAOA-07-2023-0048</a></p> <p>Young, A., Tipton, R., Rodriguez-Vicente (2023). Mind your language. Interpreters in Mental Health Act assessments. Policy@Manchester. Access via this <a href="#">link</a>.</p> <p>Young, A., Vicary, S., Tipton, R., Rodriguez Vicente, N., Napier, J., Hulme, C., Espinoza, F. (2023). Survey of AMHP perspective on interpreter mediated Mental Health Act assessments. Journal of Social Work. doi: <a href="https://doi.org/10.1177/14680173231197">10.1177/14680173231197</a></p> <p>Rodriguez Vicente, N., Young, A., Tipton, R., Napier, J., Vicary, S., Hulme, C. (under review 2024) A Scoping Review of interpreter-mediated assessments under the Mental Health Act (1983) and international equivalents. Interpreting and Society.</p>

## Improvements in aspects of health services for Deaf people

Our research work has underpinned some key improvements in aspects of health services for Deaf people encompassing changes in how Deaf people are assessed, adaptations in interventions and changes in the structures of services to meet Deaf people’s needs.

<p><b>Lack of standardised assessments that have been normed on Deaf populations nor have translations been made available in BSL and been investigated for their validity and reliability. We have addressed this particularly with respect to common mental health problems and health status.</b></p>	
<p>We have identified the main challenges when translating/adapting the standardised instrument into sign language to ensure key concepts were culturally equivalent. This included: translating between modalities (written text to a visual language); the influence of an on-screen format; expression of pre-vious emotional states in sign language; problems associated with iconic signs.</p>	<p>Rogers, K. D., Young, A., Lovell, K., &amp; Evans, C. (2013). The challenges of translating the clinical outcomes in routine evaluation-outcome measure (CORE-OM) into British Sign Language. <i>Journal of Deaf Studies and Deaf Education</i>, 18(3), 287-298. doi: <a href="https://doi.org/10.1093/deafed/ent002">10.1093/deafed/ent002</a></p>
<p>Previously, the standardised outcome measures that are part of the minimum data set collected by the NHS Talking therapy services were not available in BSL, therefore Deaf people were missing out. Following the work on the adaptation of the three standardised assessments (one measure for depression, one for anxiety, and one for the functioning of the person), we produced validated assessments in BSL which are now available and used within the NHS. Secondly, we have established the clinical cut-offs for the BSL versions of PHQ-9 BSL and GAD-7 BSL using two datasets (one from a specialist IAPT service for Deaf people (n=502), and one from a previous study), which were found to be lower than that for the general population. Applying the new clinical cut-offs, the percentage of Deaf BSL IAPT service users showing reliable recovery is 54.0 % compared to 63.7 % using the cut-off scores used for English speaking hearing people. The correct clinical cut-offs for the PHQ-9 BSL and GAD-7 BSL enable meaningful measures of clinical effectiveness and facilitate appropriate access to treatment when required. The resources and the guide for using the PHQ-9 BSL and GAD-7 BSL are available on the SORD resources webpage.</p>	<p>Rogers, K. D., Young, A., Lovell, K., Campbell, M., Scott, P. R., &amp; Kendal, S. (2013). The British sign language versions of the patient health questionnaire, the generalized anxiety disorder 7-item scale, and the work and social adjustment scale. <i>Journal of Deaf Studies and Deaf Education</i>, 18(1), 110-122. doi: <a href="https://doi.org/10.1093/deafed/ens040">10.1093/deafed/ens040</a></p> <p>Belk, R., Pilling, M., Rogers, K., Lovell, K., &amp; Young, A. (2016). The theoretical and practical determination of clinical cut-offs for the British Sign Language versions of PHQ-9 and GAD-7. <i>BMC Psychiatry</i>, 16, Article 372. doi: <a href="https://doi.org/10.1186/s12888-016-1078-0">10.1186/s12888-016-1078-0</a></p> <p>BSL version reporting the clinical cut-offs is available at this link: <a href="#">Clinical cut-offs for the BSL versions of the PHQ-9 BSL and GAD-7 BSL</a></p> <p>Rogers, K. (2017, Sept 21). <a href="#">Guide to PHQ-9 BSL and GAD-7 BSL</a>.</p> <p><a href="#">BSL video on guidelines to using PHQ-9 BSL and GAD-7 BSL</a></p>

<p>We have produced a translated BSL version of the EQ-5D-5L (which measures health status). This is the first time EQ-5D-5L has been translated into a signed language internationally for use with Deaf people and is a significant step forward towards conducting studies of health status and cost-effectiveness in this population.</p> <p>This study has highlighted that nearly 9% of Deaf participants stated that they did not know if they had health difficulties, possibly indicating a lack of understanding of what is considered as 'health'. This could be due to poor access to health-related information generally as there is so little available in BSL. The EQ-5D-5L BSL is available from EuroQol.</p>	<p>Rogers, K., Pilling, M., Davies, L., Belk, R., Nassimi-Green, C., &amp; Young, A. (2016). Translation, validity and reliability of the British Sign Language (BSL) version of the EQ-5D-5L. <i>Quality of Life Research</i>, 25(7), 1825-1834. doi: <a href="https://doi.org/10.1007/s11136-016-1235-4">10.1007/s11136-016-1235-4</a></p> <p>Please see this link for explanation notes on how to obtain the <a href="#">EQ-5D-5L BSL</a>.</p>
<p>Due to the lack in validated measures of positive mental well-being in BSL, this led to the adaptation and standardisation of the SWEMWBS into BSL, along with the established validation and reliabilities.</p> <p>Instruction on how to obtain the SWEMWBS BSL, including the guidelines in BSL and English are available on the SORD resources webpage.</p>	<p>Rogers, K., Dodds, C., Campbell, M., &amp; Young, A. (2018). The validation of the Short Warwick-Edinburgh Mental Well-Being Scale (SWEMWBS) with Deaf British sign language users in the UK. <i>Health and Quality of Life Outcomes</i>, 16(1):145. doi: <a href="https://doi.org/0.1186/s12955-018-0976-x">0.1186/s12955-018-0976-x</a></p> <p><a href="#">SWEMWBS BSL resource page</a></p> <p><a href="#">BSL video on the guidelines for the use of SWEMWBS BSL</a></p>
<p>At the time of this study, little was known about the reliability and validity of mental health assessments that have been through a rigorous translation process into BSL. The findings from the psychometric properties of the CORE-OM BSL were found to be good, and showed that it is feasible to collect data from the Deaf population remotely.</p> <p>The resource and a guide on how to use and score the CORE-OM BSL is available on the SORD resources webpage.</p>	<p>Rogers, K., Evans, C., Campbell, M., Young, A., Lovell, K. (2013). The reliability of British Sign Language and English versions of the Clinical Outcomes in Routine Evaluation – Outcome Measure with d/Deaf populations in the UK: an initial study. <i>Health and Social Care in the Community</i>, 22 (3), 278-289, doi: <a href="https://doi.org/10.1111/hsc.12078">10.1111/hsc.12078</a>.</p> <p>Resource and guide for using CORE-OM BSL is available at this <a href="#">link</a>.</p>
<p>We collaborated with Deaf CAMHS to produce the BSL version of the Strengths and Difficulties Questionnaire for deaf children and young people.</p>	<p>Roberts S, Wright B, Moore K, Smith J, Allgar V, Tennant A, Doherty C, Hughes E, Moore DC, Ogden R, Phillips H, Beese L, Rogers K. Translation into British Sign Language and validation of the Strengths and Difficulties Questionnaire. Southampton (UK): NIHR Journals Library; 2015 Feb. doi: <a href="https://doi.org/10.3310/hsdr03020">10.3310/hsdr03020</a></p>

<b>Studies of interventions and service improvements for Deaf people</b>	
<p>With the shortage of specialist services for Deaf people, telemedicine intervention (i.e. the use of videoconferencing) may potentially offer assessable solutions for addressing a range of health-related matters for Deaf people. However, the findings from the systematic review, highlighted only two studies that met the criteria for inclusion in the review, that examined telemedicine intervention with signing Deaf communities. Both papers concerned mental health interventions, identified the gaps in knowledge relating to the efficacy and effectiveness of telemedicine interventions in comparison to face-to-face interventions.</p>	<p>Rogers, K., Lovell, K., &amp; Young, A. (2023). What is the efficacy and effectiveness of telemedicine intervention for deaf signing populations in comparison to face-to-face interventions? A systematic review. BMC Health Services Research, 23(1), Article 678. doi: <a href="https://doi.org/10.1186/s12913-023-09509-1">10.1186/s12913-023-09509-1</a></p>
<p>The Joint Commissioning Panel for Mental Health (Royal College of Psychiatry) published a set of guidelines for commissioners. This one refers to services for deaf adults who use BSL. We were co-opted onto the expert reference group, and co-wrote sections of the guidelines. The guidelines reference the BSL IAPT research study and its findings directly in several places as part of the evidence base for commissioning.</p>	<p>RCP (2017) Guidance for commissioners of primary mental health services for deaf people. Available at: <a href="https://www.jcpmh.info/resource/guidance-commissioners-primary-care-mental-health-services-deaf-people/">https://www.jcpmh.info/resource/guidance-commissioners-primary-care-mental-health-services-deaf-people/</a></p>
<p>We worked with British Deaf Association (Northern Ireland) and Alzheimer’s Society (Northern Ireland) to develop a pilot Deaf people with dementia advocacy service. We asked Deaf carers and Deaf community members in Northern Ireland to share their experiences of supporting Deaf people with dementia.</p>	<p>Ferguson-Coleman E, Johnston A, Young A, Brown F, de Sainte Croix R, Redfern P. How do we know what we don’t know? Exploring Deaf people’s experiences of supporting their Deaf family member living with dementia. Dementia. 2020;19(5):1381-1396. doi:<a href="https://doi.org/10.1177/1471301218798993">10.1177/1471301218798993</a></p>
<p>A culturally competent framework for hearing aid clinics was formulated through a synthesis of studies exploring Deaf people’s experiences with audiology services, coupled with in-depth case studies focusing on two hearing aid clinics. These case studies entailed a comprehensive exploration of the clinics, encompassing examination of policies and guidance, service design, as well as staff knowledge and experience of dealing with BSL users. The resulting cultural competency model was conceived from a whole service perspective, encompassing structural, organisational and interpersonal elements. This model delineates specific</p>	<p>Hulme, C., Young, A., Rogers, K. et al. Cultural competence in NHS hearing aid clinics: a mixed-methods case study of services for Deaf British sign language users in the UK. BMC Health Serv Res 23, 1440 (2023). doi: <a href="https://doi.org/10.1186/s12913-023-10339-4">10.1186/s12913-023-10339-4</a></p>

<p>areas that require attention within each domain and can be adaptable for implementation across various health service providers.</p>	
<p>We contributed to the development of the Good Work Framework for healthcare professionals working with Deaf people with dementia with Social Care Wales. This is the first published guidelines for supporting front-line staff in working with Deaf people with dementia within healthcare.</p>	<p>Social Care Wales. (2022). Good Work framework working with people living with dementia who have hearing loss, or use British Sign Language. Available at: <a href="#">Good Work framework</a></p>
<p>We are currently evaluating the Self-Help UK Deaf Cancer Support project funded by Macmillan. This is an intervention that is specifically for Deaf people living with cancer and their carers.</p>	<p><a href="https://sites.manchester.ac.uk/deaf-cancer-support-evaluation/">https://sites.manchester.ac.uk/deaf-cancer-support-evaluation/</a> <a href="https://deafcancersupport.org.uk/evaluation/">https://deafcancersupport.org.uk/evaluation/</a></p>
<p>As part of the Diagnostic Instruments for Autism in Deaf Children (DIADS) project, funded by MRC, we interviewed parents, throughout the UK, who were either Deaf or hearing, who had children, who were both Deaf and hearing with autism. We explored their perspectives of their child's development milestones and how these were understood by health professionals involved in their child's care.</p>	<p>Young, A., Ferguson-Coleman, E., Wright, B., LeCouteur, A. (2019). "How do parents conceptualize the relationship between autism and deafness?" Journal of Deaf Studies and Deaf Education, 24(3) 280-288. doi: <a href="https://doi.org/10.1093/deafed/enz002">10.1093/deafed/enz002</a></p> <p>Hodkinson, R., Phillips, H., Allgar V., Young, A., Le Couteur, A., Holwell, A., Teige, C., Wright, B. (2023). Comparison Of Diagnostic Profiles Of Deaf and Hearing Children With A Diagnosis Of Autism. International Journal of Environmental Research and Public Health. Special Issue Child Mental Health in a Modern World. <a href="https://www.mdpi.com/1660-4601/20/3/2143/pdf">https://www.mdpi.com/1660-4601/20/3/2143/pdf</a></p>

<p><b>Deaf people being excluded from health-related research</b></p>	
<p>Deaf people have traditionally been excluded from clinical trial studies. We co-produced alongside Deaf people, appropriate terminology in BSL for key concepts used in clinical trials that are relevant to recruitment and participant information materials. These materials are available in the NIHR journal library.</p>	<p>Young, A., Oram, R., Dodds, C., Nassimi-Green, C., Belk, R., Rogers, K., Davies, L., &amp; Lovell, K. (2016). A qualitative exploration of trial-related terminology in a study involving Deaf British Sign Language users. Trials, 17, Article 219. doi: <a href="https://doi.org/10.1186/s13063-016-1349-6">10.1186/s13063-016-1349-6</a></p> <p>URL link for <a href="#">BSL trials related materials</a></p>

<p><b>Deaf patient and public involvement in health services research</b></p>	
<p>In recent years there has been movement towards fostering patient and public involvement and engagement (PPIE) in research, distinct from just participating in research activities such as interviews or surveys. PPIE is about empowering the public to have influence on research outcomes. This includes</p>	<p><a href="https://www.rdsresources.org.uk/public-involvement">https://www.rdsresources.org.uk/public-involvement</a></p> <p><a href="https://wearevocal.org/opportunities/deaf-experts-by-experience-group/">https://wearevocal.org/opportunities/deaf-experts-by-experience-group/</a></p>

<p>shaping research questions, designing studies, ensuring appropriateness of recruitment and data collection materials for the target demographic, recruitment practices, analysing findings and participating in project dissemination. However, despite the growing recognition of PPIE, Deaf people have faced barriers to learning and accessing courses relating to PPIE. This has meant that BSL users are underrepresented on PPIE panels. Recognising this disparity, SORD took proactive steps to address the issue by offering an intensive training course focusing on equipping Deaf people with skills and knowledge needed to become effective PPIE members. This training initiative garnered significant interest and received attention from deaf organisations and service providers. This success of SORD's initiative caught the attention of the NIHR which recognised it as a valuable case study. NIHR subsequently incorporated this practice into their EDI Toolkit as an exemplar of best practice. There remains a need for further expansion of this training programme to ensure broader participation of Deaf people in PPIE panels.</p>	
<p>We have consulted with Deaf people about their view on the importance of involving Deaf people in PPI work.</p>	<p><a href="#">BSL video on the importance of involving Deaf people in PPI work</a></p>