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Selby, A., Sutton, A., Bamford, E. et al. (2026) Factors and mitigating strategies impacting receipt of healthcare by the Deaf community: an umbrella review. BMC Health Services Research, 26. 703. ISSN: 1472-6963

<https://doi.org/10.1186/s12913-026-14444-y>

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SYSTEMATIC REVIEW

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Factors and mitigating strategies impacting receipt of healthcare by the Deaf community: an umbrella review

Anna Selby^{1*}, Anthea Sutton², Emma Bamford¹ and Andrew Booth²

Abstract

Background Despite over 70 million Deaf people using sign languages worldwide, their ability to access and receive health services remains disproportionately limited. The Deaf community commonly encounter reduced access to preventive care compared to the hearing population. This umbrella review aims to collate and appraise systematic reviews examining factors and mitigating strategies influencing Deaf people's receipt of healthcare.

Methods The protocol was registered in PROSPERO (CRD42024563083). Eligible systematic reviews investigated factors affecting healthcare receipt among the Deaf communities in any Organisation for Economic Co-operation and Development (OECD) country. Databases searched included MEDLINE, Embase, Cochrane Database of Systematic Reviews, CINAHL, PsycINFO, Science Citation Index, Social Sciences Citation Index, and PROSPERO. Screening, data extraction, and quality appraisal (AMSTAR 2) were undertaken independently by reviewers, with disagreements resolved by consensus. Data were synthesised narratively using a purpose-specific conceptual framework, categorising factors as individual or environmental.

Results From 3,749 records, 32 systematic reviews were included. Most reviews (78%) were rated critically low in quality. Individual-level barriers were dominated by reduced health literacy (reported in 26 reviews), including inadequate access to sign language health information, limited family awareness, and poorer knowledge of medicines and preventive practices. Socioeconomic status, rural residence, minority ethnic background and limited family support were also linked to reduced healthcare access. Environmental factors included communication barriers, low Deaf awareness among healthcare professionals and shortages of qualified interpreters, all of which fostered Deaf people's mistrust and disengagement with healthcare. Inadequate recording of communication needs, inaccessible complaints processes and COVID-19 policies further exacerbated inequalities. Strategies identified included sign language-adapted health education, interpreter provision, telehealth services, and specialist Deaf health clinics with interpreters, however few reviews offered evidence for effectiveness.

Conclusions Deaf people experience persistent, multifactorial barriers to equitable healthcare, driven by low health literacy, social disadvantage, poor communication support and systemic failings. Current evidence is largely of low methodological quality, underscoring the need for robust, co-produced research with Deaf communities. Priority

*Correspondence:
Anna Selby
anna.selby@nhs.net

Full list of author information is available at the end of the article



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areas include redesigning healthcare processes for accessible communication, expanding interpreter provision, and embedding Deaf awareness training into professional education to achieve systemic change.

Keywords Deaf, Sign language, Healthcare, Health inequality

Introduction

Over 70 million people are Deaf and use sign languages worldwide [1]. However, systematic review and meta analysis shows that Deaf people have poorer health than the general population, with an increased all-cause and cardiovascular mortality rate [2]. Deaf people experience health inequalities in all seven non communicable diseases (ischaemic heart disease, stroke, chronic obstructive pulmonary disease, lung cancer, dementia, diabetes and kidney diseases) that are the leading cause of death globally [3].

Deaf people have a higher prevalence of obesity, heart disease and diabetes and are more likely to receive a late stage cancer diagnosis [4, 5]. Evidence from review literature shows consistent patterns of disadvantage across multiple areas of healthcare. The review literature demonstrates similar patterns across multiple aspects of healthcare: a systematic review of cancer screening found that disability including deafness is associated with reduced odds of attendance [6]. Similarly, a systematic review of antenatal care reported that Deaf pregnant women receive fewer antenatal visits than hearing pregnant women, are more likely to have extended hospitalisation after delivery and have a modestly increased risk of undergoing a caesarean delivery [7]. A systematic review of pain assessment and communication in Deaf people reported a lack of validated pain assessments in this population and concluded that ‘individuals with Deafness still represent a neglected population’ [8]. In addition, a scoping review of oral health showed that Deaf adults and children experience a lower rate of toothbrushing and a higher rate of tooth decay compared to their hearing peers [9]. Mental health disparities were also evident, with the Deaf community presents with a higher prevalence of anxiety and depression [10, 11].

Multiple factors contribute to health inequality experienced by Deaf people. A conceptual model of deaf inequalities summarises the literature into 4 themes: vicious cycle between deafness and socioeconomic inequalities, socioeconomic position may interact with less healthy lifestyles, increasing health literacy could improve outcomes and that Deaf people are vulnerable to receiving low quality and less safe healthcare [12].

The aim of this umbrella review was to synthesise the evidence from published systematic reviews on the factors that contribute to the receipt of healthcare for the Deaf community in order to inform future research priorities.

The objectives were to identify, appraise and synthesise systematic reviews:

- 1) To determine factors that influence the receipt of healthcare services for Deaf people.
- 2) To identify mitigating strategies that influence the receipt of healthcare services for Deaf people.
- 3) To compare results with a research prioritisation exercise conducted with the Deaf community [13].

Methods

This review was funded as part of a NIHR Programme Development grant (NIHR207088). Ethics and Consent to Participate declaration: not applicable.

The grant also funded a research prioritisation exercise. In summary, Research Prioritisation by Affected Community methodology was adapted for the Deaf population [13]. Forty-three Deaf BSL users shared their experiences of healthcare receipt across seven NHS services. Statements were extracted from the focus groups and categorised using a conceptual framework for understanding healthcare disparities in disability [14]. These were then refined into nine research themes. A further round of focus groups was conducted to prioritise the nine themes [13].

This umbrella review was conducted following Cochrane Handbook Chapter V and PRIOR reporting guideline [15, 16].

Eligibility criteria

The Umbrella review protocol was published on the prospective register of systematic reviews (PROSPERO) CRD42024563083 on 1st October 2024.

Eligibility criteria were established prior to the initiation of searches. Reviews were considered eligible if they met all of the following criteria: Condition or domain being studied: Receipt of healthcare; Population: Deaf populations, Intervention: Factors influencing healthcare receipt, Context: Studies conducted in any healthcare setting in Organisation for Economic Co-operation and Development (OECD) countries. Reviews were included if the majority of included studies were based in OECD countries.

Data sources and search strategy

Searches of MEDLINE, Embase, Cochrane Database of Systematic Reviews, CINAHL, PsycINFO, Science Citation Index and Social Sciences Citation Index and

PROSPERO Systematic Reviews Register (for ongoing reviews) were conducted to identify published reviews.

No publication date or language restrictions were applied to the searches.

Search terms included free-text and thesaurus terms (where available) relating to the population (deaf/hearing impaired/hearing loss) and healthcare access. Population and service access terms were combined using Boolean operators. In summary, the search terms encompassed Deaf, healthcare factors and systematic reviews. Searches were conducted on 16th August 2024. The full search terms are provided in supplementary document 1.

Study selection

Titles and abstracts were screened against the eligibility criteria and full-text articles were obtained for all titles that met the inclusion criteria or those demonstrating uncertainty around eligibility. Eligibility criteria were agreed by all reviewers in conjunction with public contributor advice before screening and was piloted on 100 titles prior to full screening. A second reviewer independently screened 20% of all titles and abstracts and 20% of included full texts. Any discrepancies were resolved by discussion and a consensus was reached. Where consensus could not be reached, a third author arbitrated. All review types were included, providing there was evidence of systematic methodology. Reviews had to meet a minimum description of a systematic process for study identification including more than one database searched and clear inclusion/exclusion criteria.

Data extraction

A data extraction table was developed during the review process and piloted and refined prior to full data extraction. Data extraction focused on the factors identified as influencing patients' receipt of healthcare. These data were collected and categorised according to a conceptual model understanding healthcare disparities experienced by individuals with disabilities [14]. This model combined earlier models of healthcare quality and access onto models of disability to develop the Model of Healthcare Disparities and Disability. Deductive categorisation was carried out independently by two reviewers and any discrepancies were resolved by a third reviewer.

Risk of bias assessment

Methodological quality was assessed for each included study using the AMSTAR 2 tool with reviews categorised as high, moderate, low, or critically low quality [17]. Publication bias assessment was not completed for this review.

Synthesis methods

Synthesis was conducted according to Cochrane Handbook Chapter V, with synthesis across reviews rather than each review narrated individually [15]. Primary studies within included reviews have not been cited.

As the data extracted was narrative or qualitative, statistical pooling and meta-analysis was not appropriate. Synthesis of the findings was undertaken using a narrative approach. Overlap between the papers included in each systematic review was assessed. A conceptual framework for understanding healthcare disparities experienced by individuals with disabilities was used to categorise the data extracted [14]. Factors were categorised as either individual (patient) level factors or environmental (systemic) factors. Individual factors were then subdivided into social and cultural factors, particularly health literacy and social situation. Environmental factors were subdivided into support and relationships, products and technology and health delivery systems. This aligned with the conceptual model.

Public contributors with lived experience of Deafness advised the review team on study inclusion and exclusion criteria, particularly the exclusion of papers that included Deafblind people, as they are a distinct group with different healthcare access needs. Public contributors also reviewed the conceptual model and confirmed its suitability.

Results

Literature searches identified 3205 potential articles. Screening of title and abstracts against the eligibility criteria removed 3157, resulting in 48 remaining papers. At full-text screening, 16 papers were excluded. In total, 32 papers were included in this review (see Fig. 1).

Characteristics of included systematic reviews

Table 1 summarises the characteristics of the included systematic reviews. The majority were published in the last 5 years with primary authors predominantly based in the UK or USA. The number of included papers within eligible reviews ranged from 2 to 72.

A matrix was produced to explore overlap of primary studies across more than one included review. Across the 32 reviews; 85 and 28 papers were included in two and three reviews respectively. Three papers were included in seven reviews with four papers reported in as many as eight reviews (25% of the included reviews).

A risk of bias assessment was conducted for all of the included reviews (Table 1). The majority of the included reviews were assigned an AMSTAR rating of critically low (25 out of 32, 78%).

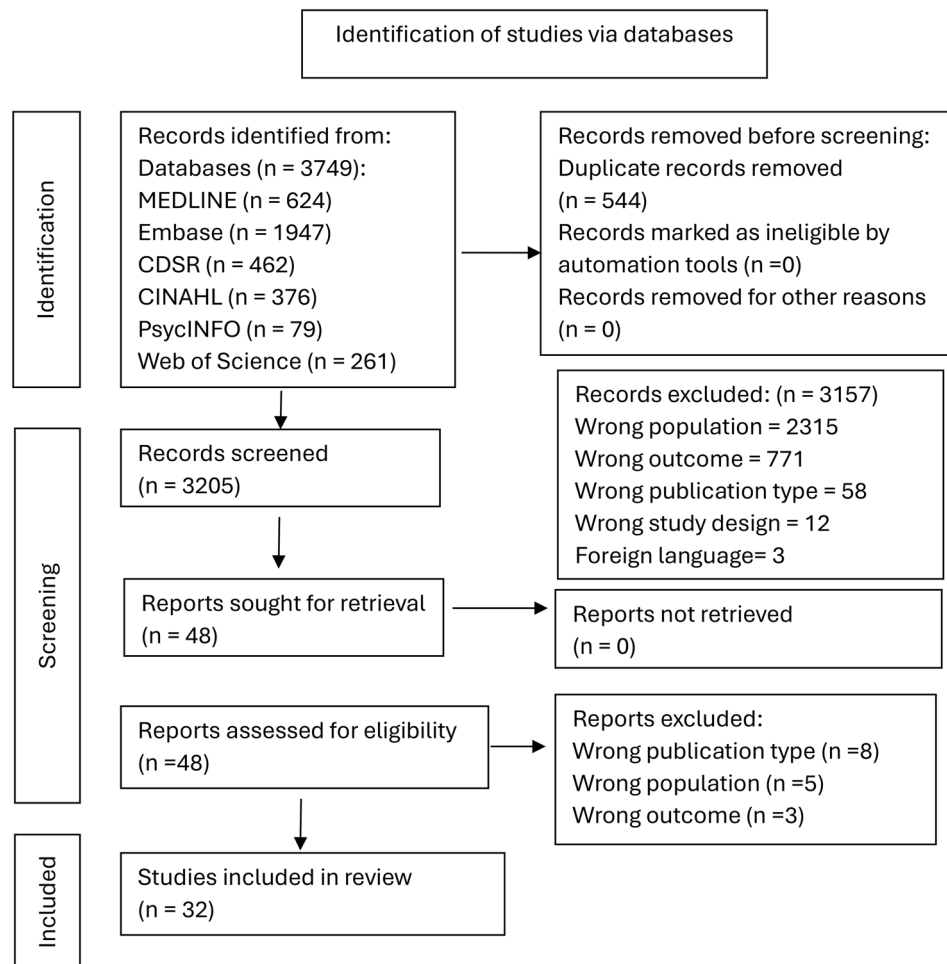


Fig. 1 PRISMA flow diagram of the review selection process

Summary of synthesis of results

The predominant individual factor identified in 26 reviews was reduced health literacy [9, 18–42]. Reduced health literacy in Deaf people has been observed in a variety of health conditions varying from oral hygiene to contraceptive knowledge [9, 23]. Health literacy was reported as either a lack of health-related knowledge in the Deaf community or Deaf person's (particularly children's) family members. Three reviews identified a lack of family awareness or knowledge as a barrier to children attending newborn hearing screening or follow up testing [20, 24, 35].

Reviews linked this reduction in health literacy to Deaf people having inadequate information about medicines [26], inaccessible health information and care [27, 31], higher medical costs [34] and risker sexual behaviour [41].

Twelve reviews reported strategies to improve health literacy for Deaf people [18, 19, 21, 22, 25, 28–31, 33, 37, 39, 40]. Health information interpreted into sign language improved Deaf participants knowledge.

Participants particularly benefited when the educational material was person-centred and co-designed with the Deaf community [19]. However, some reviews reported that single contact education risks poor knowledge retention and behavioural change [18]. Additionally, the accuracy of some of the instructional videos was inconsistent and healthcare facilities can be reluctant to adopt assistive technology [19].

Another individual level factor identified in the reviews was the social and cultural situation of the Deaf person. Four main areas contributed to poor receipt of healthcare. Firstly, location of the health facility if public transportation is unavailable [22] or whether the recipient lives in a rural population [35, 42]. Secondly, lower socioeconomic status was associated with reduced access to healthcare for Deaf people [9, 20, 22, 24, 26, 27, 35, 36], particularly for children [35], women [25–27] and those with no medical insurance or reliant on public hospitals [9, 35].

Thirdly, Deaf people in marginalised communities, including some cultural minority groups, experience

Table 1 Characteristics of included reviews

First Author	Publication year	Country of primary author	Methodology	Number of included papers	AMSTAR rating
Barr, M	2018	Australia	Mixed	28	Critically low
Besoain-Saldaña, I	2023	Chile	Mixed	37	Critically low
Campos, V	2020	Chile	Mixed	51	Critically low
Chatzidamianos, G	2021	UK	Mixed	30	Critically low
Choi, G	2023	Rep. of Korea	Mixed	18	Critically low
Cooper, L	2023	UK	Mixed	17	Critically low
Davis, T	2009	USA	Mixed	14	Critically low
Findlen, U	2023	USA	Mixed	62	Low
Hill, C	2020	USA	Mixed	34	Critically low
Hinchcliff, A	2022	USA	Mixed	45	Critically low
Horner-Johnson, W	2018	USA	Mixed	54	High
Jabbour, J	2017	USA	Mixed	61	Low
Kuenburg, A	2015	Austria	Mixed	87	Critically low
Lesch, H	2018	USA	Mixed	40	Critically low
Luton, M	2024	UK	Mixed	11	Critically low
Mansutti, I	2022	Italy	Mixed	14	Critically low
Morisod, K	2022	Switzerland	Mixed	46	High
Münstermann, J	2023	Germany	Mixed	16	High
Naseribooriabadi, T	2017	Iran	Mixed	72	Critically low
Naseribooriabadi, T	2018	Iran	Mixed	12	Critically low
Neto, N	2019	Brazil	Mixed	19	Critically low
Piao, Z	2023	Rep. of Korea	Mixed	29	Critically low
Ren	2023	Australia	Mixed	59	Critically low
Rogers, K	2024	UK	Mixed	35	Low
Rogers, K	2023	UK	Quantitative	2	Moderate
Tuer, C	2019	UK	Quantitative	6	Critically low
Turner, O	2007	UK	Qualitative	13	Critically low
Velarde, M	2022	Switzerland	Mixed	15	Critically low
Vieira, D	2023	Brazil	Mixed	16	Critically low
Weerapol, N	2024	Thailand	Quantitative	20	Critically low
Wuryandari, N	2024	Indonesia	Mixed	21	Critically low
Yet, A	2022	Malaysia	Mixed	10	Critically low

additional barriers to healthcare receipt [20, 24–26, 35]. Fourthly, family situation can also influence receipt of healthcare including the majority of Deaf people being born to a hearing parent [36], parental uncertainty around hearing devices [35], if the family lacks social support or has other health needs [20, 36].

Environmental factors influencing receipt of healthcare for Deaf people include support and relationships, products and technology and health delivery systems. The reviews identified three support and relationships factors - communication barriers, Deaf awareness amongst healthcare professionals and interpreters.

Communication barriers were highlighted in eight reviews [9, 25, 26, 34, 36, 38, 40, 43]. The communication preferences of Deaf people differ from what is provided [40] and communication between Deaf people and healthcare professionals is rarely effective, except in very simple specific situations [9, 25]. This leads to Deaf people reporting less value in healthcare consultations [36] along with fear, mistrust and frustration [26].

Reviews highlighted a lack of healthcare professional Deaf awareness as a barrier to healthcare for Deaf people [9, 21, 25–27, 29, 32, 38, 40, 41, 43–45]. Healthcare professionals also reported mixed comfort levels [38], incorrect beliefs [41] and not feeling qualified to work with Deaf patients [9]. Healthcare professionals also lacked cultural competency [21, 25, 26, 40]. Training programmes have been shown to improve Deaf awareness [9, 21, 25, 29, 32, 44], although it is unknown if this has led to system wide changes.

The third support and relationships factor relates to interpreters. Reviews identified that Sign Language interpreters reduced communication barriers [9, 22, 25, 29, 32]. However, a lack of interpreter provision impacted access to services [41] and exacerbated difficulties in understand health information [26]. Deaf people use family to act as interpreters [9, 26] but this may prove inappropriate and lead to a lack of privacy [41]. A deficit of skilled sign language interpreters [26] and an inability to meet the financial cost [9] have been attributed as

factors when Deaf people receive healthcare without an interpreter present.

Products and technology were also identified as factors that can influence healthcare receipt for Deaf people. Use of telehealth services may improve healthcare access [42] and communication [19, 22, 25, 45, 46] but how remote access compares to face to face interpretation is unknown [47]. Benefits of remote interpretation include improved interpreter efficiency and reduced costs. However, virtual interpretation also relies on a stable internet and has been developed with little Deaf community engagement [45]. The visualisation of a 3D language on a 2D screen can also be problematic.

Reviews identified systemic healthcare barriers as influencing receipt of healthcare by Deaf people. Time constraints impact communication between healthcare professionals and Deaf patients [9, 40]. Other systemic barriers include Deaf people being incorrectly recorded as hearing English speakers [20, 36] or their communication needs omitted when information is transferred between services [20]. Policies introduced during the COVID-19 pandemic - such as social distancing and face coverings- further hindered Deaf people's access to healthcare [28]. Three reviews identified the need to develop validated clinical tools and scales translated into sign language to more accurately capture Deaf people's symptoms [29, 44, 48]. In addition, healthcare complaints procedures may be inaccessible or difficult for Deaf people to navigate [36].

Strategies to overcome these systemic barriers include specialist healthcare services designed for Deaf people [9, 25] and adaptations to healthcare facilities and service delivery [29, 41]. Commentators have suggested policy changes to support communication adjustments, for example longer appointment times for Deaf people and non-telephone methods for contacting healthcare providers [22].

Discussion

Statement of key findings

The review identified 32 systematic reviews examining factors that influence receipt of healthcare for Deaf people. Across the included reviews, reduced health literacy emerged as the most frequently reported individual barrier, particularly in relation to inaccessible health information, limited family awareness, and adverse outcomes such as poorer knowledge of medicines and sexual health. Social and cultural circumstances, such as rural residence, low socioeconomic status, minority ethnic background, and limited family support were also consistently linked to reduced healthcare access.

Environmental factors were largely reported as communication barriers, limited Deaf awareness among healthcare professionals, and shortages in qualified

interpreters, with evidence suggesting these issues foster mistrust, frustration, and reduced engagement with healthcare services. Structural barriers, including inadequate recording of communication needs in health records and inaccessible complaints procedures further compounded inequalities. COVID-19 related policies, including mask wearing and social distancing, exacerbated these inequalities during the pandemic. While some strategies were identified, such as sign language-based education, interpreter provision, telehealth services, and specialist Deaf clinics with interpreters, their effectiveness was inconsistently reported and limited by systemic constraints.

Interpretation of findings

Factors identified in this umbrella review match the research priorities of the Deaf community. The priority setting partnership used Research Prioritisation by Affected Community methodology adapted for the Deaf population. The exercise involved 43 Deaf people across eight groups. There were 294 statements extracted from the focus groups and categorised using the same conceptual framework as this review. Public contributors refined the statements into nine research themes for ranking. The Deaf community ranked process changes that enable direct communication with healthcare providers as their top priority. Deaf awareness training for healthcare professionals was ranked second. Research into individual factors, like health literacy, were ranked lower. The Deaf community indicated that institutional barriers must be addressed before individual-level interventions can be effective (paper currently under review).

Factors influencing receipt of healthcare for Deaf people identified in this umbrella review have been observed for people with other disabilities. Despite, WHO publishing global standards to ensure accessibility in telehealth services for persons with disabilities [49], a recent scoping review reported persistent digital exclusion among vulnerable populations [50]. Access changes were particularly pronounced for people with sensory impairment, who rely on appropriate camera positioning and high-quality internet, to use telehealth. It is also difficult to build rapport and conduct remote assessments, often increasing the time required for clinical encounters.

Cancer is one of the leading causes of death globally [3] and Deaf people have a higher incidence of late stage cancer diagnosis [5, 51]. Heslop et al. reported case studies of reasonable adjustments to healthcare including bowel screening [52]. However, a recent service evaluation of breast screening non-attenders found that a quarter of non-attenders had disabilities, and that 30% of all non-attenders found it difficult to book a convenient appointment [53].

A recent cross sectional study identified significant mental health care inequalities for people with disabilities and concluded that substantial reform of healthcare professional education and training is required [52].

Strengths and limitations

Limitations to this umbrella review include the high proportion of included reviews having an AMSTAR rating of critically low. This limitation was mitigated by using multiple reviews to identify primary studies as demonstrated by the studies-reviews matrix. Additionally, the factors identified are similar to those reported for other physical disabilities. However, the results should be treated with caution and not used for clinical decision making, but viewed alongside the Deaf community's experiences of healthcare and research priority setting.

The intersectionality between Deafness and other protected characteristics in influencing receipt of healthcare has not been explored in depth and is therefore a limitation. Several reviews highlighted that being black or Hispanic, having lower socioeconomic status and being female further exacerbated health inequalities for Deaf people [9, 24, 26, 35, 36, 42]. A further limitation is that the Deaf population is not a homogenous cohort and cultural diversity may influence receipt and experience of healthcare - an issue not explored in this review.

Additionally, this review focused on receipt of healthcare in OECD countries. A limitation is that the differences between resource wealthy and poor ODEC countries has not been explored. Additionally, an estimated 70 million deaf people belong to signing deaf communities worldwide [1], with deafness in children being more prevalent in non-OECD countries due to preventable diseases like measles and rubella [54]. Further work should seek to understand the factors that influence receipt of healthcare for Deaf people in developing countries.

Implications for practice and research

Although extensive searching of bibliographical databases has revealed limited high quality evidence exploring Deaf people's experiences of receiving healthcare, several barriers have been identified including reduced health literacy in the Deaf community. Further work should be undertaken and co-produced with the Deaf community to seek to improve health literacy.

Furthermore, an overhaul of local processes enabling Deaf people to be able to independently book and manage healthcare appointments and attend with a face to face or virtual signing interpreter must be prioritised. Co-produced research studies should explore the best processes and pathways to achieve this [13]. Research should also focus on Deaf awareness training for healthcare professionals. In particular, the optimal design

should increase an individuals' knowledge and confidence alongside systemic organisational changes.

Conclusion

Overall, the findings underscore persistent individual, cultural, and systemic barriers to equitable healthcare for Deaf people, alongside a need for higher-quality evidence to guide sustainable interventions.

Abbreviations

COVID-19	Coronavirus disease 2019
NIHR	National Institute for Health and Care Research
OECD	Organisation for Economic Co-operation and Development
WHO	World Health Organisation

Supplementary Information

The online version contains supplementary material available at <https://doi.org/10.1186/s12913-026-14444-y>.

Supplementary Material 1

Acknowledgements

The authors would like to express their gratitude to Daniel Hind, University of Leeds for his oversight and all of the public contributors who advised the team.

Author contributions

All authors contributed to this review. AS, ASu, AB conceptualised the design. ASu designed the search strategy, AS and ED screened the articles, conducted quality appraisal and extracted the data. AS conducted data analysis under the guidance of ASu and AB. AS drafted the manuscript. All authors revised the manuscript and approved the final version.

Funding

NIHR Programme Development Grant (NIHR207088).

Data availability

Data extraction table is available on from the corresponding author on reasonable request.

Declarations

Ethics approval and consent to participate

Not applicable.

Consent for publication

Not applicable.

Competing interests

Professor Andrew Booth is in receipt of an NIHR Senior Investigator Award (2024-2029).

Author details

¹Pulvertaft Hand Centre, Royal Derby Hospital, Derby, UK

²School of Medicine and Population Health, Sheffield Centre for Health and Related Research, University of Sheffield, Sheffield, UK

Received: 25 September 2025 / Accepted: 23 March 2026

Published online: 09 April 2026

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