## INPLASY PROTOCOL

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Conflicts of interest: None declared.

# A scoping review of deaf sign language users' perceptions and experiences of well-being in South Africa

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Background: This scoping review concerns deaf adult sign language users from any country (e.g. users of South African Sign Language (SASL), British Sign Language (BSL), American Sign Language (ASL) and so forth). It concerns well-being understood to include subjective well-being and following the WHO's (2001) definition of well-being as "mental health as a state of well-being in which every individual realises his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully and is able to make a contribution to his or her community." Well-being has three components (Steptoe, Deaton, and Stone, 2015; Stewart-Brown, Tennant, Tennant, Platt, Parkinson and Weich, 2009): (i) Live evaluation, also referred to life satisfaction, which concerns an individual's evaluation of their life and their satisfaction with its quality and how good they feel about it; (ii) hedonic well-being which refers to everyday feelings or moods and focuses on affective components (feeling happy); (iii) eudaimonic well-being, which emphasises action, agency and self-actualisation (e.g. sense of control, personal growth, feelings of purpose and belonging) that includes judgments about the meaning of one's life. Well-being is not defined as the absence of mental illness but rather as a positive state of flourishing that encompasses these three components. The review is not concerned with evidence concerning mental illness or psychiatric conditions amongst deaf signers. A specific concern is deaf sign language users' perceptions and experiences of well-being.

**INPLASY registration number:** This protocol was registered with the International Platform of Registered Systematic Review and Meta-Analysis Protocols (INPLASY) on 17 November 2022 and was last updated on 17 November 2022 (registration number INPLASY2022110082).

#### **INTRODUCTION**

Review question / Objective: The purpose of this scoping review is to identify and

map evidence on deaf sign language users' perceptions and experiences of well-being and evaluate the relevance of this evidence

to the situation of deaf sign language users in South Africa. The guiding questions are:

1) do deaf signers experience good well-being? 2) What are the characteristics of the available literature describing deaf sign language users' well-being? 3) What evidence is available on deaf sign language users' perceptions and experiences of well-being in their country's context? 4) What evidence is available specifically concerning the well-being of deaf signers in South Africa?

**Background: This scoping review concerns** deaf adult sign language users from any country (e.g. users of South African Sign Language (SASL), British Sign Language (BSL), American Sign Language (ASL) and so forth). It concerns well-being understood to include subjective wellbeing and following the WHO's (2001) definition of well-being as "mental health as a state of well-being in which every individual realises his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully and is able to make a contribution to his or her community." Well-being has three components (Steptoe, Deaton, and Stone, 2015; Stewart-Brown, Tennant, Tennant, Platt, Parkinson and Weich, 2009): (i) Live evaluation, also referred to life satisfaction, which concerns an individual's evaluation of their life and their satisfaction with its quality and how good they feel about it; (ii) hedonic well-being which refers to everyday feelings or moods and focuses on affective components (feeling happy); (iii) eudaimonic well-being, which emphasises action, agency and self-actualisation (e.g. sense of control, personal growth, feelings of purpose and belonging) that includes judgments about the meaning of one's life. Well-being is not defined as the absence of mental illness but rather as a positive state of flourishing that encompasses these three components. The review is not concerned with evidence concerning mental illness or psychiatric conditions amongst deaf signers. A specific concern is deaf sign language users' perceptions and experiences of well-being.

Rationale: There is a growing body of work on the well-being of deaf sign language users. Literature has primarily focused on well-being measurement, including the validation of instruments to be used in deaf signing populations, exploring deaf sign language users' experiences of mental health in general, and the quality of life and life satisfaction of deaf sign language users. Far less evidence is available that has focussed on how deaf sign language users perceive and experience their wellbeing and the extent to which cultural factors and deaf life experience influence that perception and experience. Furthermore, the vast majority of research on deaf well-being is generated within economically well-resourced countries, with far less emerging from Low and Middle Income Countries (LMIC) and those of the Global South (GS). Contextual issues are likely to be important in any research concerning the well-being of deaf signers. Although there are many transnational similarities, nonetheless the experience of being deaf and a sign language user is not the same in every country. Both external and internal factors associated with being deaf in any specific country will be important and may impact well-being. Very little consideration has been given to deaf well-being in South Africa and what might influence it. This review will aim to address the gap in the literature concerning wellbeing from a deaf perspective with a focus on the extent to which cultural and national context is considered in conclusions drawn about deaf signers' well-being and the applicability of the available evidence to deaf signers in South Africa.

#### **METHODS**

Strategy of data synthesis: The review will be reported following the PRISMA Extension for Scoping Reviews (PRISMA-ScR) (Tricco et al., 2018). PubMed, PyschInfo, ProQuest Social Science, ProQuest Sociology, CINAHL, Project Muse, Web of Science, and EthOs are the primary databases that will be searched. In addition to the primary databases, key journals (Lancet Global Health, JDSDE) reference lists and grey literature (e.g.

policy, practice and guidelines documents, and theses) will be searched for additional references. The search strategy will include the following headings or keywords: 1) descriptors of deaf terms (e.g. hard of hearing); 2) descriptors of well-being terms (e.g. subjective well-being); and 3) descriptors of perspective and experience terms (e.g. opinion). The literature search will be conducted with the use of free-text words, truncation (e.g. deaf\* will generate the words: deaf and deafness), and use of Boolean operators (e.g. AND and OR). It is anticipated that there will be few studies involving deaf sign language users' perceptions and experiences of well-being therefore, the data will be narratively synthesised following a thematic structure generated by the evidence in the studies.

#### Eligibility criteria:

- 1. Studies/grey literature with a focus on aspects of deaf sign language users' perceptions and experiences of well-being
- 2. Studies/grey literature published in English, South African Sign Language (SASL), British Sign Language (BSL), American Sign Language (ASL), International Sign (IS)
- 3. Studies/grey literature focusing on deaf adults (18+) will be included
- 4. Studies/grey literature published within the date range of 1980 to 2022 inclusive, however, if there is anything exceptional before the date range, it will be included Exclusion criteria:
- 1. Studies/grey literature with a focus on deaf sign language users' mental health with no overlapping aims with/direct relevant to deaf sign language users' perceptions and experiences of well-being
- 2. Studies/grey literature published in a language other than English, South African Sign Language (SASL), British Sign Language (BSL), American Sign Language (ASL), International Sign (IS)
- 3. Studies/grey literature with a focus on deaf children and youth (below the age of 18 years old)
- 4. Studies/grey literature with a focus on people with disabilities that do not include deaf people
- 5. Studies/grey literature that falls outside the date range (1980 2022 inclusive)

however, if there is anything exceptional before the date range, it will be included

- 6. Studies/grey literature where it is not possible to disaggregate data from deaf signers from overall data concerning deaf people
- 7. Editorials, newspapers, newsletters, pamphlets, tweets, Wikis, book chapters, books and professional opinion pieces.

Source of evidence screening and selection: The study selection will have two main stages: 1) screening of the title and abstract, which will be carried out by two people (RS and AY) with a yes/no/maybe conclusion applied to each study. If there is a conflict of opinion between the two reviewers, the third reviewer (CS) will be brought in if no agreement has been set between the first two reviewers; and 2) screening of full text will be carried out by two people (RS and CS) resulting in a yes/ no decision. If there is a conflict of opinion between the two reviewers, AY will resolve the conflict. At both stages, inclusion and exclusion criteria will be applied.

Data management: Studies from all database searches (including additional sources such as dissertations, grey literature database and hand searching) will be exported into Zotero reference manager. Zotero will screen for duplicates via titles, DOIs, and ISBN fields. Manual screening for duplicates will also be done. These records will then be exported to Rayyan software for eligibility screening. All identified data extracted from the full-text screening will be charted using a bespoke Microsoft Excel template with the following characteristics: year of publication, location, research design, methods, analytical approach, participants' characteristics, setting, and studies involving secondary data. For grey literature, descriptive data will be added, which will include details of the grey literature, the reason for including the literature, content considered relevant, year of publication/posted, and location. The studies will be appraised using the Crowe Critical Appraisal Tool (CCAT) (Crowe & Campbell, 2011). The CCAT has been validated for quantitative and qualitative study designs (Crowe, Sheppard & Campbell, 2011). Grey literature will not be appraised using formal quality assessment tools.

Language restriction: Publications in English, South African Sign Language (SASL), British Sign Language (BSL), American Sign Language (ASL) or International Sign (IS) will be included in the review.

Country(ies) involved: South Africa and United Kingdom.

Keywords: Deaf; sign language users; wellbeing; subjective well-being; positive wellbeing; happiness; life satisfaction; quality of life.

Dissemination plans: The scoping review findings will be published in a peer-reviewed journal and/or presented at conferences.

#### Contributions of each author:

Author 1 - Robyn Swannack - RS developed the scoping review plan and will be involved in every stage of the review protocol (e.g. RS will carry out the literature searches, study selection, data extraction, reporting the results and preparing the manuscript for publication).

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Author 2 - Alys Young - AY also supported the development of the scoping review plan, will act as first stage reviewer and step in to resolve any conflict in the second stage, independently screen studies for selection and will review the manuscript for publication.

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Author 3 - Claudine Storbeck - CS also supported the development of the scoping review plan, will step in to resolve any conflicts in the first stage and act as second stage reviewer, and will review the manuscript for publication.

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