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Deaf adolescents' perspectives on and experiences of mental health: A scoping review

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ADMINISTRATIVE INFORMATION

Support - NIHR Pre-Doctoral Fellowship.

Review Stage at time of this submission - The review has not yet started.

Conflicts of interest - None declared.

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Amendments - This protocol was registered with the International Platform of Registered Systematic Review and Meta-Analysis Protocols (INPLASY) on 14 August 2023 and was last updated on 14 August 2023.

INTRODUCTION

Review question / Objective This scoping review aims to identify the type and scope of literature regarding deaf adolescents' (aged 15-19) perspectives on and experiences of mental health.

Guiding questions for the review include:

1. What literature is available on deaf adolescents' (aged 15-19) perspectives on and experiences of mental health (e.g. being mentally well, staying mentally well)?
2. Are there any identifiable gaps in the scope of the literature?

Background This scoping review concerns deaf adolescents' (aged 15-19) perspectives on and experiences of mental health. For this study, the term deaf includes any degree of deafness in audiological terms, including unilateral deafness and any age of onset but excludes transient or temporary hearing loss. Deaf adolescents are

included in the review regardless of their communication preferences (e.g. Signed and/or spoken languages, sign supported communication systems) and hearing technologies. The Population, Concept, Context (PCC) framework guides the research question development (Peters et al., 2020). PRISMA ScR reporting guidelines (Tricco et al., 2018) are used alongside the Patterns, Advances, Gaps, Evidence for practice, and Research recommendations (PAGER) framework (Bradbury-Jones et al., 2022).

The review focuses on mental health, utilising the World Health Organization's (WHO) definition as "a state of mental well-being that enables people to cope with the stresses of life, realise their abilities, learn well and work well, and contribute to their community" (WHO, 2022). The World Health Organization defines 'adolescents' as 10-19 years, 'youth' as 15-24 years, and 'young people' as 10-24 years (WHO, 2023). This review concerns deaf adolescents aged 15-19, spanning these three definitions. Therefore, all terms are used

within this protocol. Equally, the proposed review will encompass papers that use all terminology internationally.

Globally, one in seven adolescents (10-19) experiences a mental health condition (Institute of Health Metrics and Evaluation [IHME], 2019), the likelihood of which increases with age within this cohort. For example, in the UK, estimates suggest one in four 17-19-year-olds in the general population had a probable mental health disorder in 2022 (NHS Digital, 2022). Worldwide the fourth leading cause of death in older adolescents aged 15-19 is suicide (WHO, 2021). Given these increased risks, this specific age group is the focus of the current review.

Rationale UK research suggests deaf adolescents are 30-50% more likely to experience mental illness compared to their hearing counterparts (SignHealth, 2023), but figures vary between 42.4-71% prevalence rates within this cohort (Hindley et al., 1994; Hindley 2005; Roberts et al., 2015; Young et al., 2023). These higher rates of mental illness among this group are also found across international studies (Fellinger et al., 2009; Jiang et al., 2020; Theunissen et al., 2011; van Gent et al., 2007). Furthermore, data from the Recording Emerging Adulthood in Deaf Youth (READY) study report statistically significantly lower subjective well-being in the deaf emerging adult (i.e. older adolescent) group compared to age-matched UK norms. Only 3% (compared to an expectation of 15%) of deaf adolescents scored in the high well-being category based on the Short Warwick Edinburgh Mental Wellbeing Scale (SWEMWBS) (Young et al., 2023).

Broader literature in this area has typically focused on quality of life measurements (Aanondsen et al., 2023), including validation of instruments used in deaf signing populations (Aanondsen et al., 2021; Patrick et al., 2011) and the well-being of deaf adolescents with cochlear implantation compared to their hearing counterparts (Huber & Kipman, 2011). Some literature also exists regarding the perspectives of mental health care professionals (du Feu & Chovaz, 2014) and parental perspectives on deaf adolescents' mental health (Cagulada & Koller, 2019). However, less literature exists focusing on the views of deaf adolescents themselves concerning mental health, whether in terms of well-being or experiences of mental ill health. Also, this group has specific and highly heterogenous language and communication needs relevant to information uptake and service access, and in some cases, a distinct Deaf cultural identity. These factors are likely to moderate and influence aspects of interpersonal relationships essential for maintaining well-being and shaping their

perspectives on mental health. Consequently, it is important to scope the literature and evaluate the available evidence from deaf adolescents' perceptions and mental health experiences to better understand their needs.

METHODS

Strategy of data synthesis The review will follow the:

a) Nine-step JBI scoping review guidance (Peters et al., 2020).

b) Preferred Reporting Items for Systematic Reviews and Meta-Analyses Scoping Review extension (PRISMA-ScR) (Tricco et al., 2018).

c) Patterns, Advances, Gaps, Evidence for practice, and Research recommendations (PAGER) framework (Bradbury-Jones et al., 2022).

PubMed, PsycInfo, ProQuest Social Science, CINAHL, and Web of Science are the primary databases that will be searched, as well as grey literature (e.g. World Wide Science, OpenGrey, deaf charity specific websites). The reference lists within identified items will also be hand searched. The indexes of key journals will be searched, including Journal of Deaf Studies and Deaf Education, American Annals of the Deaf, Deafness and Education International, and Volta Review.

Search strategy: Free-text words, truncation (where possible) and Boolean operators will be used. Term descriptors and example search terms linked to the PCC framework include:

Population: 1. Deaf term descriptors: deaf, hard of hearing, dhh, sign lang*, hearing loss, hearing impair* 2. Adolescent term descriptors: young people, adolescent*, youth*

Concept: Mental health term descriptors: wellbeing, recovery, anxiety, depression, mental health, mental illness, resilience

Context: Personal experience term descriptors: perspective*, self-report, experience*, feedback, personal, patient satisfaction

Additional search term synonyms will be developed using database thesauri.

As few studies are anticipated that focus on deaf adolescents' perspectives on mental health, data will be synthesised following the Patterns, Advances, Gaps, Evidence for practice, and Research recommendations (PAGER) framework (Bradbury-Jones et al., 2022).

Eligibility criteria Few studies involving deaf adolescents' perceptions and experiences of mental health are anticipated; therefore, no date restrictions will be applied. The review will explore peer-reviewed papers and grey literature documents relating to the perspectives of deaf adolescents (aged 15-19) on mental health.

Literature that mentions general disabilities but specifically includes deaf adolescents will be included. Literature exploring children and young people outside the 15-19 age group will be excluded. However, literature that includes a portion of the 15-19 age group will be included (e.g. 16-18, etc.). Literature around deaf adolescents with comorbid experiences (e.g. deafblind, autism spectrum disorder, learning difficulties) will be excluded, given that these groups typically have multifaceted and differing mental health needs (Fellinger et al., 2017; Hindley, 2005; Rhys-Jones & Baker, 2021). See detailed inclusion and exclusion criteria below.

Inclusion criteria:

Date range: All dates

Study designs included: Literature reviews, primary research, secondary analysis.

Sources included: Peer-reviewed quantitative, qualitative and mixed-method studies. Pre-prints and book chapters. Grey literature to include working papers, policy documents, charity and government reports, opinion and experiential pieces (e.g. blogs), and student doctoral theses.

Language: Publications in English and signed languages.

Location: any country

Focus of studies: Deaf adolescents' perceptions and experiences of mental health, and well-being; literature that mentions general disabilities but also includes deaf adolescents' perceptions and experiences of mental health.

Participants: Deaf adolescents aged 15-19 with any degree of deafness in audiological terms, including unilateral deafness and any age of onset. Any communication preference (e.g. Signed and/or spoken languages, sign supported communication systems) and any hearing technology.

Exclusion criteria:

Focus of studies: Mental health professionals' perspectives regarding deaf adolescent mental health; parents' perspectives of deaf adolescent mental health; general literature on deaf adolescent mental health (e.g. prevalence rates); literature around deaf adolescents with comorbid experiences (e.g. deafblind, autism spectrum disorder, learning difficulties); research focused on quality of life instrument translation to signed languages; comparisons between deaf adolescent and hearing adolescent mental health.

Participants: Adolescents with transient or temporary hearing loss; studies that cite mean/median age only so age groups cannot be disaggregated, studies where deaf and hearing people cannot be disaggregated in the reported findings.

Source of evidence screening and selection

Evidence screening and selection will take place in two phases. Phase one includes the screening of titles and abstracts carried out by two reviewers independently. Any discrepancies between the two reviewers in this phase will be discussed and mediated by a third reviewer. Phase two will involve reviewing the full texts of the eligible items. This will also take place by two reviewers separately. Any discrepancies between the two reviewers in this phase will be discussed and mediated by a third reviewer.

Data management Retrieved records from all database searches will be exported to the software package Endnote, removing duplicates automatically. Extracted literature will then be exported to a review management system (e.g. Covidence, Rayyan) for eligibility screening.

Reporting results / Analysis of the evidence The Preferred Reporting Items for Systematic Review and Meta-Analyses Extension for Scoping Reviews – PRISMA-ScR (Tricco et al., 2018) will summarise the selection process. Following the text review, an adapted data charting form from JBI Methodology for Scoping Reviews (Aromataris & Munn, 2020) will be used to record data extracted from included literature; this process will also support synthesis. Quality assessment / Risk of bias analysis: Scoping reviews do not typically include quality assessments. However, for rigour, the Crowe Critical Analysis Tool (CCAT) (Crowe et al., 2011), validated for quantitative and qualitative study designs, will support in assessing the quality of included studies. However, as scoring is not within the remit of a scoping review, no scores will be allocated. No formal quality assessment tools will be used to appraise grey literature.

Language restriction Publications written in English or Signed Languages will be included.

Country(ies) involved United Kingdom.

Keywords deaf; adolescent; mental health.

Dissemination plans Findings will be published in peer-reviewed journals and presented at conferences.

Contributions of each author

Author 1 - Tiffany Wade - TW developed the scoping review plan for this study and will be involved in every stage of the review protocol (e.g. carrying out the search strategy; study selection; first reviewer, data extraction; reporting the results; preparing the manuscript for publication; etc).

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 Author 2 - Alys Young - AY supported the development of the scoping review plan, will review the manuscript for publication and act as the third reviewer.

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 Author 4 - Celia Hulme - CH supported developing the scoping review plan, will review the manuscript for publication, and will act as an alternate second reviewer.

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