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DIGITAL HEALTH LITERACY OF PEOPLE WITH INTELLECTUAL DISABILITIES.

A Scoping Review Protocol.

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ABSTRACT

Introduction
The aim of our project D-GeKo MmgB is to strengthen digital health literacy in people with intellectual disabilities. To our knowledge the topic is not yet well researched. Therefore there is a need to examine the current state of digital health literacy as a baseline for future directions. For this, a scoping review will be conducted. This protocol describes the approach.

Methods and analysis
The primary objective of this scoping review is to map the current state of research on digital health literacy of people with intellectual disabilities. It will be conducted and reported according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses - Scoping Review Extension guidelines (PRISMA-ScR). This article describes the protocol for a scoping review prior to its realization.

Ethics and dissemination
Ethics approval is not required. Findings will be disseminated through professional networks, conference presentations and publication in a scientific journal.

Keywords: people with intellectual disabilities, digital health literacy,

1. INTRODUCTION / STUDY RATIONALE[1]

The digital transformation is understood as a social change process based on digital technologies, which permeates all areas of everyday life, such as healthcare (Lexa 2021). The use of digital options as a source of information is now considered indispensable (Chadwick et al. 2016). Access to new information and communications technologies including the Internet is stated as a human right (e. g. the Article 9 of the United Nations Convention on the Rights of Persons with Disabilities). In Germany, the Federal Ministry of Health emphasizes the advancement of digitalization as a prerequisite for the further development of sustainable healthcare (BMG 2024).

Since 2019, health insurance funds in Germany have been obliged to promote digital health literacy (Code of social law, section 20k). At the end of 2020, the National Association of Statutory Health Insurance Funds (GKV-Spitzenverband) published regulations on needs-based objectives, target groups and the content, methodology and quality of services to promote digital health literacy in accordance with section 20k. According to this, "services to promote digital health literacy should preferably reach groups/persons with special needs, i.e. those with reduced health opportunities and particularly limited digital health literacy" (GKV-Spitzenverband 2021). However, people with intellectual disabilities participate the least in digitalization ("digital divide") for several reasons (e.g. Heitplatz 2021 und Bruland et al. 2023) and have been overlooked for strengthening digital health literacy.

The aim of our project D-GeKo MmgB is to strengthen digital health literacy in people with intellectual disabilities. This is to be achieved through a science-based, participatory and practice-oriented development, testing and evaluation of a needs-based theoretical framework to strengthen the digital health literacy of people with intellectual disabilities. Strengthening digital health literacy will ensure that this highly vulnerable population group can access and use digital health services for themselves in order to promote their own health, prevent illness and better understand the treatment measures in the event of illness, while making better use of digital healthcare services (in line with the BMG 2022). Conducting a scoping review is therefore to present the current state of research on digital health literacy as an initial knowledge basis.

2. REVIEW OBJECTIVES

The primary objective of this scoping review is to map the current state of research on digital health literacy of people with intellectual disabilities. The following questions are to be answered in addition:

- What specific challenges are mentioned for people with intellectual disabilities in relation to digital health literacy?
- What needs-oriented adaptations are proposed for digital health literacy concepts for people with intellectual disabilities?

The aim is to conduct a comprehensive search to identify as many hits as possible that are relevant to our question. Therefore, a sensitive search principle is selected. This means carrying out an extensive search with a broad search approach, e.g. in many different databases, with many conceivable search terms and only a few restrictions. A sensitive search leads to a high total number

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[1] As scoping reviews are essentially exploratory in nature, it is not expected to explain all the existing knowledge in the area under review, but rather to explain why the scoping review is being carried out and what information needs it meets (von Elm et al. 2019).

of hits being found, a high proportion of which are not relevant. It therefore involves more effort when selecting references, but the risk of relevant hits being overlooked is lower.

3. METHODS

This article describes the protocol for a scoping review prior to its realization.. To ensure rigour and facilitate replicability the scoping review based on the Preferred Reporting Items for Systematic Reviews and Meta-Analyses-Scoping Review Extension (PRISMA-ScR, Tricco et al. 2018) and methodological guidance for scoping reviews (von Elm et al. 2019) which is a shortened and adapted version of the guidelines set by the Joanna Briggs Institute (Peters et al. 2015).

3.1   Development of the search strategy

Search terms for people with intellectual disabilities were taken from previous work (Bruland et al. 2021). By means of an online narrative search, search terms for the topic of digital health literacy were selected. English search terms were tested in Medline via Pubmed and Cinahl. German search terms were tested in Psyndex in December 2023. Relevant articles were searched for further appropriate search terms e.g. Glencross (2021). The Mesh-Terms in Pubmed were proofed, but brings no further information for our search strategy. Sub-topic came up as possible search terms through the narrative research. Antonyms were also tried to be found, but with no relevant results. The development of the search strategy was conducted by one researcher (DB).

3.2   Eligibility criteria

As the scoping review has a sensitive search principle, we set the following criteria for inclusion:

Table 1: Eligibilty criteria

	Inclusion	Exclusion
Population	Adults with intellectual disabilities	People with intellectual disabilities are not addressed or are under 18 years of age
Concept	Digital health literacy and related topics	Without reference to digital health literacy and related topics
Context	Any context, e.g. outpatient care or inpatient care	None
Other	Period from 2009 (15 years) to 2023 Language German or English All relevant studies, regardless of their design and quality, including dissertations, editorial articles, overviews and systematic reviews.	Before 2009 (older than 15 years) Not written in German or English Abstracts for conferences or poster, Full Text is not available

As digital technology and applications are changing rapidly, only the last 15 years are included. The authors are convinced that a further search due to the aforementioned change in technology is also reflected in the studies to be found and that a search before 2009 has no benefit for our aim. It is difficult to pin down, however, the time completely includes the use of smartphone-enabled instant messaging service. For example, WhasApp as a popular instant messaging service was founded in 2009.

3.3   Information sources

The search will be performed across 11 databases to retrieve a wide range of potentially relevant papers and to take an interdisciplinary approach. All searches will be conducted up to January 2024. Following databases will be searched with English search terms:

1. Medline via PubMed
2. CINAHL via EBSCOHost
3. Eric viaEBSCOHost
4. Web of Science
5. LIVIVO - The Search Portal for Life Sciences
6. Wiley Online Library
7. PsycInfo via EBSCOHost

Following databases will be searched with German search terms:

8. Psyndex
9. REHADAT
10. Fachportal Pädagogik /FIS Bildung
11. CareLit

Additionally google scholar will be searched for grey literature (Haddaway et al. 2015). Grey literature includes resources published outside traditional academic journals. It is included in order to obtain a complete overview of the current status (Paez 2017). From the included literature the reference list will be searched for suitable literature.

3.4 Search terms

The search terms are as shown in Table 2 (English) and Table 3 (German). It is planned, to use these search terms for all databases, but, if necessary, adapted to the requirements of the database. For example, terms will be checked in each database for standardized search terms.

Table 2: English search terms

Target group	Topic	Sub-topic
Intellectual* disab* OR learning disab* OR cognitive* impair* OR developmental disab* OR intellectual handicap* OR mental* retard* OR mental* abnormal* OR down syndrome	digital health literacy OR ehealth literacy OR electronic health literacy OR media health literacy OR mobile health literacy OR digital competenc* OR media skill* OR media competenc* OR digital literacy	digital divide OR digital gap* OR digital inequalit* OR digital inclusion OR eHealth Services OR internet use OR social media

Table 3: German search terms

Target group	Topic	Sub-topic
geistige behind* OR Intellektuelle Behind* OR intellektuelle beeinträcht* OR menschen mit lernschwierigkeit*	digital health literacy OR digitale Gesundheitskomptenz OR digitale Kompetenz* OR Medienkomp*	digital divide OR digitale kluft OR digitale ungerechtigkeit* OR digitale inklusion OR internetnutzung OR social media OR digitale angebote

3.5 Screening procedure

The review will be conducted in Rayyan, a web-based systematic review platform. All articles obtained from the database searches will be imported. The platform will be used detect and remove duplicates. The authors check whether all duplicates have really been removed. After that, all titles and abstract will be screened from the authors DB and DG independently according to the eligibility criteria. The articles included from the authors are compared and discussed if there are any deviations. For that, the full text will be retrieved and the eligibility criteria reapplied. If no agreement can be reached disagreements will be solved by a third researcher (ÄDL).

3.6 Data charting

Data from all included articles will be extracted. It is planned that the authors DB and DG do this for all included articles independently and to discuss the information afterward. This is necessary to ensure that the most relevant information are taken into account. First, included literature will be categorized according to the type of literature (e. g. reviews, studies etc.).

Reviews shall be mapped with following categories: author, publishing year, country, research questions / objectives, inclusion and exclusion criteria, databases, search terms, No. of included studies, characteristics of included studies, main content, results, and limitation.

Other types shall be mapped with following categories:
Author, Year, Country, Sample (inclusion criteria)/target group description, setting, digital health literacy aspects, eventually intervention description, Results, Limitations.

The categories will be discussed in the charting process and adjusted if necessary.

3.7 Data synthesis

With a focus on the questions, What specific challenges are mentioned for people with intellectual disabilities in relation to digital health literacy? and What needs-oriented adaptations are proposed for digital health literacy concepts for people with intellectual disabilities? data will be analysed and summarised descriptively. In reporting our results, we will also highlight similarities and differences. The results will be discussed with projects international advisory board (see further information).

4. ETHICS AND DISSEMINATION

This work analyses existing research studies, and therefore, involves no individuals nor unpublished secondary data. As such, approval from an ethics committee is not required. Findings of the scoping review will be disseminated through professional networks, conference presentations and publication in a scientific journal.

5. STRENGTH AND LIMITATIONS

To our knowledge, this study will be the first to systematically identify the state of research of digital health literacy in people with intellectual disabilities. The review will take a rigorous approach, adhering to Preferred Reporting Items for Systematic Reviews and Meta-Analyses-Scoping Review guidelines (PRISMA-SCR). A limitation is that the search has a sensitive approach with little restriction regarding quality assessment of the included articles.

6. IMPLICATIONS

The analysis is expected to give a baseline overview about the current state of digital health literacy of people with intellectual disabilities for future directions for this vulnerable population group in terms of health in our research project and above.

7. FURTHER INFORMATION

Project partner

Bethel regional.

The Bethel.regional foundation division is part of the v. Bodelschwinghschen Stiftungen Bethel. For more than 150 years Bethel helping people who are dependent on support or assistance with a wide range of services. The aim of the services is to empower people with cognitive impairments to exercise their right to participate in social, political and cultural life and to integrate into everyday social life.

Project advisory board

Diane Levin-Zamir, Full Professor – School of Public Health – University of Haifa - National Director of Department of Health Education and Promotion - CLALIT - Israel

Orkan Okan – Assistant Professorship of Health Literacy | Health Literacy Unit | Center for Health and Medicine in Society | Department of Health and Sport Sciences | Center for Health and Medicine in Society | Department of Health and Sport Sciences | TUM School of Medicine and Health | Technical University of Munich - Germany

Susie Sykes - Professor – Public Health and Health Promotion | Director PHIRST South Bank | School of Health and Social Care | London South Bank University - England

CRediT authorship contribution statement

DB: Conceptualization, Findings, Discussion, Conclusion, Writing – original draft.
DG: Conceptualization, Methodology, Aim, Findings, Writing –editing.
ÄDL: Conceptualization, Methodology, Aim, Findings, Writing –editing.

Declaration of competing interest

All authors declare that they have no conflicts of interest.

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