

Participatory Research and Project Work with Individuals with Low Literacy: A Critical and Reflective Review of Ableism in Health System and Research During the Coronavirus Pandemic

Merle Heyrock, Kiel University (CAU)

Ayça Polat, University of Oldenburg

Britta Thege, Kiel University of Applied Sciences

Abstract: The article explores the experiences derived from a participatory research project designed to create a health app for individuals identified as having 'low literacy' with the aim of enhancing their health literacy skills. It concentrates on the methodological challenges encountered in implementing participation and involvement during the app's development process, alongside a critical examination of the limitations imposed by the COVID-19 pandemic and other constraints. It also highlights the solutions that have emerged through adjustments and close cooperation with the target groups. The aim is to show perspectives for social work in the context of promoting health literacy.

Keywords: Participatory research; app development; low literacy; ableism

1 Introduction

This article discusses the findings and insights from a research-project 'DiGeKo-Net' which aimed to design and develop a health app tailored for individuals identified as having 'low literacy' (Grotlüschen/Buddeberg/Solga, 2020; Grotlüschen/Riekman, 2012). On an international level, adult literacy is commonly assessed through the *Programme for International Assessment of Adult Competencies* (PIAAC), which provides a comparative benchmark across countries. In Germany this framework is complemented by the LEO studies conducted by the University of Hamburg, which provide representative data on reading and writing skills among German-speaking adults aged 18 to 64. According to LEO 2018, approximately 6.2 million adults in Germany have no or only very basic literacy skills, as measured using the Alpha Level scale. More recent analyses combining PIAAC and LEO data (Grotlüschen et al., 2025) indicate that around 10.6 million adults – about 20% of the population - have literacy skills at Level 1 or below. Drawing on these data, public and political debates in Germany increasingly frame low literacy as a structural factor contributing to social inequality and exclusion. On this basis, political programmes and measures have been developed that seek to address low literacy within broader educational and social policy frameworks. Against this backdrop the health app was developed with the intention of enhancing access for people with low literacy to health-related information. As part of this initiative, the health app was created through close collaboration with practice partners and the individuals it aimed to serve. Furthermore, the project led to the formation of a cross-institutional competence network. This network raises public awareness about the needs of the target group and is tasked with sustaining the project's objectives and updating the app.

The central strategy of our method involved intensive collaboration with individuals with low literacy levels throughout the development process of the app, encompassing all phases from the initial generation of ideas to the final version, and engaging both conceptual and content-related aspects. This article outlines the steps of our specific approach and, simultaneously, offers a critical reflection on our experiences during project realisation and the accompanying research process. Our work does not adopt participatory research as a comprehensive methodological framework. Instead, it is informed by participatory principles as they were applied within the development of a health app for people with low literacy levels, rather than within the research process itself. The analysis therefore focuses on *participatory moments* emerging in design and development activities, and on how such moments could be facilitated under the constrained conditions imposed by the COVID-19 pandemic. Although participation was situated primarily within the development process rather than the research process itself, the article refers throughout to both research and development, as these were closely intertwined in practice and mutually informed on another.

Engaging research participants directly in the research process – and approach known as participation - aims to transform the traditional roles of research subjects and researchers, fostering more interactive and reciprocal relationships. Such approaches emphasise the mutual exchange of experiences, insights, and perspectives, often with the goal of producing knowledge that is considered more context-sensitive and credible. Central to these approaches is a critical engagement with power relations, as participatory research seeks to challenge established hierarchies and address power asymmetries, particularly in relation to the phrasing of research questions, the organisation of the research process, and the interpretation of findings. For participation to be effective, it necessitates a critical examination of power positions and the fostering of open communication to amplify the voices and enhance the independence of all participants within the process.

While our study does not implement participatory research in its strict methodological sense, it draws on participatory ideas as an analytical and normative point of reference. Participation in this project was situated primarily within the development of the app, where individuals with low literacy levels contributed experiential knowledge, perspectives, and priorities. These contributions did not constitute participation in the research process itself; however, they substantially shaped how the research was approached. In particular, insights emerging from the development process influenced methodological decision including the selection, adaptation, and reflection of data collection and analysis methods. At the same time, the article focuses on *participatory moments* within the development process - that is, situational instances in which participation became possible, meaningful, and consequential despite structural constraints and the conditions by the COVID-19 pandemic. Acknowledging that projects aimed at supporting groups often labelled as “vulnerable” are not immune to stereotyping and power imbalances, we conclude with a self-critical reflection on the limitation and tensions inherent in such *participatory moments*. Prior to this, we briefly outline our conceptual understanding of participatory research.

2 Participatory research as an approach to critical-reflexive research with “vulnerable” target groups

Participatory research is distinguished by a dual aim: it not only facilitates the involvement of social actors but also strives to empower them to partake more fully in society. This approach does not adhere to a standardised procedure or a set methodology but is regarded as a style of research (von Unger, p. 1). This implies, for instance, that the opportunities for participation

may not be established from the start and can become possible, evolve, or reduce as a project progresses (von Unger, p. 38). Given such flexibility, meticulous planning and, particularly, open discussion about the expectations and limitations of participation are crucial to avoid giving false hopes and inciting disappointment.

In addition to the opportunities for participation, the research mentality is also concerned with acknowledging that research is invariably imbued with power structures and dynamics. This recognition points to an inherent domination of knowledge and interpretation on specific topics, which influences the research outcomes and thereby affects potential subsequent changes in policies and practices (Hartung/Wihofszky/Wright 2020, p. 6). If new insights and research discoveries are "not seen as the privilege of scientists, but as a co-production of all researchers involved" (von Unger, p. 2), it becomes essential to continuously reflect on one's own stance within the research process and become attuned to the perspectives of other participating actors. In practical terms, within the scope of the project, it was particularly crucial to critically examine the position of researchers who possessed proficient literacy skills and were embedded in the academic field, an area traditionally esteemed for its written language prowess.

The foundation of our research perspective was the understanding that health literacy is intrinsically linked to the basic abilities of reading and comprehending information, suggesting that individuals with low literacy skills are likely to find it considerably more difficult and challenging to develop or sustain adequate skills and access pertinent information about their own health maintenance or disease management (Heilmann, 2020). In this context, it was imperative for us to acknowledge and highlight the viewpoint that literacy is constructed by social norms, making it inherently ideological (Street, 2003). Such norms foster a hierarchy as well as the normalisation of a legitimate or dominant form of literacy, against which all individuals in a society are evaluated (Barton & Hamilton, 2000, p. 10). Being proficient in this accepted form of literacy renders one 'norm-literate' (Steuten, 2014), thereby facilitating participation and access to privileges.

Against this backdrop, we critiqued the notion that those who fail to meet this normative standard are inherently deficient, a perspective that unfairly extends to other competencies such as health literacy. Thus, the participatory approach of the project was not solely aimed at enhancing health literacy but was also intentionally focused on valuing the existing knowledge and experiences of individuals with low literacy as crucial elements in the development of the health app. This approach was also meant to challenge the notion that literacy is the sole means of improving health opportunities and dismantling barriers.

3 Participation in a pandemic situation - is it possible?

The project targeted individuals with low literacy across all genders and age groups, situated in both urban and rural settings, and encompassing those for whom German is either the mother tongue or a second language. The aim was to encompass as broad a spectrum of problem-solving approaches and experiences as possible, thereby amassing a rich variety of relevant information. It was underpinned by the principles of participation and empowerment, adopting a resource-oriented viewpoint. Empowerment is considered a crucial conceptual component in the development of health literacy, while participation is viewed as an essential asset for enhancing health opportunities.

The approach within the project was both process-oriented and impact-oriented. The practical component involved developing an accessible, target group-specific app for individuals with

low literacy through interdisciplinary cooperation, alongside establishing a competence network. The accompanying research aimed to examine the extent to which this target group-specific intervention concept could enable individuals with limited reading and writing capabilities to enhance their health literacy. This was premised on two foundations: firstly, an understanding of health literacy that requires neither literacy as a prerequisite nor as an objective, and secondly, an intersectional perspective. This perspective considers social categories such as gender, age, ethnicity, and social status in their interrelatedness (Winker/Degele, 2009). In the sections that follow, we delve deeper into our research steps, contextualising them by taking into account the specific needs of the target group, the unique challenges posed by the pandemic situation, and the intertwining of these two elements.

3.1 The research methodological approach

The research design of the project was primarily qualitative, utilising expert interviews, focus groups with affected individuals, and online workshops for professionals. The original plan for the participatory process involved conducting twelve focus groups, each consisting of six to eight individuals with low literacy levels. These groups were to be divided by spatial category (urban/rural), gender, and, where relevant, language group, with the objective of exploring their specific (collective) knowledge and enabling them to utilise it effectively. Within these focus groups, individuals with literacy needs were expected to discuss health topics and their experiences within the German healthcare system in a safe environment. The goal was to foster an open discussion atmosphere, focusing on participant interaction, particularly because the sensitive nature of the topic often leads to isolation of those affected, who seldom have opportunities to engage in dialogue with one another.

The commencement of our project coincided with the outbreak of the coronavirus pandemic. Initial contact restrictions were implemented in November 2020, escalating to a stringent lockdown from December until May 2021, significantly impacting the project's execution. Specifically, the planned in-person formats could not proceed, and the anticipated outcomes could not be realised. With the imposition of contact restrictions during the pandemic, it became necessary to identify alternative methods to the planned in-person meetings for the focus groups. Online formats were adopted as substitutes for face-to-face events. Although expert interviews and professional workshops were successfully transitioned online, the focus groups faced challenges. Feedback from experts indicated that many participants either lacked the necessary technical skills or the appropriate equipment, making the organisation of an online session more likely to create stress than a productive interview setting. As an alternative, individual telephone interviews were conducted during both phases of the survey, and four smaller focus groups were organised once in-person gatherings became feasible. Overall, 82 individuals participated in the project and the development of the app.

The adoption of the telephone interview format was met with positive reception, proving to be an accessible means of engaging with the participants. Significant emphasis was placed on informing the interviewees about their rights within the context of the interview (including study information and consent forms) before the commencement of the actual interview.

In the second phase of the survey, further interviews were conducted, particularly as part of the prototype testing for the app. In some of the test groups—though not all—additional inquiries were made to ascertain the support preferences and requirements of individuals with literacy needs. The objective was to develop offerings that would enhance the health literacy of the

target group in conjunction with the app. Upon the completion of the app in early 2023, satisfaction surveys were carried out in three focus groups to gather immediate feedback.

3.2 Agile development process and design of the DiGeKo-app

The process of developing the app commenced in May 2021, concurrently with the initial survey phase. Drawing from the insights gathered through ongoing analyses of the data collected from telephone interviews and focus groups, the project team embarked on crafting an initial version of the app during various internal workshops. This phase entailed considerable experimentation, requiring time to refine the content and graphical interface.

A significant insight from the first phase of interviews identified the medical history form, which patients are required to fill out at the commencement of treatment in a doctor's surgery, as a substantial barrier for individuals with low literacy levels. This challenge significantly impedes their ability to access medical services. Consequently, the primary feature of the app to be developed and tested was a medical history form that users could complete using voice input. Unfortunately, due to concerns regarding data protection, this functionality was ultimately not incorporated into the final version of the app. An information landscape with five main topics and several subtopics in simple language (Jacobi 2021) was designed as the "heart" of the app. Each new development in the app was tested by the target group. This iterative approach allowed the app to be better and better adapted to the needs of the target group. The focus of the 10 tests was primarily on the navigation in the menu and the design of the icons. There were three major revisions before the release in May 2023. To provide information about the app, an explanatory video (YouTube) was created, which can be accessed via a QR code and contains information on how to download, install and access the app.

4 Participatory elements in the research-project DiGeKo-Net: Critical reflection on the research and development process

The bond between literacy and the prevailing societal perception of education is remarkably strong. Literacy skills are considered fundamental for educational endeavors, leading to a situation where individuals lacking these skills are often labeled as uneducated. When education is further construed as a prerequisite for successful societal participation, the ramifications of such labeling are profound. This results in stereotypes about individuals' lack of agency, independence, and their inability to engage meaningfully with society. Such stereotyping, including the notion that individuals with insufficient literacy skills struggle with day-to-day life, generally fosters deficient (self-) perceptions among those affected. Becoming a subject in such conditions is marked by a social order that values motivation, educational achievement, and 'usefulness,' predominantly placing the burden of 'inabilities' on individuals themselves (Groß/Hövermann, 2015). Following Hirschauer, (2017) and Karim/Waldschmidt, (2019), ascribed 'inabilities,' along with the consequent devaluation and exclusion, can be recognised as social dispositives. These are produced "structurally, praxeologically, and through theories of subjectivisation" and should be seen as a "tense interrelationship between 'normality' and a specific type of 'otherness'" (Karim/Waldschmidt, 2019, p. 270). These insights align with ableist perspectives. Ableism is an attitude "deeply entrenched and closely tied to social notions of normality" (Köbsell, 2016: 93). It permeates social structures and practices "that unilaterally and essentialisingly assess individuals' worth based on their abilities, thereby legitimising the discrimination and marginalisation of those deemed incapable" (Karim/Waldschmidt, 2019, p. 271). From this viewpoint, it's not just the ability and performance orientation of societies that needs questioning but, similar to other "isms," the polarisation and hierarchisation of

individuals into groups, which further legitimises social exclusion and power dynamics (Köbsell 2016).

The deep-seated nature of "ability regimes" within society (Campbell, 2009: 6) is also evident in the ways individuals subject to ableist discrimination internalise these norms or construct their identities around them. The essentialising processes facilitated by social evaluations, assessments, and classifications can cultivate a deficient self-image of 'otherness.' This perception complicates the ability to critically interrogate the practices of 'doing inability' (Karim/Waldschmidt, 2019) or to engage in resistant practices. The impact of the 'inability' dispositive necessitates critical examination within research endeavors. From our standpoint, it is crucial to question the extent to which we, as researchers, contribute to the perpetuation of social stigmatisation and power imbalances through our chosen research questions and methodological pursuits.

Consequently, adopting a critical-reflexive posture towards markers of difference and associated devaluative practices throughout the research and development process was essential for our perspective. Involving the users of the app as early and comprehensively as possible is vital, but so is engaging with their often complex experiences of discrimination and stigmatisation, along with their practices of "undoing" (Karim/Waldschmidt, 2019). Following Hirschauer (2017), we interpret "undoing" as everyday practices that disregard, negate, and undermine a marker of difference (Heyrock/Polat/Thege 2022), offering a path towards deconstructing these deeply embedded social norms.

Despite the challenging circumstances outlined earlier, ensuring the engagement of our target groups and cooperation with practice partners and other stakeholders remained a pivotal concern throughout all phases of the project. During the focus group discussions with our participants, it became evident that the participatory app motivates individuals with lower literacy levels to engage with digital technology and broadens their health knowledge. However, given the framework conditions described and other influencing factors, we have acquired valuable experiences in the research and development process that, in retrospect, prompt us to reconsider or refine certain methodologies in future projects. We aim to share these insights below.

4.1 Dealing with forms and complex language

Feedback was actively sought from the target group at every phase of the design and development process. This approach enabled the project team to adjust both the management of project formats and the employment of technical terms to better meet the needs of the target group. A common theme across almost all interviews was the respondents' sense of uncertainty surrounding medical history forms and other information documents encountered in doctors' surgeries, especially concerning the requirement to sign these forms at the end.

In an attempt to mitigate concerns similar to those experienced in medical settings, participants were provided with a study information sheet and requested to sign a declaration of consent as part of their engagement in the project. To address their concerns, the details contained within both documents were communicated to the participants via telephone and in person. Special attention was given to explaining the anonymisation or pseudonymisation of their data, how the data would be used in publications, and their right to withdraw from the study. Supportive measures included the provision of reading aids in simple language to further clarify these points.

Additionally, the forms were made available to participants prior to the interview, enabling them to complete them independently of the project staff and, if needed, with assistance from others. Implementing an audio version of these documents and making them available in accessible PDF formats would have been advantageous to ensure that the information remained accessible to the participants following the information sessions. However, these were not implemented within the scope of the project.

The use of language, especially the employment of specialist terminology, necessitates ongoing reflection on the language utilised. Specialised language has a distinct within research contexts; however, it should not be taken for granted that academic terms are universally understood. This insight was particularly underscored through reports of interactions with healthcare professionals. Consequently, this understanding informed our development of interview guideline questions that were suitable for our target audience, as well as our approach to conveying information about data protection and consent forms.

Especially in settings such as interviews and focus groups, there is a tendency among researchers to use terms and phrasings that are deeply rooted in theoretical frameworks. This practice can inadvertently create a barrier between the researchers and the interviewees, potentially leading to misunderstandings and complications within the interview context. Recognising and addressing this issue is crucial for facilitating clearer communication and ensuring that all participants are able to engage meaningfully with the research process.

4.2 Literacy as a spectrum and heterogeneity of the target group

When discussing the design of the app, it was crucial for everyone involved – both participants and project staff – to underscore that the term "limited literacy" encompasses the reading and writing abilities as well as the life experiences of a highly diverse group of people, whose needs may vary significantly (Grotlüschen/Buddeberg/Solga, 2020). A notable illustration of this was the strong preference expressed by numerous participants for text to be displayed on the app screens. They found it exceedingly helpful to visually track the information being read aloud, thereby enabling individuals with basic literacy skills to independently engage with the content. Conversely, some participants perceived the initial desire to exclude text from the app as discriminatory – a viewpoint that exposed the project staff's stereotypical assumptions about the supposedly textless existence of individuals with low literacy, thereby misrepresenting their actual living conditions. According to Heyrock (2023, p. 224), this approach also overlooked the diverse "strategies and skills that people with reading and writing difficulties develop in a society centred around writing".

For the project staff, this entailed navigating ambiguities, given that a small fraction of the target found texts on the screens to be somewhat daunting and confusing. Given the project's commitment to accommodating the varied needs and preferences of individuals in line with their heterogeneity, an additional survey was conducted among other participants. This aimed to discern a trend that culminated in the decision not to entirely eliminate written texts from the app. Furthermore, project flyers were produced using straightforward language and enlarged fonts, and the option to access a video elucidating the flyer's content via a QR code was introduced.

4.3 Lack of anonymity during prototype testing

The target group regularly tested various prototypes of the app, exploring the latest functionalities. These tests were accompanied by a project member through participant

observation, with the app's usage being recorded in a log. Following the tests, participants were invited to complete a brief questionnaire about their experiences. The questionnaire's inquiries were centred around the app's design, such as the placement of images and text, as well as its functionality.

While devising the questionnaire, the project team pondered over ensuring the anonymity of participants who might face challenges with reading and writing. After exploring digital versions equipped with a read-aloud feature without success, the team decided on response options represented by three distinct thumb positions: thumbs up for agreement, thumbs sideways for ambivalence, and thumbs down for disagreement. Each query was symbolised by a specific icon, with project members identifying the icon and voicing the related question or statement. Participants could then privately indicate their response and deposit the folded questionnaire into a sealed box.

This approach was successful to an extent but also led to confusion among participants; it was not always clear whether the responses corresponded accurately to the intended questions or statements. Some interviewees independently proposed forgoing anonymity to facilitate an open survey. Others expressed a preference for direct discussions from the beginning to convey their feedback on the app prototype. Consequently, the project team was confronted with the challenge of balancing the requirement for quantifiable data against the merit of direct feedback from participants for the app's continued development. Considering the often stressful scenarios associated with anonymous data collection, the team resolved to discontinue the use of questionnaires in favour of alternative feedback methods in the further development of the app.

Having delineated the obstacles encountered during the research process and the ensuing conclusions for subsequent research endeavours, we now wish to illustrate, through two particular instances, how project and research goals were refined in a manner more aligned with the target group's needs. This was achieved through impromptu suggestions from the target group, leading to pivotal modifications during the research process.

4.4 Interactional health literacy through conversational opportunities

While we distance ourselves from the premise that health literacy can only be attained if individuals possess adequate reading and writing skills, the categorisation of health literacy into functional, interactional, and critical levels serves as a fitting framework for operationalising and rendering health literacy "measurable". Nutbeam (2015) defines interactive health literacy as the capability to extract health information from diverse sources, such as through conversations and various media. This form of health literacy development can empower individuals, enhancing their confidence and autonomy in managing health information and engaging with healthcare professionals (Nutbeam, 2015, p. 17). The survey scenarios within the project itself served as catalysts for such interactional opportunities. Even in the absence of healthcare professionals, numerous chances arose to inquire about health and the healthcare system and to engage in discussions on these subjects.

During the prototype testing phase, we attained valuable insights, particularly from utilising various icons that represented health issues. Following a brief overview of the project and its objectives, participants were invited to examine a selection of icons, share their impressions of them, and attempt to identify the health matters they depicted. Notably, the icon representing a health card sparked animated discussions. Some participants, unacquainted with such a notion from their countries of origin, relayed challenging experiences faced during periods without a

health card. Specific queries emerged, for instance, regarding the card's utility during medical appointments, which were predominantly addressed by the participants themselves rather than by the project team. This highlighted to the project team that the concept of the health card necessitated further clarification in certain situations and perhaps could not be adequately conveyed by a single icon alone. It became evident that the participants actively seized the chance to assist each other by posing and responding to questions. This collaborative exchange was acknowledged as a substantial contribution to the enhancement of health literacy.

4.5 Self-efficacy experiences

Nutbeam (2015) underlines that the enhancement of health literacy transcends the mere acquisition of knowledge, such as learning to read and write. A pivotal component is self-efficacy – the belief in one's capability to positively influence one's own health and to exchange information about it: “Progression between categories is not only dependent upon cognitive development but also exposure to different forms of information (content and media). It also hinges on a person's confidence to respond effectively to health communications – usually described as self-efficacy” (Nutbeam, 2015, p. 17). The participatory process of app development provided numerous opportunities for participants to experience self-efficacy. This was particularly noticeable among participants who were involved over the long term, as they could observe the incorporation of their own suggestions and modifications during the testing phases of the prototypes. The responsibility for actioning change requests, or explicating why this might not be feasible, in a clear and open manner, and discussing this with participants, was borne by the members of the project team.

5 Conclusion

Throughout the research project, we were able to cultivate a deeper understanding of the diverse needs and viewpoints of the target groups and raise awareness among pertinent stakeholders through the project's networking activities. Information significant to the project was conveyed to the members of the project steering group during collaborative meetings. The findings from interviews, which covered topics such as experiences of discrimination, barriers and challenges within healthcare, coping mechanisms, and resources, were shared with professionals and key influencers in online workshops. Furthermore, target group-specific needs were explored alongside them. It was of paramount importance for us to engage in self-reflective and critical discussions with all participants concerning potential stereotypes associated with individuals referred to as “low-literate” and to actively work against such perceptions.

Adopting the viewpoint that one can navigate an “educated” society even without literacy skills, we seized various moments throughout the project development phase to deconstruct (our own) perceptions and images of individuals with low literacy skills. This involved a continual negotiation of the demands and constraints set by the framework conditions. Like many other sectors, the pandemic exacerbated disadvantages and curtailed participation opportunities. For individuals with low literacy levels, access to nearly all services was lost during this period, and the transition to digital alternatives was often unfeasible due to a scarcity of digital resources and limited skills.

In the context of the project, this scenario led to the impossibility of reaching certain segments of the target group, and the surveys conducted, such as those via telephone, encountered obstacles due to the lack of personal interaction. As a result, fulfilling essential needs of the target group, like establishing trust, proved to be substantially more difficult. Although it was not always feasible to fully realise the deconstructive and participatory aims, discussions with

both internal and external project partners underscored the notion that literacy should not be viewed as the sole avenue to participation and equal opportunities. The findings of our project and our interactions with test subjects highlight the need to challenge an inclusion approach that operates under the premise of compliance with predefined ideas and prerequisites (Hussain 2010, p. 204). Instead of viewing poor reading and writing abilities as deficiencies, they should be recognised as elements of complex life stories and social-educational processes.

These insights are not only theoretically relevant but also have clear implications for social work practice. People with low literacy constitute a significant, though often implicitly addressed, target group of social work, particularly in fields such as health-related counselling, social assistance, adult education, and community-based work. The study underscores that the barriers encountered by this group cannot be understood as individual limitations but must be analysed as structurally produced through literacy-dependent institutional and digital environments. Rather than framing participation as dependent on individual goodwill, the concept of *participatory moments* directs attention to how social work practice itself is shaped by—and can critically intervene in—these structural conditions. It highlights the ways in which participation, voice, and agency are enabled or constrained through professional routines, institutional settings, and power relations, including those embedded in communication practices and digital infrastructures. The findings further emphasise the importance of involving people with low literacy as knowledgeable actors in the development of digital tools used in social work contexts. Such participatory development processes can contribute to more accessible resources and support social work's professional commitment to inclusion, participation, and social justice.

Taken together, these considerations ultimately raise more fundamental questions about how literacy, education, and agency are normatively defined. At the heart of this issue is the critical analysis of an educational norm that regards literacy skills as the exclusive method through which to gain education and, consequently, the means to develop agency. While a binary viewpoint on literacy skills imposes uniform characteristics and capabilities upon people classified as having low literacy skills—thereby failing to acknowledge their heterogeneity—the perspective of viewing literacy as merely one of numerous competences offers an opportunity to alter our perception of individuals with low literacy skills. Rather than labelling them as "incapable," this viewpoint recognises them as individuals endowed with the necessary resources to manoeuvre through a world suffused with written communication, enabling them to perpetually create avenues for interaction and inclusion. Throughout the interviews, the participants did not express a need for literacy per se, but rather for visibility and accessibility. Consequently, the notion that literacy is the sole means to enhance health opportunities at a community level and to dismantle barriers warrants critical examination and ongoing reevaluation in professional practice, such as within health promotion interventions and strategies.

To achieve this objective, it is crucial to challenge the sensationalised depictions in the media with alternative narratives and to critically assess the impact of stereotypes on the framing of issues within research and support frameworks. The goal, therefore, should be to consistently incorporate the viewpoints of individuals with low literacy into these discussion processes, ensuring their experiences and needs inform and shape the discourse.

Ethical Approval

All procedures carried out in the study are in accordance with the ethical standards of the Federal Ministry of Education and Research Germany (BMBF) and the Committee on Publications Ethics and Research Integrity Policies for Authors. Informed consent was obtained from all persons involved in the study.

Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

Federal Ministry of Education and Research (BMBF): Funding Guideline: FH-Social 2018: Guideline for the Promotion of Research at Universities of Applied Sciences to Improve Quality of Life in Urban and Rural Areas through Social Innovations (“FH-Sozial“) as part of the programme “Research at Universities of Applied Sciences“.

Funding Code: 13FH016SX8

References:

- Barton, D., & Hamilton, M.** (2000). Literacy practices. In David Barton, Mary Hamilton & Roz Ivanič (Eds.), *Situated literacies: Reading and writing in context*, (pp. 7-15). London: Routledge.
- Campbell, F. K.** (2009). *Contours of ableism. The production of disability and abledness*. Houndsmill, Basingstoke, Hampshire: Palgrave, MacMillan.
- Groß, E., & Hövermann, A.** (2015). Die Gefährdung des Sozialen im hoch entwickelten Kapitalismus. Inklusion, Abwertung und Ausgrenzung im Namen neoliberaler Leitbilder. *Jahrbuch für Pädagogik*, 1, 41-57.
- Grotlüschen, A. & Essert (Mamedova), S. & Dutz, G. & Buddeberg, K. & Skowranek, K.** (2025): LEO PIAAC 2023 – Level One im deutschsprachigen Raum. Broschüre. DOI 10.25592/uhhfdm.17831.
- Grotlüschen, A., Buddeberg, K., & Solga, H.** (2020). Leben mit geringer Literalität – ein Paradigmenwechsel. In Anke Grotlüschen/Klaus Buddeberg (Eds.), *Leo 2018. Leben mit geringer Literalität* (pp. 5-11). Bielefeld: wbv Media GmbH & Co KG.
- Grotlüschen, A., & Riekman, W. (Eds.)** (2012). *Funktionaler Analphabetismus in Deutschland. Ergebnisse der ersten leo. – Level-One Studie*. Münster, New York, München, Berlin: Waxmann.
- Hartung, S., & Wihofszky, P., & Wright, M. T.** (2020). Partizipative Forschung – ein Forschungsansatz für Gesundheit und seine Methoden. In S. Hartung, P. Wihofszky & M. T. Wright (Eds.), *Partizipative Forschung* (pp. 1-19). Wiesbaden: Springer Fachmedien.
- Heilmann, L.** (2020). Literalität, gesundheitsbezogene Praktiken und Grundkompetenzen. In A. Grotlüschen & K. Buddeberg (Eds.), *Leo 2018. Leben mit geringer Literalität* (pp. 122-285). Bielefeld: wbv Media GmbH & Co KG.
- Hirschauer, S. (Eds.)** (2017). *Un/doing Differences. Praktiken der Humandifferenzierung*. Weilerswist: Velbrück Wissenschaft.
- Hussain, Sabina** (2010). Literalität und Inklusion. In M. Kronauer (Eds.), *Inklusion und Weiterbildung. Reflexionen zur gesellschaftlichen Teilhabe in der Gegenwart* (pp. 185-210). Bielefeld: W. Bertelsmann Verlag.

Jacobi, P. (2021). *Barrierefreie Kommunikation im Gesundheitswesen. Leichte Sprache und andere Methoden für mehr Gesundheitskompetenz*. Berlin: Springer Verlag GmbH.

Karim, S., & Waldschmidt, A. (2019). Ungeahnte Fähigkeiten? Behinderte Menschen zwischen Zuschreibung von Unfähigkeit und Doing Ability. *Österreichische Zeitschrift für Soziologie*, 44(3), 269-288.

Köbsell, S. (2016). Doing Disability: Wie Menschen mit Beeinträchtigungen zu „Behinderten“ werden? In K. Fereidooni & A. P. Zeoli (Eds.), *Managing Diversity* (pp. 89-103). Wiesbaden: Springer VS.

Nutbeam, D. (2015). Defining, measuring and improving health literacy. *JAMHTS* 42(4), 450-456.

Steuten, U. (2014). Literalität und Stigma. *Hessische Blätter für Volksbildung* 64, 125-135.

Street, B. (2003). What's 'new' in New Literacy Studies? *Critical approaches to literacy in theory and practise. Current Issues in Comparative Education*, Vol. 5(2), 77-91.

von Unger, H. (2014): *Partizipative Forschung*. Wiesbaden: Springer Fachmedien Wiesbaden.

Winker, G., & Degele, N. (2009). *Intersektionalität. Zur Analyse sozialer Ungleichheiten*. Bielefeld: transcript Verlag.

Author's Address:

Merle Heyrock
Kiel University (CAU)
Institute of Educational Sciences, Department of Social Pedagogy
heyrock@paedagogik.uni-kiel.de

Author's Address:

Ayça Polat, Prof. Dr
Carl von Ossietzky University Oldenburg
Center for Migration, Education and Cultural Studies
ayca.polat@uol.de
<https://uol.de/ayca-polat>

Author's Address:

Britta Thege, Prof. Dr.
Kiel University of Applied Sciences
Institute for Interdisciplinary Gender Research and Diversity
britta.thege@haw-kiel.de