Evidence Based Library and Information Practice

# For Optimal Inclusivity in the Research Process, Researchers Should Reflect Early and Often on How to Create Welcoming Research Environments

## Muir, R., & Coe, M. (2023). 'Out of sight, but not out of mind': A collaborative reflective case study on including participants with invisible disabilities in LIS research. Journal of Australian Library and Information Association, 72(1), 26–45. https://doi.org/10.1080/24750158.2023.2168115

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Article abstract

Objective – To reflect on what it means to include people with invisible disabilities as research participants in research projects.

Design – Collaborative, reflective case study using interviews.

Setting – Doctoral-granting institution in Australia.

Subjects – 2 LIS professionals who were also pursuing doctorates (practitioner-researchers) interviewed each other, each participant fulfilling the role of both interviewer and interviewee.

Methods – The researchers did a reflective case study, each reflecting on their own past experiences of including people with invisible disabilities (PwID) as research participants in projects for their doctoral theses. They then interviewed each other and engaged in collaborative discussions. Each interviewer audio recorded and transcribed their own interview, which they also coded individually. The researchers then reviewed the individual coding together and subsequently created a single collaborative codebook that described the emerging themes. The researchers used NVivo software in the development of both the initial codes and final codebook.

Main Results – The authors discuss four broad themes that emerged from their coding: "ethical approval for research," "creating welcoming research environments," "disclosure of invisible disabilities," and "use of data." Key topics in the discussion include questioning assumptions about research subject vulnerability, the value of being sensitive to individual participant voices, the difference between formal disclosure of invisible disabilities (ID) and disclosure that emerges organically throughout the course of an interview, and how research designs that do not consider PwID can create limitations on the use of data from PwID.

Conclusion – The article authors noted that researchers should expect that those who participate in their research studies may be PwID, whether or not it is disclosed or explicitly relevant to the project. Thus, they suggest that when researchers shape the research design of their projects, they should thoughtfully engage in questioning their own values regarding inclusivity and not rely exclusively on ethics boards to support ethical and welcoming research environments. Thoughtful engagement might include researching what is involved in creating a safe space by considering such elements as lighting, seating arrangements, colors, and accessibility to restrooms and parking areas. In addition, the authors suggest that researchers should ensure flexibility and responsiveness within the research design and approach the project with full awareness of the impact ID may have on the research processes and the data. They indicate that researchers should remain open to acknowledging their own knowledge gaps, as well as educating others when opportunities arise. Additionally, they suggest that creating welcoming environments for research participants with ID is best done from the very beginning of a project, when it can be integral to the study design and should remain present throughout the course of the research process.

**Evidence Based Library and Information Practice**

*Evidence Summary*

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## Abstract

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## Commentary

The authors observe a gap in the literature on creating research designs and environments with PwID in mind. Hill (2013) identified this gap with a content analysis of library and information science (LIS) literature on disability and found that although much LIS literature focuses on electronic accessibility, especially in relation to visual disabilities, people with disabilities (PwD) were not often identified or included as direct participants. In research that does explore the participation of PwD, the focus is mostly on intellectual disabilities (e.g., Frankena et al., 2018). Although some types of intellectual disabilities are included in the definition of ID, additional examples of ID are chronic pain, depression, and diabetes (Disability Australia Hub, 2022), and many of these voices remain absent in LIS research.

This article was appraised using *The CAT: A Generic Critical Appraisal Tool* (Perryman & Rathbun-Grubb, 2014). Its strengths include the expertise and interests of the authors. Although they self-identify as "novice researchers," one author has extensive experience in diversity, equity, and inclusion (DEI), both in her research, in which she has deliberately recruited PwID, and in her experience as a neurodivergent librarian, and the other author with LIS research, including topics such as data management, information behavior, and metadata. Together they bring two perspectives on LIS research—one is explicitly interested in inclusivity as a research topic, and one who does not research DEI topics, but who is nevertheless interested in how inclusivity impacts research processes and data uses. Other strengths are that they define their terms, such as the difference between “reflection” and “reflexivity,” and explain the coding process in detail. They also acknowledge how their positionalities, viewpoints, and experiences as practitioners inform their research approach.

The most obvious limitation, and sometimes strength, of the study is that each of the authors plays the role of both researcher and research subject. Although this is inherent in the design of a reflective case study, the role of the “interview” merits a lengthier explanation than what the authors provide. They describe their exchanges as interviews but also as "autobiographical storytelling." No interview questions are provided via appendix, and no clear explanation of why the researchers interviewed each other, as opposed to a larger group of researchers or participants. Inclusion or exclusion criteria are ignored, which although appropriate for a reflective case study, may be questionable in a study where coded interviews serve as the data. The study also lacks clarification as to how the discussion might be different if it were not exclusively focused on ID but on all disabilities.

This study design, however, did allow for extensive "recapturing, thinking, mulling over, and evaluating" of the authors' own research experiences, as well as the complementary pairing of two researchers with different levels of experience with inclusivity to code their own thoughtful dialogue. The results are honest, helpful, and thought-provoking. They challenge the reader to question assumptions and be aware of their own standards regarding inclusivity, not only those of research ethics committees (RECs). For example, what does it mean to identify a population as "vulnerable," and how might we go about de-homogenizing this concept? And how can researchers advocate for inclusivity to RECs, especially when one's own ethical code contradicts REC guidance? There are no definitive conclusions, but their suggestions will provide a useful starting point for researchers who need guidance on how to proactively create research environments that welcome PwID.

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