

Key considerations when doing research involving people with disabilities

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Abstract

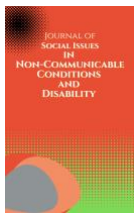
This article explores key considerations for researchers engaged in studies involving people with disabilities, drawing upon the author's experience as a researcher in various capacities within Zimbabwean tertiary institutions. Highlighting ethical practices, the article emphasizes the critical importance of obtaining informed consent, employing a person-centered approach, and ensuring accessibility throughout the research process. It discusses the necessity of building trusting relationships with participants and the value of collaboration with local disability organizations to enhance cultural competency and community engagement. The article further addresses the concept of power dynamics between researchers and participants, advocating for practices that empower individuals with disabilities and affirm their dignity. Through a comprehensive examination of these considerations, the article aims to guide researchers in conducting inclusive and impactful studies that contribute to the understanding and advocacy of the rights of individuals with disabilities. Researchers may significantly contribute to tackling the difficulties encountered by this marginalised population by emphasizing ethical frameworks and creating collaborative environments. This will ultimately advance social justice and inclusive practices.

Key words

accessibility, advocacy, cultural sensitivity, disabilities, empowerment, ethical research practices, inclusive language

Key points

1. The article emphasizes the importance of informed consent when doing research with people with disabilities.
2. It is important to employ a person-centered approach and ensuring accessibility throughout the research process.
3. As researchers, we have a responsibility to advocate for the rights and dignity of all individuals, ensuring that their voices are heard and respected within our research.



Introduction

As a social work researcher with extensive experience since 2018, I have had the privilege of working across various capacities within Zimbabwean tertiary institutions, including the University of Zimbabwe (UZ), Reformed Church University (RCU), Midlands State University (MSU), and currently at Women's University in Africa (WUA). My roles have also included serving as an enumerator for Dan Church Aid, Primson Management Services, engaging in research assistance at Friendship Bench, and working as a programmes intern at the Department of Social Development (DSD), culminating in 33 publications to date. With my academic background, holding both a BSc and MSc in Social Work, and being a registered social worker, I offer the following key considerations when researching people with disabilities.

Key considerations

1. Prioritise ethical considerations

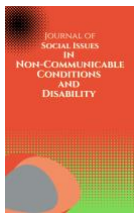
When conducting research involving individuals with disabilities, ethical considerations should be at the forefront. Researchers must obtain informed consent, ensuring that participants completely understand the nature of the study, the use of data, and their right to withdraw at any time without repercussions. Furthermore, special attention should be given to safeguarding vulnerable populations and involving guardians or caregivers when necessary, especially for minors or individuals with cognitive impairments.

When working with individuals with disabilities, it is essential to ensure that the consent process is accessible and understandable. For example, in my role as an Enumerator at Dan Church Aid, I adapted consent forms into simplified language and utilised visual aids to ensure comprehension among participants with cognitive disabilities. This not only empowered participants but also strengthened the integrity of my research (Mwapaura, Chikoko, Nyabeze, and Zvokuomba, 2021; Mwapaura, 2021; Mwapaura, 2019).

2. Adopt a person-centered approach

Researching individuals with disabilities necessitates adopting a person-centered approach. It is crucial to recognise each participant's unique experiences, preferences, and capabilities. This not only enhances the quality of the data collected but also affirms the dignity and agency of individuals with disabilities. Engaging participants in the development of the research questions and methodology fosters inclusion and ensures that the research reflects their lived realities.

My experience at the Friendship Bench highlighted the importance of co-designing research tools with participants. In one project, we collaborated directly with individuals with mobility impairments to develop mobility-related questions that were relevant and respectful of their



experiences, which enriched the quality of our findings (Mwapaura and Chikoko, 2020; Mwapaura, 2023).

3. Ensure accessibility

Accessibility in both recruitment and data collection processes is paramount. Researchers should consider the physical, communication, and cognitive accessibility of research materials and settings. Providing information in multiple formats (for example, braille, easy-read, or sign language interpretation) can facilitate better participation from individuals with diverse disabilities (Mwapaura, 2021).

4. Build trusting relationships

Establishing trusting relationships with participants is essential for successful research outcomes. This involves taking the time to engage with individuals and communities, understanding their cultural context, and demonstrating genuine commitment to their well-being. Researchers should be transparent about the purpose and potential impacts of the study to build rapport and alleviate concerns.

In Zimbabwe, cultural attitudes towards disability can shape experiences and perceptions significantly. When conducting research, sensitivity to these cultural dynamics is vital. In one study undertaken at MSU, we included community leaders in the research process, which fostered trust and facilitated more honest and open discussions about the challenges faced by individuals with disabilities within their communities (Mumemo and Mwapaura, 2024).

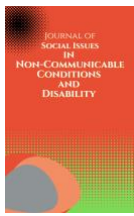
5. Collaborate with disability organisations

Collaborating with local disability organisations can enhance the research process through shared insights and advocacy. These organisations often have established trust and credibility within the community and can provide valuable assistance in recruitment strategies and cultural competency. Their involvement can also help ensure that the findings are translated into actionable solutions for the community.

Engaging with professionals from various disciplines can enhance research outcomes. Working alongside health workers, educators, and psychologists during various research projects in Zimbabwe has enriched my understanding and provided diverse perspectives, leading to comprehensive findings that can inform policy and practice (Mwapaura and Chikoko, 2021; Chikoko and Mwapaura, 2022).

6. Reflect on power dynamics

It is imperative to be mindful of the power dynamics inherent in the researcher-participant relationship. Researchers must strive to minimise these power imbalances by fostering a



collaborative environment where participants feel empowered to share their stories without fears of judgment or exploitation.

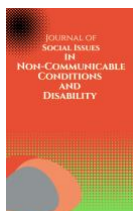
When researching vulnerable populations such as individuals with disabilities, ethical guidelines must always be followed to protect their rights. In my research experiences, particularly when working with children with disabilities, I established strict protocols for confidentiality and data protection to ensure participants were safeguarded and comfortable during the process (Mwapaura, Magavude, Munyanyi, Rufurwokuda, and Chisosa, 2022).

7. Intergenerational solidarity for enduring wellbeing

Actively including people of all ages, seniors, caregivers, and young people in the study process allows us to shed light on the common experiences and stories that define our communities. For instance, engaging grandparents of children with disabilities not only honours their wisdom but also provides valuable insights into family dynamics, care practices, and traditional forms of support that enhance resilience (Munemo and Mwapaura, 2023; Munemo and Mwapaura, 2024). This emphasis on intergenerational collaboration strengthens familial bonds and encourages a more inclusive approach to social work, promoting the wellbeing of all community members, especially those with disabilities.

Conclusion

Researching people with disabilities is a vital and impactful endeavor that requires careful consideration and sensitivity. Researchers can add to the body of knowledge that supports people with disabilities and advances social justice by emphasizing ethical practices, taking a person-centered approach, making sure that information is accessible, establishing trustworthy relationships, working with organisations, and considering power dynamics. As researchers, we have a responsibility to advocate for the rights and dignity of all individuals, ensuring that their voices are heard and respected within our research.



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