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# Reflections on the Relationship Between the Researcher and Persons With Intellectual Disabilities in an Ethnographic Study

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## Abstract

Ethnographic research entails spending time with research subjects over extended periods of time, to gain insights about aspects of their lives and their experiences. Furthermore, research participants in ethnographic studies are often referred to using terms such as interlocutors or informants, or even as friends or teachers. Such terms describe the nature of the relationship and interaction between researcher and research participant in the study, and they can reflect different epistemological assumptions held by the researcher.

Relationships with research participants with intellectual disability (ID), however, require both heightened ethical sensibility and methodological rethinking. This paper contributes to such rethinking by exploring relationships formed as part of an ethnographic study in Norway. The fieldwork focused on the everyday lives of adults with intellectual disabilities, mostly in the range of mild to moderate intellectual disability. While the need for rethinking is obvious in some cases – such as in the very “narrow” lives of people with profound intellectual and multiple disabilities (Vehmas and Mietola 2021; Skarsaune, Hanisch, and Gjermestad 2021) – the methodological potential in this kind of ethnography needs further exploration.

Through such explorations, I try to conceptualize two aspects:

- Interpretative uncertainty: How do we converse with subjects who to some extent live in different conceptual worlds, shaped by differences in cognitive capacity? Interpretations of interactions with research participants with ID can pose distinct challenges to the ethnographer. This interpretative uncertainty takes on a different character from situations involving non-disabled participants, but also in contrast to participants who are non-verbal, such as persons with PIMD. This paper explores how such situations can be approached through careful attention to details observed during participation in situations of interaction and “thick solidarity” (Liu and Shange 2018), or careful attention to the voices of participants with ID.
- Voice multiplicity: Not only is the empirical material “thick” regarding empirical detail, but it is also characterized by a “thickness” in voices surrounding research participants with ID. The paper also considers these multiple voices – the voices of family members and professionals involved in the care of persons with ID, in addition to the voice of the person with ID himself or herself – that shape the narrative of the person with ID, and how to deal with these voices. This is done, following Moser and Law (2003), with an awareness that voices do not exist in isolation and that there is more to articulation than the use of words.

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## References

Liu, Roseann, and Savannah Shange. 2018. "Toward Thick Solidarity: Theorizing Empathy in Social Justice Movements." *Radical History Review* 2018 (131): 189–98. <https://doi.org/10.1215/01636545-4355341>.

Moser, Ingunn, and John Law. 2003. "'Making Voices': New Media Technologies, Disabilities, and Articulation." In *Digital Media Revisited: Theoretical and Conceptual Innovation in Digital Domains*, edited by Andrew Morrison, Terje Rasmussen, and Gunnar Liestøl, 491–520. Cambridge, Massachusetts: The MIT Press.

Skarsaune, Synne Nese, Halvor Hanisch, and Anita Gjermestad. 2021. "Self-Determination: What Can We Learn from Persons with Profound Intellectual and Multiple Disabilities?" *Scandinavian Journal of Disability Research* 23 (1): 317–27. <https://doi.org/10.16993/sjdr.830>.  
Vehmas, Simo, and Reetta Mietola. 2021. *Narrowed Lives: Meaning, Moral Value, and Profound Intellectual Disability*. Stockholm University Press. <https://doi.org/10.16993/bbl>.