



Recruitment of research participants with intellectual disability in a Norwegian context – a response to Williams

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Recruitment of research participants with intellectual disability in a Norwegian context – a response to Williams

Williams's paper discusses a very important topic for researchers that want to include the voices of people with intellectual disability (ID): how to get in touch with possible participants.

When I was asked to give a response to Williams's paper, I could draw on some experiences from my own projects, but I also checked some other Norwegian projects where people with ID have been participants. Although I know from personal communication with several researchers that recruitment often has been difficult, and there are some hints of this in papers and reports, it seems to be a topic that calls for further investigation. In relation to recruiting people with ID as researchers, the term 'gatekeepers' is rarely mentioned or used. A term used by e.g. Kittelsaa (2008) is 'door opener' that might give the same consequences for recruitment as 'gatekeeper'. But the context in which the term is used gives it a more positive association. 'Opening doors' is less restrictive than 'keeping the gate'. Kittelsaa describes managers, parents and legal guardians as possible 'door openers'. She also describes how staff in a day care centre refused access, although the manager had permitted it, and in this case she uses the term 'gatekeeper' instead of 'door opener'. She describes that she chooses to take a humble role as a trainee in such situations, based on the recognition of the staff as gatekeepers. Nevertheless, both the terms door opener and gatekeeper point to the fact that there is some kind of a hurdle, even if this might be necessary, between the researcher and possible participants.

In the project, 'That's the way I like it! Self-assertiveness and self-determination in persons with intellectual disability' (Østby et al. 2018), we experienced that it was difficult to get the invitation and information through the system, from managers and out to the persons we wanted to recruit. This was especially difficult in the largest municipality, and we had to settle with fewer participants than we wanted. This is in line with Williams's experiences. Due to time limitations, we did not investigate the reasons for this. One explanation might be that the topic itself, self-assertiveness and self-determination, might be challenging for staff. The same was found in Witsø and Hauger (2019), a study where staff shared experiences on recruitment to a workshop on everyday life. They were shocked by the fact that some staff from their own services hampered users' participation out of fear of giving them «wrong ideas».

Williams also found gatekeepers at the system level. In Norway we have The Norwegian Centre for Research Data (NSD) and The Norwegian National Research Ethics Committees (REK) who assess research projects to ensure that the process of collecting personal data meets the requirements of the law. There are specific requirements for the information and content forms, and this is important for the safety of the persons involved. However, the form is not accessible for some of the participants with intellectual disability. Cameron and Murphy (2006) suggest a variety of accessible information and content forms, but these would not comply with the demands of the NSD and REK. Possible participants then would have to receive oral explanations or extra written information, and then sign the official form. The necessity of being sure about the rights of protections for the participants is clear and the main function of NSD and REK, but it is a dilemma that might be experienced as paternalistic and over-protective and prevent participation from people with ID. In such cases, the system might function as a gatekeeper.

This brings me to Williams's discussion of vulnerability, and the importance of seeing this in a wider context of discrimination. A lack of recognition of abilities and capacity in people with ID has, according to Chalachanová, Gjermestad, and Lid (2019), led to protective and paternalistic attitudes from the people supporting them. This has again led to omission from research.

To ensure that the voices and meanings of peoples with ID can contribute to better understanding of their lives and to better services, one has to consider how to work to get through to possible participants. The risks of harm have to be met by getting to know the participants and their way of expressing themselves, making information more accessible as Williams suggests and constantly checking participants' well-being during research. Researchers in Norway pay increasing attention to how gatekeepers might prevent recruitment, and need more knowledge about why this happens and how to resolve these situations.

Disclosure statement

No potential conflict of interest was reported by the author.

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