
Navigating barriers to human rights based participatory research with persons with learning disabilities. A Spanish experience.

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Résumé

This paper explores persistent forms of institutionalization in persons with learning disabilities' lives identified through the experience of conducting a co-researched project during the pandemic in Spain and strategies to overcome some of the barriers and institutionalized forms of relations.

During the pandemic, I conducted human rights based participatory research with people with disabilities in Spain, which I followed through recordings and reflexive note taking. One of projects was together with people with learning disabilities who attend different service providers linked to the umbrella organization Plena Inclusión Madrid. During our project, we explored the impact of covid on the lives of people with learning disabilities in Madrid. The project was done online during the year 2021, with two in person meetings in September and November. We developed a questionnaire and, at a second stage, a group interview. The categories to select participants were based on their living arrangement, i.e. at home with parents, alone, supported flat or residential care. The analysis was carried out jointly, and the write-up was delegated to the academic researcher under the supervision of the co-researchers. Presentations are due in January 2022.

The experience of being a co-researcher made me encounter barriers they experience on a daily basis or institutionalized norms which hindered the course of the project, e.g. lack of intimacy or of flexibility on behalf of services. For instance, it was particularly hard to reach people living in residential care or to arrange in person meetings that could cater everybody's needs due to inflexible schedules. Some participants also had less access to an electronic device, poor wifi, less choice during the pandemic on what activities to do and little choice over risk taking. Control exercised over them but also by fellow residents or users of services for people with disabilities was also a common theme in the co-researched project and in my own project. I had to manage or address these barriers without reinforcing them or putting my co-researchers in an uncomfortable position. I was concerned that challenging them bluntly could lead to denial, a reduction of opportunities for participation and inclusion or withdrawal from the research project. Moreover, it may be an unwanted intromission into the persons' lives and lifestyle.

The paper will describe the methodology used during the project in alignment with the Convention on the Rights of Persons with Disabilities. My call for participants was in the form of an inverted job offer, in which offered my services as researcher to do a research project together. The group hiring me was to choose topic, methodology and author the research. We put together a collaboration agreement to hand over control over the research process

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and activities to my co-researchers. The project began with an eight-module training in combination with work sessions to design the research project. We met on a weekly basis over zoom and communicated over email and whatsapp. The paper will cover some reflections on institutionalized forms encountered in doing research collaboratively, both in form of self-reflexions on my style of facilitation and in the findings of our co-researched project. Further, I will share some of the ways I shaped my work to ensure choice and criticism was possible and to create opportunities to engage with research beyond this project, as well as recommendations on how to tackle the barriers encountered.