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# ‘Nothing Without Us... Not Even Research’: Opportunities and Challenges of Developing Participatory Research With Persons With Intellectual and Psychosocial Disabilities

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## Résumé

Traditionally, persons with disabilities were excluded from research processes, reproducing in the scientific arena the barriers and discrimination they faced in everyday life (Oliver, 1992). While this historical invisibility is slowly being overcome, research continues to be conducted from a medical and individual perspective that perpetuates unequal power relations, with persons with disabilities being treated as objects, rather than active subjects of research.

For persons with intellectual and psychosocial disabilities, exclusion and disempowerment in research processes is compounded by the invisible nature of their impairments, and the pervasive negative social representations that enclose their lives. Holding a core belief in the capacity and right of all disabled persons to be engaged in the decisions that affect them, including research decisions, as in article 12 of the UNCRPD, this presentation draws from a participatory research project that aims to assess the implementation of the law on legal capacity in Portugal. Applying the lens of the sociology of human rights as a theoretical framework, methodologically the research adopts a participatory research approach that promotes the active involvement of a team of co-researchers with intellectual and psychosocial disabilities working alongside a multidisciplinary team of researchers to design and apply qualitative data collection tools, such as photovoice, interviews and focus groups.

This presentation will proceed in two parts. First, we will describe this experience of research co-production, which lasted for over a year, and the various steps it encompassed, including the last one which involved gathering the perspectives of all researchers (disabled and non-disabled) about the research process and the research collaboration. Then, we will develop a critical reflection, guided by three key questions: (1) How do the multiple actors (non-disabled researchers and co-researchers) view their lived experiences of collaboration in this project? (2) What ethical, methodological and practical challenges were faced and what opportunities were found? (3) What lessons can be learned from this participatory research design?

We hope with this paper to be able to devise some tips and recommendations for the future

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development of participatory research with persons with intellectual and psychosocial disabilities, while addressing some of the issues and shortcomings that we have faced. Placing persons with disabilities at the forefront of scientific production is an important goal that allows us to start redressing power inequalities, while extending the motto of the international disability rights movement, "nothing about us without us", to all stages of research production.