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Despite the rise of participatory approach in research productions, the research practices that involve persons with disabilities remain decidedly limited. To date, evidence of co-researching with persons with disabilities is mostly concentrated in health studies (Stewart and Bhagwanjee, 1999), and in intellectual and learning disabilities literature (Nind and Vinha, 2012; Bigby, et al., 2013). Research conducted or led by persons with disabilities in humanitarian studies, however, is lacking (Robinson et al., 2020). Tanabe, et al. (2017) has explored participatory research in humanitarian settings, however with an emphasis on the health sector only.

We seek to fill the knowledge gap with evidence of co-researching with persons with disabilities. We will share the lessons learned from implementing methods that ensure the active participation of persons with disabilities as co-researchers. These methods include building the capacity of persons with disabilities on the research topic and instruments, pre-interview role-plays, field pilot testing, post-data collection debriefing and reflective learning through writing learning diaries. Our experiences show that persons with disabilities have the drive and the capacities to contribute to research. Methods such as continuous engagement, capacity building, and feedback mechanisms are essential to enable their participation and influence in the research production process. These methods have the potential to provide empowering experiences for persons with disabilities, however, they are often time-consuming and can be convoluted.

References:

- Bigby, C., Frawley, P., and Ramcharan, P. (2013). "Conceptualizing Inclusive Research with People with Intellectual Disability", *Journal of Applied Research in Intellectual Disabilities*, Vol. 27, pp. 3–12, <https://doi.org/10.1111/jar.12083>.
- Nind, M. and Vinha, H. (2012). "Doing research inclusively, doing research well? Report of the study: Quality and capacity in inclusive research with people with learning disabilities", Economic and Social Research Council, University of Southampton, available at https://cdn.southampton.ac.uk/assets/imported/transforms/content-block/UsefulDownloads_Download/97706C004C4F4E68A8B54DB90EE0977D/full_report_doing_research.pdf
- Stewart, R. and Bhagwanjee, A. (1999), "Promoting group empowerment and self-reliance through participatory research: a case study of people with physical disability", *Disability and Rehabilitation*, Vol. 21, No. 7, pp. 338-345.
- Robinson, A. Marella, M. and Logam, L. (2020), "Gap Analysis: The Inclusion of People with Disability and Older People in Humanitarian Response", https://www.elrha.org/wp-content/uploads/2020/07/Elrha-HIF_Gap-Analysis_Inclusion-of-people-with-disability-and-older-people_Literature-Review2020-A.pdf (accessed 12 November 2020).
- Tanabe, M., Pearce, E., and Krause, S. K. (2017). "“Nothing about us, without us”: conducting participatory action research among and with persons with disabilities in humanitarian settings", *Action Research*, pp. 1-19, DOI: 10.1177/1476750316685878.

Emerging voices and pathways to inclusive disaster studies