

Tips for Co-researching with Persons with Disabilities

Research practices that involve persons with disabilities as co-researchers are extremely limited. In fact, the participations of persons with disabilities, especially in the research regarding disability issues, are significant to ensure the research process and results are relevant to their experiences.

Here are some tips to ensure the meaningful participation of persons with disabilities in a research.



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Tips for Planning

-  Develop a research design by identifying the roles of persons with disabilities throughout the entire research process.
-  Design inclusive methods and methodologies, ethical protocols, and research instruments.
-  Plan and consult on an inclusive and transparent research budget.
-  Plan an activity on comprehending disability inclusion for all partners involved in the research team.
-  Identify and plan format tool options that are easy for all members of the research team to understand and use.
-  Identify and plan adaptations to languages and terms in the research.
-  Identify Organisations of Persons with Disabilities (OPDs) and local persons with disabilities in the research target areas and build partnerships.
-  Identify the capacities and needs of the persons with disabilities and Organisations of Persons with Disabilities (OPDs) that will be involved.
-  Identify important capacities, including experience in implementing activities that are part of the research, for example, experience in collecting data (interviews, focus group discussions).
-  Needs that must be identified include capacity building, accessibility and reasonable accommodation, needs for participating, protection and safety.
-  Involve persons with disabilities in all decision making.

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Tips for Implementation

-  Consult with persons with disabilities and ensure accessibility and reasonable accommodation to support the roles of co-researchers with disabilities.
-  Increase the capacity of co-researchers with disabilities according to the needs identified.
-  Build the capacity about disability inclusion towards other partners in the research team, including capacity building for staff.
-  Trial the research tools with persons with disabilities.
-  Facilitate and provide opportunities for consultations according to the needs of persons with disabilities.
-  Involve persons with disabilities in coordination and consultation activities with other stakeholders.
-  Do not hesitate to follow up on feedback or complaints from persons with disabilities during the research process.



Create a monitoring, evaluation and learning framework to monitor the capacity building results of the co-researchers with disabilities.



Include representatives of persons with disabilities on the research steering committee or other similar committees.



Make sure the research allows for a reflective process and aids learning for everyone involved. Develop tools or methods to assist all research team members to reflect on their experiences and lessons learned throughout the research process. For example, using learning diaries.



Document the results of the lessons learned together with the co-researchers with disabilities.



Ensure that persons with disabilities, whether members of the research team or research informants can provide feedback, suggestions, and complaints through safe and easy channels.



What did the co-researchers with disabilities say after participating in the research?



"Initially, we thought that the researchers in the research [were limited to] people with post-graduate degrees, like professors and doctors ... But once we got involved, [we realised] actually everyone was able to do it. And in terms of the self-development that took place, I certainly felt competent in conducting the research." – Irmansyah, a co-researcher with disabilities from the Dolo Barat Cluster.



"[I will] continue to learn and practice. Hopefully, I'll get involved in other research projects. Maybe our organisation will conduct research and I can take part in it." – Kusmiran, a co-researcher with disabilities from the Dolo Barat Cluster team.



"I will use this knowledge for further disaster situations and WASH services in the future." – Fadlianur, a co-researcher with disabilities from the Sindue Cluster team.

These tips are based on the experience of Arbeiter-Samariter-Bund (ASB) Indonesia and the Philippines in co-researching with persons with disabilities from the Working Group of Organisations of Persons with Disabilities in Palu, Sigi and Donggala (OPDs) Central Sulawesi. The OPDs took part as co-researchers in a research 'Investing in Inclusive Water, Sanitation, and Hygiene' (iiiWASH) in 2020-2021. The iiiWASH research also collaborated with the Center for Health Policy and Management of Gadjah Mada University (CHPM UGM).

Further guidelines, tips and lessons learned can be accessed in:



ASB Indonesia and the Philippines (2021). [Practical Guidelines for Co-researching with Persons with Disabilities: Reflections and lessons learned in participatory research on Inclusive WASH in humanitarian responses.](#)



- 'Investing in Inclusive Water, Sanitation, and Hygiene' (iiiWASH) research is funded and supported by Elrha's Humanitarian Innovation Fund (HIF) programme, a grant making facility which improves outcomes for people affected by humanitarian crises by identifying, nurturing and sharing more effective, innovative and scalable solutions.
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