



“Everyone can be involved in research”

Practical Guidelines

Tips and lessons learned from inclusive research with persons with disabilities



*Easy read
format*

Photographer:

Dwi Oblo, © ASB Indonesia and the Philippines, 2021.

All photos and testimonies in this document were obtained with the consent of the persons concerned.

Complete document of the practical guidelines can be read 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.](#)

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Terms

research ethics



Procedures or rules that should be followed in research activities. For example: always ask for the consent of research informants when collecting data from them.

inclusion or inclusive



Something is to be called inclusive if it involves everyone regardless of ages, genders, types of disabilities, and socio economic backgrounds.

research partners



Individuals or organisations which collaborate in research. For example: OPDs as research partners.

research informants



Individuals who provide information to researchers from activities like interviews, questions and answers, group discussions, and so on.

research tools



Tools to help conducting research. For example: interview questions document, informed consent document, and so on.

WASH



Safely managed water, sanitation and hygiene services.

Introduction



Photo 1: Fadlia and Zainab (members of OPDs) are interviewing a research informant.



In 2020-2021, Arbeiter-Samariter-Bund Indonesia and the Philippines (ASB) co-researched with persons with disabilities from the Working Group of Organisations of Persons with Disabilities in Palu, Sigi, Donggala (OPDs), Central Sulawesi.



The research intends to understand the barriers that persons with disabilities and older people encountered in accessing WASH or water, sanitation and hygiene services following the earthquake, tsunami and liquefaction disaster in Central Sulawesi, Indonesia in 2018.



We want to share the experiences of co-researching with persons with disabilities in these guidelines.



We wrote these guidelines because the practices of co-researching with persons with disabilities are still limited.



Usually, the roles of persons with disabilities in research have been largely limited to being the researched ones. In fact, research on disability issues should be conducted with persons with disabilities.



In this research, persons with disabilities directly and actively involved as co-researchers.



These guidelines share the lessons learned obtained from our experiences in co-researching with persons with disabilities.



It is hoped that these lessons learned will inspire a broader audience to co-research with persons with disabilities.



These lessons learned can provide information for persons with disabilities and Organisations of Persons with Disabilities (OPDs) about what should be fulfilled in research practices with persons with disabilities.



These guidelines are written by ASB, and have been consulted with the co-researchers with disabilities.

12 Tips for Planning Research with Persons with Disabilities



 Photo 2: Kusmiran (member of OPDs) is planning the research activities with ASB staff.



- 1. When planning a research, explore the interest and roles of persons with disabilities in the research.**



2. Consult with persons with disabilities on the research problems being discussed, the research methods, and plans for research activities.



3. Involve persons with disabilities in all decision making.



4. Identify OPDs and local persons with disabilities in the research target areas and build partnerships.



5. Identify the needs of the persons with disabilities that will be involved in the research. For example: accessibility needs, reasonable accommodation, and protection.



6. Identify the capacities of the persons with disabilities in practicing research activities. For example: capacity in interviewing informants.



7. Plan an activity to ensure all partners involved in the research team understand disability inclusion.



8. Identify and plan adaptations to languages in the research. For example: use local language, sign language, and simple language.



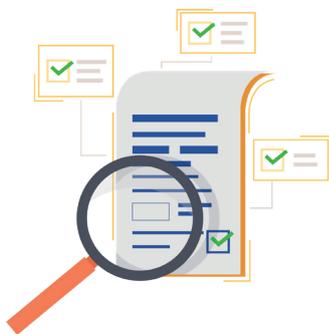
9. Identify and plan format tool options that are easy for all members of the research team to understand and use.



10. Create materials in a variety of formats that are accessible and user-friendly to persons with disabilities. For example: video, visual images, audio, braille, and easy to read format.



11. Plan and consult on an inclusive and transparent research budget.



12. Design inclusive research methods, research ethics, and research instruments.

12 Tips for Implementing Research with Persons with Disabilities



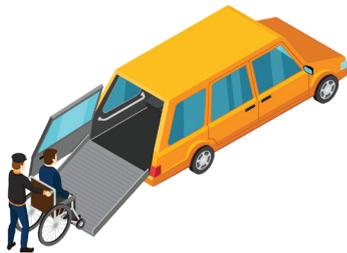
 Photo 3: Abed (member of OPDs) and Daniel (support person) are interviewing a person with disabilities.



- 1. Design trainings to increase the capacities of co-researchers with disabilities according to the needs identified.**



2. Build the capacity on disability inclusion for other research partners involved in the research.



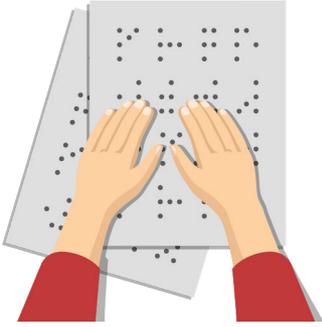
3. Ensure the accessibility and reasonable accommodation to support the roles of persons with disabilities.



4. Conduct a briefing before each activity and a discussion after each activity to get input.



5. Do not hesitate to follow up on feedback or complaints from persons with disabilities during the research process.



6. Trial the research tools with persons with disabilities.



7. Adapt and improve the research tools according to the trial experiences. Always consult with persons with disabilities when improving the research tools.



8. Facilitate and provide opportunities for consultations according to the needs of persons with disabilities.



9. Involve persons with disabilities in coordination and consultation activities with other stakeholders, for example: local governments and steering committee of the research.



10. Involve persons with disabilities and OPDs in dissemination activities of the research results.



11. Ensure the readiness and capacity of persons with disabilities in facilitating the research dissemination activities.



12. Identify how the research results can support OPDs' advocacy efforts more broadly.

7 Tips for Monitoring, Evaluation and Learning



 Photo 4: Zainab, Sultan and Irmansyah (members of OPDs) are writing learning diaries.



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



2. Create a feedback and complaints mechanism that persons with disabilities can easily and safely use to provide their feedback, complaints, and opinions.



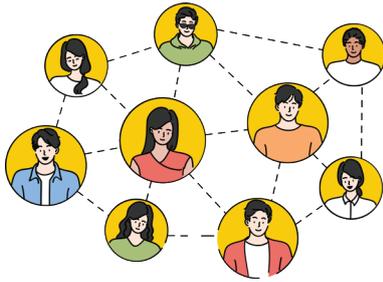
3. Make sure everyone involved in the research can learn some lessons from the research process.



4. Make sure the lessons learned of each member of the research team are discussed in group discussions.



5. Use learning diaries for persons with disabilities to write their experiences and reflections during the research activities.



6. Disseminate the results of the lessons learned from co-researchers with disabilities to support inclusion widely.



7. Make sure the results of the lessons learned are disseminated in various accessible formats for everyone.

Reflections of the Persons with Disabilities on the Experience of Co-researching



1. Skilfully applying knowledge and skills



The co-researchers with disabilities declared that they were effective and felt fully confident in practicing the research activities.

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“[What I did well] was the interviews and coordinating with the villages.” - Sultan, a co-researcher with disabilities from Sindue.

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“[What I did well] was conducting the interviews as I was able to simplify the questions without compromising the meaning” – Daniel Paembonan, a co-researcher with disabilities from Dolo Selatan.



“[What I did well was] interviewing the informants as I used language that they could easily understand” – Rizal, a co-researcher with disabilities from Dolo Barat.



“Initially, we thought that the researchers in this 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 Dolo Barat.

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2. Better understanding of applying research ethics



The co-researchers with disabilities learnt the importance of valuing the rights of the research informants. They learnt how to interact with research informants from different backgrounds.

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“I acquired new skills in these activities, that is, how to present something in a tactful and respectful manner that is easily understood by the community, in particular by persons with disabilities.”

– Abednego, a co-researcher with disabilities from Dolo Selatan.

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“[What I did well was] respecting the rights of the research subjects and their privacy and not using any form of coercion.” – Rina Hardianti, a co-researcher with disabilities support person.

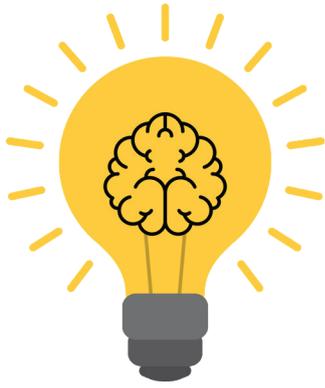


“[My opinion on today’s activity, I learnt] how to communicate tactfully so that informants would not take offence.” – Zainab, a co-researcher with disabilities from Dolo Selatan.



“[Something new that I learnt from this activity was] I realised that when dealing with people it is essential to comply with the research ethics and be tolerant as everyone has their own unique character.” – Asbiyah, a co-researcher with disabilities from Dolo Selatan.

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3. Gaining research knowledge for future use



The co-researchers with disabilities acquired new knowledge on how to conduct research and collect data for research with accountable results.



The co-researchers with disabilities shared that they want to use their knowledge and capacities acquired in this research for the benefits of the broader society.

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



“[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 Dolo Barat.



“[I will] be in charge of collecting data on disabilities, older people, mothers and children who are victims of violence; and disaster victims.” – Berlian Arta, a co-researcher with disabilities from Dolo Barat.

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“In the future, I want to conduct simple research projects using simple tools.”

– Samsinar, a co-researcher with disabilities from Dolo Selatan.



“I will apply this knowledge well in the future, including in forum meetings, musrenbang [development planning meetings] and in the community.” –

Jumaiya, a co-researcher with disabilities from Sindue.



“[I will use these skills and knowledge in the future to] assist others to increase their knowledge on inclusive WASH services.” –

Elias Katapi, a co-researcher with disabilities from Sindue.

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“[The new skills and knowledge that I have acquired include] learning how to be a researcher and facilitator for the benefit of many people.” – Yassin Ali Hadu, a co-researcher with disabilities from Dolo Barat.



“Once I am really proficient in inclusive WASH, I will be active in campaigning.” – Hery Yulianto, a co-researcher with disabilities from Sindue.



“[I will use my skills and knowledge in the future] by conducting learning activities with the community and with groups in the [WASH] field so that I continue to utilise what I have gained in this experience.” – Sadri, a co-researcher with disabilities from Dolo Selatan.

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Conclusion



The co-researchers with disabilities have involved throughout the research process and provided various inputs.



They had a very significant role in striving to improve research processes and the quality of research results.



Research can bring benefits and empowerment for the co-researchers with disabilities.



Research is no longer perceived as a difficult process exclusively for experienced academics, professors, or researchers.



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