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“Everyone can be involved in research”



Practical Guidelines for Co-researching with Persons with Disabilities

Reflections and lessons learned in
participatory research on Inclusive
WASH in humanitarian responses

About Us and Acknowledgements

Arbeiter-Samariter-Bund (ASB) Indonesia and the Philippines

ASB is a German relief and social-welfare organisation engaged in a wide range of social service provision in Germany and abroad. ASB started working in Indonesia in 2006 following the Yogyakarta earthquake and in the Philippines in 2014 following Typhoon Haiyan.

ASB is committed to improving meaningful access and participation for all. Strengthening individuals, communities, organisations, networks and decision makers' capacities to create positive change, and enhance societies' ability to manage risk. For more information, visit www.asbindonesia.org

The Working Group of Organisations of Persons with Disabilities in Palu, Sigi Donggala (Working Group of Pasigala OPDs), Central Sulawesi

The Working Group of Pasigala OPDs was established with the intention to facilitate capacity building and the active contributions of persons with disabilities in the inclusive humanitarian response following the 2018 earthquake, tsunami, and liquefaction disaster in Central Sulawesi.

The Working Group of Pasigala OPDs is an association consisting of several community-based OPDs in Central Sulawesi, namely Perkumpulan Penyandang Disabilitas Indonesia – PPDI (Indonesian Association of People with Disabilities), Himpunan Wanita Disabilitas Indonesia - HWDI (Indonesian Women with Disabilities Association), Persatuan Tuna Netra Indonesia – Pertuni (Indonesian Blind Association), and Gerakan untuk Kesejahteraan Tuna Rungu Indonesia - Gerkatin (Movement for Indonesian Deaf Peoples Welfare).

The Working Group of Pasigala OPDs continues to be actively involved in the process of inclusive community recovery in the Sigi and Donggala regions, particularly in community resilience and the WASH sector.

Elrha's Humanitarian Innovation Fund

The 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.

Elrha's HIF is funded by aid from the UK Foreign, Commonwealth and Development Office (FCDO). Elrha is a global charity that finds solutions to complex humanitarian problems through research and innovation. Visit www.elrha.org to find out more.

Research Team and Authors of the Guidelines

The research was conducted through a partnership between ASB Indonesia and the Philippines, the Working Group of Pasigala OPDs, and the Center for Health Policy and Management of Gadjah Mada University (CHPM UGM).

The research team from ASB Indonesia and the Philippines are the authors of the guidelines with contributions and reviews from the research partner teams from the Working Group of Pasigala OPDs and CHPM UGM:

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All photos and testimonies in this document were obtained with the consent of the persons concerned, including the co-researchers with disabilities, the informants, the informants' support persons, the community and local village officials.

About the iiiWASH Research

These guidelines are based on ASB's perspective as the agency leading the research "Investing in Inclusive Water, Sanitation, and Hygiene (WASH)", hereinafter referred to as iiiWASH. The iiiWASH research received funding and support from Elrha's Humanitarian Innovation Fund (HIF) program. The iiiWASH research was implemented over 18 months in 2020-2021.

The iiiWASH research aims to understand the barriers that persons with disabilities and older people encountered in accessing and participating in WASH services or the post-disaster situation following the earthquake, tsunami, and liquefaction in Central Sulawesi in 2018. The results of the iiiWASH research are anticipated to influence policies and ensure more inclusive practices in WASH services.

The Working Group of Persons with Disabilities in Palu Sigi Donggala (Working Group of Pasigala OPDs) in Central Sulawesi served as co-researchers in this research. Co-researching with researchers with disabilities was made possible through the use of participatory research strategies.

The iiiWASH research was not specifically designed to focus on building the capacity of organisations of persons with disabilities (OPDs) to become accomplished researchers, but rather to understand the inhibiting and supporting factors in providing inclusive WASH in disaster situations.

Elrha's HIF program requires collaboration with local OPDs, which is in line with the ASB program approach that prioritises partnerships and OPDs engagement to ensure inclusiveness. In regard to this, ASB designed capacity building activities for the co-researchers with disabilities to participate more meaningfully in the research. These capacity building activities included training, technical skills development, trials, as well as mentoring and coaching on implementing a series of activities for different stages of the research.

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Abbreviations

ASB	Arbeiter-Samariter-Bund Indonesia and the Philippines
CHPM UGM	<i>Pusat Kebijakan dan Manajemen Kesehatan Universitas Gadjah Mada</i> (Center for Health Policy and Management of Gadjah Mada University)
Gerkatin	<i>Gerakan untuk Kesejahteraan Tuna Rungu Indonesia</i> (Movement for Indonesian Deaf Peoples Welfare)
HIF	Elrha's Humanitarian Innovation Fund
HIS	Humanitarian Inclusion Standards for Older People and Persons with Disabilities
HWDI	<i>Himpunan Wanita Disabilitas Indonesia</i> (Indonesian Women with Disabilities Association)
iiiWASH	Investing in Inclusive WASH
KAP	Knowledge, Attitudes, and Practices
OPDs	Organisations of Persons with Disabilities
Pertuni	<i>Persatuan Tuna Netra Indonesia</i> (Indonesian Blind Association)
PPDI	<i>Perkumpulan Penyandang Disabilitas Indonesia</i> (Indonesian Association of People with Disabilities)
SC	Steering Committee
SIM	Structured Interview Matrix
WASH	Water, Sanitation and Hygiene
Working Group of Pasigala OPDs	<i>Kelompok Kerja Organisasi Penyandang Disabilitas Palu, Sigi dan Donggala</i> (Organisations of Persons with Disabilities in Palu, Sigi and Donggala)

Executive Summary

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

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

The research was conducted in partnership with the Center for Health Policy and Management of Gadjah Mada University (CHPM UGM) with funding support from Elrha's Humanitarian Innovation Fund (HIF) program.

These guidelines chronicles the experiences of co-researching with persons with disabilities in the research process through documentation of reflections, lessons learned and examples of practices. Such documentation is important given the lack of research practices that prioritise the meaningful involvement of persons with disabilities in all stages and key processes of research.

Thus far, the roles of persons with disabilities in research have been largely limited to being the research objects or enumerators.

In fact, research on disability subjects should always be conducted with persons with disabilities. Their involvement is imperative for upholding the principle of direct representation of persons with disabilities in matters that are related to them and the principle of 'nothing about us without us.'

When persons with disabilities do get the opportunity and support to become co-researchers, they bring so many benefits to a research process and it also empowers them.

These guidelines provide tips for participatory research with persons with disabilities. This includes strategy development and reflections on aspects that have worked well and those that need to be improved. It is hoped that these tips and reflections will be used as references and lessons learned for participatory research or studies with persons with disabilities, particularly in the field of humanitarian response and social inclusion.

The guidelines are presented as in a project management cycle, commencing with planning, implementation, monitoring, evaluating through to learning outcomes. Each section consists of three main topics, namely:

1. Tips, in the form of brief instructions on co-researching with persons with disabilities based on reflections and lessons learned;

2. Strategies for achieving participatory research and examples of practices; and
3. Key lessons learned and their implications for future research with co-researchers with disabilities.

The guidelines also contain reflections from the co-researchers with disabilities, the ASB research team and the CHPM UGM research team on how participatory research can be an empowering experience.



Photo 1.

A co-researcher with disabilities, Abed is interviewing an informant who is a person with a disability, using a braille document. Abed is assisted by his support person, Daniel.

Introduction

Why are these guidelines important?

The role of persons with disabilities in a variety of research that focuses on disability issues is largely limited to being the research subjects. Research practices very rarely involve persons with disabilities as co-researchers when, in fact, they are the ones who are experienced in disabilities. Their authentic experience provides significant added value to a research production process on disability issues.

It is therefore imperative that persons with disabilities are involved as co-researchers in the production of research regarding disability issues. Through meaningful involvement, persons with disabilities can ensure that research results are relevant to their experiences and that they are engaged in discussions about themselves, in line with the principle of ‘nothing about us without us’.¹

It is unfortunate that although co-researching with persons with disabilities can provide significant added value, such research practices are still very rare.² Additionally, guidelines on methods and practices for co-researching with persons with disabilities are extremely limited, thus adding to the barriers for researchers who want to conduct participatory research with persons with disabilities.³

In considering the limitations, these guidelines have an important role. They were developed based on the experiences of co-researching with persons with disabilities in the research ‘Investing in Inclusive Water, Sanitation, and Hygiene (iiiWASH)’.

These guidelines share tips, strategies and lessons learned for co-researching with persons with disabilities on humanitarian response issues, particularly in post-disaster situations, by raising topics on inclusive WASH (water, sanitation and hygiene).

Experiences in the participatory research with persons with disabilities, therefore, are a central theme throughout the guidelines. Although the experiences of persons with disabilities in accessing and participating in post-disaster WASH services are also examined, the guidelines do not intend to delineate how to collect data from persons with disabilities as research subjects.

¹ Academics with disabilities and disability activists have criticised the exclusion of persons with disabilities in research processes since the 1990s. See Oliver (1992); Barnes and Mercer (1997); Balcazar et al (1998); French and Swain (1997); Zarb (1992). They assert that research processes should be an opportunity to change the unequal power relations between researchers and those being researched. They also emphasise that research results should not have a detrimental impact on persons with disabilities, therefore engaging persons with disabilities in research production is highly recommended.

² There are a few examples of research conducted with persons with disabilities in the health sector such as Stewart and Bhagwanjee (1999) and the education sector related to intellectual disability issues, including people with learning difficulties, for example, Knox, Mok, and Parmenter (2000); Walmsley and Johnson (2003); Bigby, Frawley and Ramcharan (2013).

³ Starting in 2020, there were publications of guidelines on co-researching with persons with disabilities. See Strnadová, Dowse, and Watfern (2020); and RDI Network (2020). These two guidelines are more general and not specific to research in humanitarian responses or WASH.

The tips in these guidelines focus on how to co-research with persons with disabilities, in particular for humanitarian response practitioners who are planning or conducting research, or looking for research references on disability issues. The guidelines are also intended for persons with disabilities and Organisations of Persons with Disabilities (OPDs) wanting to know about experiences of being involved in research as co-researchers.

It is hoped that these guidelines will inspire a broader audience, including researchers from other sectors who wish to conduct inclusive research with persons with disabilities in a meaningful and empowering manner.

The guidelines are based on the project's cycle, starting from planning, implementation, reviewing, evaluation through to lessons learned. The following points are shared at each stage of the project: (1) tips for co-researching with persons with disabilities; (2) developing strategies and examples of practices to inspire research practices with OPDs; and (3) lessons learned on using strategies that generate good practices as well as supporting and inhibiting factors.

The guidelines provide reflections from participants involved in the iiiWASH research. Data sources reflecting the co-researchers with disabilities views and experiences are based on their testimonials on lessons learned and their reflections documented in 'learning diaries' and other activities, such as debriefing sessions, group discussions, and project evaluations.

The co-researchers with disabilities participated in the consultation and review stages of the guidelines as the main reviewers.

Finally, as this research was conducted in the COVID-19 pandemic context, the guidelines provide information on various adjustments made in adapting to the current situation.

Some key terms

The term 'co-researching with persons with disabilities' refers to a process of conducting joint research. The term 'co-researching with OPDs' is also used as this research was conducted in collaboration with OPDs as co-researchers with disabilities. The terms "partner researchers with disabilities" and "OPDs research partners" throughout the guidelines refer to members of the OPDs as the co-researchers in the iiiWASH research.

The term 'participatory research' is used to describe the methods and strategies adhered to in this research that seek to engender meaningful participation and empower the co-researchers with disabilities. These methods, for example, include building the capacity of the co-researchers with disabilities and providing opportunities for them to be involved in decision-making and provide inputs and complaints safely.

Participatory research, in this context, goes hand in hand with guaranteeing 'accessibility' and providing 'reasonable accommodation' to ensure that the co-researchers with disabilities can participate in the research equally.

The guidelines underlying principles and context

The development of these guidelines observed two main principles. *First*, barriers to disability inclusion arise as a result of the interaction between a person's body function difficulties and the barriers they encounter around them, such as an environmental barriers or information that is inaccessible, the stigmatising behaviour of others, and policies that do not support persons with disabilities.⁴

Second, ensure disability inclusion by overcoming various barriers that exist outside of individuals with disabilities and at the same time provide special support to persons with disabilities.

In ensuring disability inclusion, this research employed the Five Inclusion Musts⁵ reference, namely:

- (1) identify persons with disabilities who may be involved, including their capacities and needs;
- (2) ensure that they are supported to access information and their environment through reasonable accommodation and accessibility;
- (3) facilitate capacity building for persons with disabilities as a means of encouraging empowerment;
- (4) encourage them to have meaningful participation, including in decision making, and
- (5) prioritise the safety and protection of persons with disabilities involved, including compliance with research ethics.

Additionally, this participatory research was made possible due to the context of established partnership between ASB and the Working Group of Pasigala OPDs (hereinafter referred to as OPDs). ASB has been working in Central Sulawesi since 2018 on humanitarian responses and has built partnerships with several local OPDs that represent a diverse range of disabilities. ASB also facilitated the OPDs in the process of forming the Working Group of Pasigala OPDs.

The partnership that was established in 2018 greatly supported the collaboration in this research as communication and relationships had already been developed. In this regard, as ASB had a history of working with these OPDs, mutual trust and positive relationships had already been fostered. It is not easy to instantaneously develop partnerships such as this.

The humanitarian response in Central Sulawesi in 2018 provided the OPDs with experience in data collection, mainly through rapid assessments and post-disaster needs assessments. They conducted surveys to collect disaggregated data and identify

⁴ This concept is known as the social model in defining disability (UPIAS, 1975).

⁵ See Kusumowardoyo and Margaretha (2019) and ASB (2017) for further understanding on how to ensure inclusion through the Five Inclusion Musts..

the needs of persons with disabilities in the disaster areas that were based on the Washington Group Short-Set Questions on Disability (WG-SS).

The OPDs also had an active role in supporting WASH activities, such as constructing accessible latrines, distributing hygiene supplies, conducting hygiene promotion outreach and building capacity with ASB. These experiences developed their capacity and were supporting factors for ASB and the OPDs to explore partnerships with persons with disabilities in the iiiWASH research.



Photo 2. A co-researcher with disabilities is explaining the iiiWASH research to an informant using sign language.

Planning Research with Persons with Disabilities



Photo 3.
Persons with disabilities having a group discussion with ASB staff.

Tips for the Planning Stage



Develop a research design by identifying the roles of persons with disabilities throughout the entire research process.

- Consultations with persons with disabilities is the primary key in this stage, including consultations on agendas or issues raised in the research, the research methods and methodologies, and plans for various activities.

Avoid stigma or assumptions that the involvement of persons with disabilities is only limited to certain roles and activities.



Involve persons with disabilities in all decision making.

- Strengthen commitment, efforts and effective methods to include persons with disabilities in decision-making processes. Consult with the persons with disabilities concerned on what forms of decision-making mechanisms are suitable for their needs and safety.



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

- Research needs to utilise local resources and ensure that local OPDs can continue to use the research results. This is a means to influence change in existing policies and practices, address any barriers, and improve future disability inclusion programs in the research target areas.
- Map and identify each of the existing OPDs in the research location and their activities. They can be mapped through information sources from network organisations, including persons with disabilities network organisations, such as PPDI, Gerkatin, HWDI, and Pertuni that exist in Indonesia. Following, encourage them to commence dialogue and simultaneously initiate partnerships with the OPDs and persons with disabilities.
- These partnerships can begin by jointly mapping problems and hopes for the future. Following, plan strategies for resolving the problems and strategies for achieving them.



Identify the capacities and needs of the persons with disabilities and OPDs that will be involved.

- Ensure to always consult and jointly identify capacities and needs to support meaningful involvement in the research process.
- 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.



Plan an activity with all partners involved in the research team on comprehending disability inclusion.

- Ensure that all members of the research team share the same perspective and understanding on disability and all aspects of disability inclusion, as well as policies that ensure the inclusion of persons with disabilities.
- The way to ensure this is to hold an activity that involves all members of the research team to deliver concepts and practices related to disability inclusion. As this is not only a matter of knowing or understanding but

also involves one's point of view, this kind of activity should be done more than once, for example, at the outset and the middle of a project.



Identify and plan language adaptations in the research.

- Adapt the language used in the research to the local language and sign language and translate any foreign language terms. Use language that is easier to understand by turning complex or academic terms into simpler explanations.
- This can be done by requesting persons with disabilities and OPDs to provide input in the process of translating the language into a local language and simplifying complex and academic terms. In this way, the results will be consistent with the situation of the persons with disabilities who are the research partners and the informants.



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

- Ensure that all tools and materials are available in a variety of formats that are accessible and user-friendly to persons with disabilities, for example in the form of video, visual images, text, audio, braille, easy to read, and other formats that are easy to understand.
- Even better, test all the tools and materials with the co-researchers with disabilities once they have been transferred to various formats.



Plan and consult on an inclusive and transparent research budget.

- Create a research budget that accommodates all costs for ensuring easy accessibility and meaningful involvement of persons with disabilities, including cost components that will support the economic income of persons with disabilities or that can be used for post-disaster economic recovery.
- Always be open and consult with persons with disabilities involved in the research team on the budget components. There is no need to feel uncomfortable communicating with persons with disabilities to inform them what can and cannot be accommodated based on the capacity of available research funding.



Design inclusive methods and methodologies, ethical protocols, and research instruments.

- Ensure that all methods, protocols and instruments used to conduct the research guarantee accessibility, participation, capacity building, protection rights and data disaggregated at least by sex, age group, and a wide variety of disabilities or bodily function difficulties.

Tips for Developing Planning Strategies

Establishing partnerships with OPDs as research partners

The main strategies for co-researching with persons with disabilities include:

- identify members of local OPDs with disabilities who represent a variety of disabilities and genders,
- explore their interest, capacities and needs to be involved in the research,
- make a partnership agreement for implementing the participatory research together, and
- establish capacity building mechanisms for persons with disabilities as researchers.

Ensuring that persons with disabilities represent various disabilities and genders is an important strategy as experiences of life with disabilities are certainly not uniform. Experiences vary greatly based on the barriers according to different disabilities.

Working with persons with disabilities who represent a variety of disabilities, such as mobility, sight, hearing, and communication barriers, allows them to become research partners who are able to develop an affinity with research informants who share a diverse range of disabilities.

At the same time, also ensure there is a gender-balanced composition of co-researchers with disabilities as quite sensitive questions need to be asked in WASH research, pertaining to personal hygiene practices during menstruation, the possibility of violence due to inadequate sanitation facilities, and so on.

The iiiWASH research involved co-researchers with disabilities with a composition of 8 women and 10 men. This fairly balanced gender composition enabled them to overcome any potential barriers with the informants in talking about quite sensitive matters.

A practical way to identify persons with disabilities who are interested in becoming research partners is by contacting the OPDs in the research location. As OPDs tend to represent only one type of disability, be sure to contact several OPDs so that they can meet the requirement of representing a variety of disabilities.

If you do not know of any local OPDs, the easiest way is to contact OPDs in other areas and request for referrals. In Indonesia, several OPDs at the national level have branches at the regional level. It is usually relatively easy to ask for information about OPDs in the area from one of the regional level OPDs.

After successfully identifying the local OPDs, the next step is to explore the interest, capacities and needs of persons with disabilities who are members of each of the OPDs. This strategy is important to help both parties plan the division of roles based on individual's capacity to contribute to each stage of the research.

Additionally, identify the forms of support needed to ensure that persons with disabilities can actively participate as co-researchers.

Always remember, empowerment is a process that requires the active participation of those who take part in the empowerment efforts. Whoever the initiator is, it is important to ensure that persons with disabilities have an interest or develop an interest in being involved so that there is no coercion. Having an interest in being involved is a valuable asset in empowerment processes and reciprocal partnerships.

The way to identify the interest, capacities and needs of persons with disabilities is through direct consultations with them. Explain in detail the research plans, why the involvement of OPDs is important, and the strategic roles of persons with disabilities.

Explain the forms of support available for persons with disabilities and also the limitations, for example, it is not possible to involve all members of OPDs as research partners but only those who are interested. Based on this process, expectations can be managed and the purpose and scope of the partnership in the research are clear.

Following the discussion process and reaching a verbal agreement to co-research together, the next step is to develop a written agreement. A written agreement provides a clear reference for each stakeholder in regard to the goals of the partnership and the division of roles throughout the project cycle. The agreement can be drawn up in the form of a partnership agreement or a memorandum of understanding. The contents of the agreement include the objectives of the partnership, the division of roles, the forms of support for research partners, the duration, how the cooperation is to be implemented, and what results are expected from each partner.

Examples of Practices 1 presents the role of the co-researchers with disabilities as outlined in the iiiWASH research partnership agreement. Regarding the division of tasks in the agreement, ASB developed research protocols that outlined the research objectives and designs with technical assistance from the CHPM UGM research partners. Consultations took place with the co-researchers with disabilities regarding all aspects of the research protocols.

Meanwhile, the co-researchers with disabilities provided input on upholding inclusion in general, planning the data collection stage, especially involving the informants with disabilities and trialling the research tools that had been developed. The capacities and expertise of each stakeholder had to be taken into consideration in developing agreement upon the division of tasks.



Examples of Practices 1. What roles can be implemented by co-researchers with disabilities?

Based on consultations with the OPDs in the project planning stage, the tasks of the co-researchers with disabilities agreed upon in the iiiWASH research partnership agreement included:

- Developing capacity by participating in training programs related to research, inclusive humanitarian response, and WASH.
- Providing training on inclusion and the ethics of interacting with persons with disabilities for the research teams from ASB and CHPM UGM.
- Coordinating and consulting with local governments and community representatives in the research target areas.
- Trialling the research tool designs and providing feedback.
- Conducting data collection in the research target areas following research ethics and protocols.
- Disseminating the research results in various forums at local and national levels, including through OPDs disability group networks.
- Supporting project monitoring, evaluation and learning processes.

6699 *Examples of Practices 1.*

What roles can be implemented by co-researchers with disabilities?

Developing a budget for participatory research

Develop a budgeting strategy based on the consideration of providing the co-researchers with disabilities with reasonable accommodation so they can be involved in all stages of the research. This is not only limited to just data collection and dissemination of research results, but all supporting activities such as training, consultations and so on.



Photo 4.

Co-researchers with disabilities using a rental car for research activities supported by one disability support person.

Following are some cost components of the budget that enabled the active involvement of the co-researchers with disabilities:

- Daily allowances as compensation for the work of the partner OPDs. The daily amounts were determined in line with regional regulations concerning local minimum wage standards.
- Daily allowances for co-researchers with disabilities who require a support person.
- Communication expenses to enable coordination with co-researchers with disabilities.

- Sign language interpreter fees for all face-to-face and online activities to ensure that co-researchers who are deaf can participate and access information equally.
- Costs for printing interview guidelines into a braille format.
- Transportation in the form of rental cars to transport co-researchers with disabilities to various research locations for all of the activities: during initial coordination with the government, data collection, and dissemination of research results.

Although some of the co-researchers with disabilities rode motorbikes, these costs were necessary considering that the research locations were quite far away and it was unsafe to travel to them by motorbike.

- Costs to ensure that consultations and training activities could be conducted in places that provided optimal accessibility for co-researchers with disabilities.

Budget adjustments for the provision of reasonable accommodation and compliance with COVID-19 health protocols:

- Phone credit costs to support communication in the coordination and training processes, which were mostly online due to the COVID-19 pandemic.
- Car rental costs taking into account the maximum number of passengers allowed in a car was four people including the driver to allow for social distancing.
- Costs of providing personal protective equipment and hygiene for the OPDs and research informants to prevent the transmission of COVID-19, such as masks, face shields, and hand sanitiser.
- Costs of procuring stationery for each person so that no one had to borrow stationery items from someone else.

Planning research ethics compliance



Photo 5.

A co-researcher with disabilities asking for an informant's consent via a form with an easy-to-read format with the assistance of a support person.

In the iiiWASH research, there were two types of strategies for complying with research ethics, namely ethics compliance strategies that focused on the informants and ethical strategies intended for persons with disabilities as the co-researchers. Developing participatory research with OPDs as research partners included several aspects:

- Inclusion: all stages of the research had to directly and actively involve the co-researchers with disabilities.
- OPDs safety and well-being: during the research activities the OPDs had to be protected from various risks, including disaster risks, the risk of discrimination, and the risk of COVID-19 transmission etc.
- Sufficiently 'equipped' to be involved: the OPDs needed to have the knowledge and skills to enable them to implement various activities, in accordance with their duty and responsibility in compliance with research ethics.

To ensure that the research process was inclusive, the co-researchers with disabilities trained all of the research teams involved in the iiiWASH on disability inclusion and the ethics of interacting with persons with disabilities at the outset of the project. This training was useful for ensuring ethics compliance in interactions with the co-researchers with disabilities throughout the research process.

Adjustments for reducing the risk of COVID-19 transmission:

To ensure the safety of the co-researchers with disabilities regarding the risk of COVID-19 transmission, we agreed upon a protocol which briefly included:

- Always adhere to COVID-19 protocols in all face-to-face activities, including training and data collection.
- Communicate all visit schedules to ensure that informants are willing to be visited and are in good health.
- The co-researchers with disabilities, the informants and all participants in the face-to-face research activities must wear a mask, a face shield, and use hand sanitiser.
- Limit the number of passengers in vehicles transporting OPDs to the research locations.

It was important to make sure that the OPDs had identification that identified them as research partners when data was collected in the nine research location villages to maintain their safety and well-being. This meant that the communities could easily recognise them and they knew why the co-researchers with disabilities were visiting residents' homes to conduct interviews.

It was also important to ensure that there was coordination with the village government and local community leaders, so that they were aware of the research and could provide support for the activities implemented by the co-researchers with disabilities.

Another measure was to ensure that the co-researchers with disabilities had sufficient information so that they felt comfortable about being involved as research partners. Thus, an orientation on the iiiWASH research was arranged at the beginning of the project that outlined all of the research stages as well as the OPDs involvement in each stage of the research. Additionally, the OPDs acquired knowledge through training sessions that were held prior to conducting data collection in the field.

Before involving persons with disabilities in any activities, always go through a process of implementing one routine procedure with the partner OPDs to ascertain the readiness of the persons with disabilities. This procedure was referred to as a 'trial' or practice meeting before implementing the actual activity, where the co-researchers with disabilities were informed of the activity goals and could practice facilitating the activity or presentation. These strategies were developed so that the OPDs acquired sufficient knowledge and skills to take on their roles with awareness and willingness and without coercion.

Lessons Learned from the Planning Strategies

Partnerships need to be built before research begins: the relationships that were established with persons with disabilities in the OPDs before the research process began were very influential in building the partnership in the research process. Co-researching with persons with disabilities was new to the research team, the research partners, and also the co-researchers with disabilities. The experience of previous collaboration proved to be a great asset in jointly exploring new areas of collaboration, namely co-researching.

If you want to conduct research with persons with disabilities, you need to consider a time frame for establishing a working relationship in the research planning.

Budgeting needs to be relevant: knowledge of who the partner OPDs were, the kinds of barriers encountered in each type of disability and what the needs were for reasonable accommodation greatly assisted in formulating the budget.

For example, there was no need to budget for the cost of procuring an application to convert text to voice as this application was not preferred by the co-researchers with difficulty seeing. Audio recordings of all written documents, such as the training materials and interview guidelines were developed to ensure reasonable accommodation was provided. No budget was needed for providing the interview guidelines in an easy-to-read format, as it was not required by the co-researchers with disabilities.

If you are planning a budget, be sure to consult with the co-researchers with disabilities so that the budgeting is relevant to their needs.

There needs to be budget flexibility: in preparing the budget it was necessary to account for the possibility of additional types of activities that involved persons with disabilities as the co-researchers. There were several activities with the OPDs that were not initially included in the planning, for example, training on data analysis and how to facilitate discussions. Due to a growing interest from the co-researchers with disabilities, some additional training series were also added. One of the reasons the additional activities were made possible was because of the budgeting flexibility.

If you are planning a budget, you need to create room in the budget for accommodating further development of activities with co-researchers with disabilities. This development is a good sign in a collaborative research process with persons with disabilities.

Ensure that ethical compliance is balanced for both the informants and the co-researchers with disabilities: research accountability included involving the informants before and after the interview.

This 'involvement' included:

- (1) an initial visit to identify the suitability of potential informants based on criteria, and exploring the interest of the potential informants to be involved in the research;
- (2) a visit to request written consent from those informants who met the research criteria using an easy-to-read consent form and to provide detailed explanations to the prospective informants;
- (3) an interview visit to the informants who had consented; and
- (4) a follow-up visit two weeks after the interview, to ensure that the informants were still willing for their data to be used in the research and to check if they had any questions or input following the interview.

In order to complete the four stages of the informants' involvement, the team of co-researchers with disabilities had to visit the informants' homes at least four times amid the COVID-19 pandemic.

To minimise risks for the co-researchers with disabilities, the informants' 'involvement' could be simplified, for example, by combining the first and second visits, and conducting the fourth follow-up 'visit' via telephone.

When planning research ethics compliance, ensure that there is a balance between complying with ethics regarding both the informants' and the partner OPDs as the researchers.

Co-researching with Persons with Disabilities



📷 **Photo 6.**

Fadlia and Zainab, co-researchers with disabilities, are interviewing a research informant with a support person.

Tips for the Implementation Stage



Increase the capacity of co-researchers with disabilities according to the needs identified.

- Capacity building activities should be able to support the capacity of persons with disabilities and empower them to have a role and participate in a meaningful way in the research process.
- Remember to create capacity building activities that are in line with the capacity building needs assessment results.



Build the capacity of other research partners involved in the research.

- This capacity building, for example, may be about perspectives and capacities regarding disability inclusion towards other partners in the research team.

This includes strengthening the capacity of staff of the organisations implementing the research by facilitating training or knowledge transformation to partners with disabilities.



Consult with persons with disabilities and ensure accessibility and reasonable accommodation.

- Accessibility and reasonable accommodation are extremely important in supporting the roles and contributions of persons with disabilities in research and capacity building activities.

Always remember to make any adaptations needed in a situation based on the results of consultations with persons with disabilities.



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

- Conduct a briefing and a debriefing session for each activity to get input prior to the activity and feedback after the activity has been implemented.
- If co-researchers with disabilities have input or complaints related to how to conduct the research or how to manage the partnerships, make sure to accommodate their input and make adjustments as needed.

It is better to have the flexibility to adapt and make changes in research, rather than to continue a process that turns out to be unsuitable for co-researchers with disabilities.



Trial the research tools with persons with disabilities.

- Always trial the research tools with partners with disabilities, for example, the data collection tools, the consent form, the monitoring, evaluation and learning tools, as well as the suggestion and feedback mechanism.
- Collect and document the experiences of partners with disabilities using all of the research tools. Consult with them to adapt and improve the research tools as needed.
- Ensure that the adaptations and improvements facilitate partners with disabilities in understanding, acquiring information, and using the research tools.



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

- Ensure that persons with disabilities are provided with adequate assistance and opportunity to assist them to participate in the process equally in all of the research activities, for example, in the data collection and analysis stages.



Involve persons with disabilities in coordination and consultation activities with other stakeholders.

- The involvement of persons with disabilities includes engaging them in coordination activities with local governments in the research target areas, for example, in arranging permits and in consultations on the research results.
- Involve persons with disabilities in activities with other stakeholders, for example, in validating the research findings with WASH actors or the Steering Committee with representatives of organisations from other sectors.

Developing Implementation Strategies

Building the capacity of co-researchers with disabilities

Capacity building strategies for the co-researchers with disabilities included:

- Conducting a training needs assessment at the planning stage.
- Conducting training on topics based on the assessment results.
- Conducting training with the provision of reasonable accommodation.

Methods to assess training needs vary, but in the iiiWASH research, the assessment was part of the survey on knowledge, attitudes and actions at both the beginning and the end of the project. The purpose of this survey was to assess the knowledge and attitudes and practical experiences of the co-researchers with disabilities related to the research stages and topics, namely inclusive WASH.

The OPDs were familiar with practices and had practice examples in the WASH-related activities from the WASH humanitarian response with ASB in Central Sulawesi. An example of this knowledge and these practices was the training at the time of the humanitarian response program, even though it was brief given the disaster response situation. Although they already had the knowledge and were familiar with some practices related to WASH, it was still important to conduct sessions on inclusive WASH for the co-researchers with disabilities.

Meanwhile, training sessions on public speaking techniques and theory as well as self-confidence were eliminated as most of the OPDs were already experienced in public speaking and their self-confidence was robust. Most of the co-researchers

with disabilities had significant experience in advocacy in general, as did many of the OPDs. However, only a small proportion of the OPDs were experienced in engaging in research. Even those who had been involved in research, had only been enumerators.

In addition to providing WASH sessions, persons with disabilities received technical training on facilitating more structured group discussions, according to the needs of the iiiWASH research. An introduction to all the stages of the research was an important part of the training topics given the co-researchers with disabilities lack of research experience and knowledge.

All of the training topics, provision of accessibility, and reasonable accommodation needs were determined based on the data collection results.

The training topics in the iiiWASH research can be seen in Examples of Practices 2.



Examples of Practices 2. What do co-researchers with disabilities need to know about research on inclusive WASH?

Following is a list of training topics that equipped the co-researchers with disabilities in the iiiWASH research:

- Introduction to inclusive WASH that refers to the Sphere, the Humanitarian Charter and Minimum Standards for Humanitarian Response, and the Humanitarian Inclusion Standards (HIS) for Older People and Persons with Disabilities.
- Introduction to the research, including the research concept and the research subjects (population and sample).
- Introduction to the research proposal and research results analysis.
- Introduction to research ethics.
- Introduction and trial focus group discussion methods using SIM (Structured Interview Matrix).
- Deepening on the informant consent form that was developed for the iiiWASH research and data collection steps.
- Introduction to the interview guidelines and the field trials.
- Deepening on data processing and analysis.

669 *Examples of Practices 2.*

What do co-researchers with disabilities need to know about research on inclusive WASH?



Photo 7.
Co-researchers with disabilities, Daniel and Abed are doing an online training

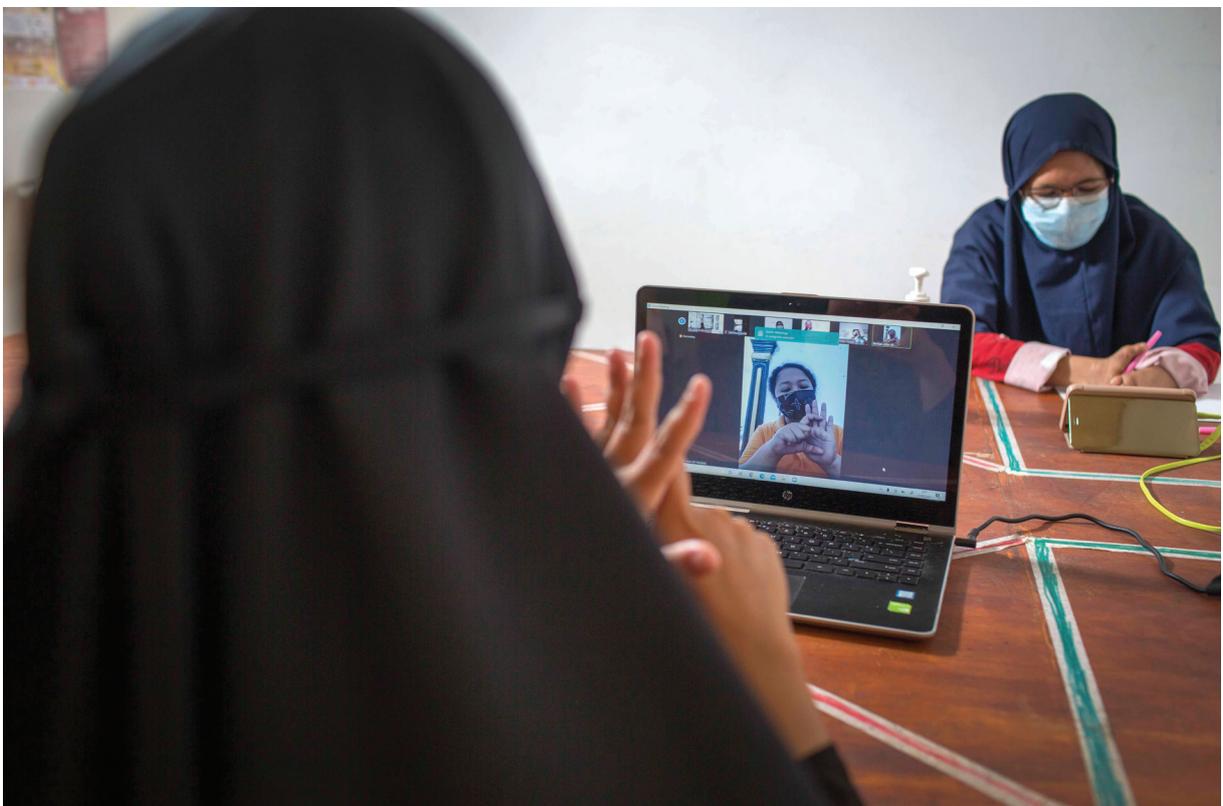


Photo 8.
A co-researcher with disabilities, Arta, is participating in an online training with the support from a sign language interpreter.

Training methods were significantly impacted by the COVID-19 pandemic. Class meetings were changed to online meetings and efforts were made to keep the training that tended to be one-way more interactive, as illustrated in Examples of Practices 3.



Examples of Practices 3. How can you optimise interaction in online training?

The online training on coding and data analysis divided the trainees into breakout rooms via the Zoom conference media. In the breakout rooms, the OPD participants received data in the form of an interview transcript to be categorised into codes according to the research analysis framework.

The OPDs participants discussed the coding data in small groups before sharing the results of their discussion with a larger group with other group participants and training facilitators.

Such interactive and practice-focused learning techniques proved to be more effective in increasing the understanding of the trainees, especially regarding research materials that tended to be theoretical and included a lot of academic terms.

Examples of Practices 3. *How can you optimise interaction in online training?*

Another way that ensured the online training achieved maximum results was by providing personal study materials while having face-to-face activities for certain sessions. These face-to-face activities were intended to allow the OPDs to practice using the consent forms and the interview guidelines before they went out into the field to conduct interviews for the data collection.

This trial served two purposes. *First*, ensuring that the interview guidelines are easy to use. *Second*, ascertaining that the OPDs involved understand the contents of the interview guidelines and the interview questions, including proficiency in probing the informants for answers.

The trial was conducted in several stages through role-plays where the co-researchers with disabilities took turns interviewing each other in pairs and practised interviewing with 'mock informants' who were from the community.



📷 **Photo 9.**

Arta and Yassin are role-playing an interview facilitated by a sign language interpreter

Although most of the training activities were implemented online, efforts to provide reasonable accommodation were still absolutely imperative to ensure the active participation of persons with disabilities. To ensure reasonable accommodation, the training materials and research instruments were provided in a variety of formats including printed materials, digital documents, audios, easy-to-read and braille formats. During the training, the facilitators explained each image, graphic, and any other visual component verbally so that the participants with difficulty seeing could understand them easily.

All activities always included a sign language interpreter and support persons were always present. In particular, the sign language interpreters required some input related to training topics prior to the training, so that they could prepare translations of specific terms. The training materials were distributed to all of the research partners with disabilities and the sign language interpreters at least two days before the training so that they had the opportunity to go through the materials first.

To support the participation of persons with disabilities who did not have devices or who had limited internet networks, a suitable place and facilities for online training as well as assistance in operating the training facilities were needed. The training participants who used their own devices at home received support in the form of access to the materials and the training media, as well as data credit/packages.

Adjusting training methods due to the COVID-19 pandemic:

Most of the training was conducted online in compliance with the health protocols. The following steps were implemented for optimising the online training:

- Conducting online training twice a week for a maximum duration of two hours to optimise learning.
- Always providing materials in the form of notes in digital files, printed documents, and sound recordings for each presentation, which facilitated the OPDs to learn and understand the content. The personal study materials were distributed at least two days before the meeting.
- Complimenting the online meetings with independent training and practice for the co-researchers with disabilities so that they could absorb the materials more effectively.
- Minimising boredom with one-way learning methods by using available media, such as breakout rooms for discussions and polling features for conducting quizzes.
- Always ensuring that the participants could access the training materials and could easily understand all of them, for example by presenting a simple example, graphics, or images.
- Collecting input or conducting a training evaluation for each online session using the available survey facilities.



Photo 10.
A braille document for the interview training.

Collecting data in the research target areas

In accordance with the division of roles agreed upon, the co-researchers with disabilities played a major role in collecting research data through semi-structured interviews with the older informants and those with disabilities in the research target areas. Following are some strategy developments for ensuring that they implemented their role well:

- Ensure that the co-researchers with disabilities and informants with disabilities can easily understand and read the data collection tools⁶ by providing them in various formats.
- Divide the teams into pairs so that the co-researchers with disabilities can support each other.
- Support the co-researchers with disabilities to comply with research ethics with the informants.
- Hold a debriefing session after the interviews with the team of co-researchers with disabilities.

⁶ The data collection tools used included an identification of potential informants form, a consent form, and a list of research questions.

There were a number of ways to ensure that the data collection tools were easy to use. *First*, ensuring that there were illustrations to assist the informants to understand what was meant by WASH activities and facilities. *Second*, making sure the data collection tools were easy to read. *Third*, translating the interview guidelines into the local language given that many of the informants only used and understood their local language.

Proficiency in the local language also needed to be considered in regard to the team division strategies. It was necessary to make sure that there were co-researchers with disabilities who could communicate in the local language in each team to facilitate the interview process with the informants. Consideration was also given to the division of the team based on disabilities and gender, so that as far as possible the co-researchers with disabilities who conducted the interviews shared the same disabilities and gender as the informants they interviewed. The team was divided in consultation with the co-researchers with disabilities.

Following, several methods were used before and after interaction with the informants to ensure that the co-researchers with disabilities complied with research ethics with the informants.⁷

It was important to ensure that the co-researchers with disabilities had completed the research ethics training before the interviews, so that they understood how to comply with research ethics and why it was necessary. Following the interviews, there was a debriefing session to check whether the co-researchers with disabilities had any potential difficulties in adhering to the research ethics and if so to seek solutions together.

Examples of Practices 4. These practices show how debriefing sessions can produce steps for complying with research ethics.



Examples of Practices 4. How to use debriefing sessions for research ethics compliance

One of the functions of the debriefing session after the interviews was to check for any potential difficulties that the co-researchers with disabilities encountered in ensuring the informants' safety and protection.

⁷ In accordance with the discussion in the Planning section, there were a series of activities involving the informants so that the co-researchers with disabilities did not only meet with them at the time of the interview. Debriefing activities were conducted after interactions with the informants, for example, starting with the visits to identify potential informants for the research, the interviews, and so on.



In the debriefing session following the identification of potential informants, one of the research team members with disabilities described their interaction with an informant who showed signs of psychological discomfort when speaking about their experiences during the 2018 disaster.

Based on the discussion in this debriefing session, a decision was made to provide psychosocial support when interviewing informants who show signs of trauma. The person who provided this assistance observed the course of the interviews and only assisted when needed.

Examples of Practices 4.

How to use debriefing sessions for research ethics compliance

The debriefing session was also to check if the co-researchers with disabilities faced any challenges when interacting with the informants during the data collection and to see if any training or assistance was needed. Debriefings were usually held immediately after the OPDs team conducted the interviews, so that any challenges that arose could be immediately discussed and addressed.

An effective way of debriefing is to ask a few simple questions such as, 'how did the activity go?', 'what difficulties did you have?', or 'what did you do to overcome the difficulties?'. Questions like these assisted the co-researchers with disabilities to share their experiences and also helped to improve facilitation strategies.

If anything was unclear, for example, how to probe an informant regarding a complex interview question, they discussed it with other co-researchers with disabilities and made a list of follow-up questions, simplified sentences and the terms used, or provided explanatory examples for the informants. The debriefings also provided opportunities for the co-researchers with disabilities to reflect on their interview experiences.



Photo 11.
Debriefing with ASB staff following the interviews

Disseminating the research results

In general, the iiiWASH research dissemination activities were aimed at: (1) OPDs networks; (2) humanitarian networks including WASH actors at the national and international levels, and (3) the informants who participated in the research, as a form of reporting their support in the research process. The dissemination activity applied several strategies for disseminating the research results with the co-researchers with disabilities, as follows:

- Ensuring that the co-researchers with disabilities led the dissemination process with the OPD networks and reported the results to the informants.
- Ensuring the participation of co-researchers with disabilities representatives in all activities for disseminating the research results outside of the OPD networks.

In line with the division of roles established in the planning, the co-researchers with disabilities played a major role in sharing the research results with the OPDs networks. This was in keeping with the co-researchers with disabilities expertise in reaching out to persons with disabilities in other OPDs. Additionally, given the relationships that had developed with the informants at the research locations, the co-researchers with disabilities also led the processes of reporting back to the informants, community representatives and local village leaders.

As in some of the other activities, the co-researchers with disabilities were also involved as speakers (such as at the SC meetings and the validation of the research results with the informants, WASH actors, and so on). They were also speakers at the dissemination of the research results.

The co-researchers with disabilities readiness and capacity to facilitate the dissemination activities was developed through practising or ‘trailing’ the activities. In this activity, the co-researchers with disabilities did simulations on delivering what they wanted to say and practised how to present it. These trial practices equipped the co-researchers with disabilities to be able to deliver their presentations with confidence.

Lessons Learned from the Implementation Strategies

Do not make assumptions regarding the capacities of co-researchers with disabilities:

At the outset of the research design, we were thinking of using data collection tools that would be easier for the co-researchers with disabilities. We knew that the OPDs had gained experience in collecting data for the rapid assessments using surveys during the disaster emergency response in Central Sulawesi in 2018. On the other hand, their ability to conduct in-depth semi-structured interviews was still unknown. These interviews require a certain level of skill in probing for information through follow-up questions based on the responses of the informants.

In the end, we decided to use the semi-structured interviews. We trained the OPDs on how to use the interview guidelines and ask probing questions.

It turned out, the capacity of the co-researchers with disabilities to apply the interview strategies learnt in the training session, including the ability to follow-up with probing questions was evident in the interviews. The co-researchers with disabilities also demonstrated the ability to simplify, clarify, and create detailed illustrations when the informants encountered difficult questions.

If you are planning to select data collection tools, there is no need to limit yourself to certain methods that may be considered easier for co-researchers with disabilities. With sufficient practice, co-researchers with disabilities are very capable of conducting interviews or applying other methods that require more skill than simply reading out a list of questions.

Trialling the interview guidelines must be part of the training: the introductory training on the interview guidelines was very effective when coupled with hands-on practice using methods including role-plays and field trials.

This process was able to ensure that the co-researchers with disabilities had an in-depth understanding of the interview guidelines and the sensitivity and confidence to follow-up with probing questions. Trialling the guidelines in the field also provided meaningful input for improving the guidelines.

The interview guidelines trialling process enabled the co-researchers with disabilities to provide suggestions for improvement. Their suggestions were the basis for translating the interview guidelines into the local language to further facilitate the interview process and simplifying the language used by selecting words/terms and sentence structures that made it easier for the informants to understand the interview questions.

Furthermore, images used of examples of WASH activities and services facilitated the OPDs to better acquaint the informants with 'WASH' during the interviews.

Hence, make sure to trial the data collection tools guidelines in research with co-researchers with disabilities. You can use the results of the trials to improve the skills of co-researchers with disabilities in using data collection tools and simultaneously assist in improving the quality of the research tools.

There needs to be direct representation of co-researchers with disabilities in the dissemination activities: the participatory research with persons with disabilities was not only limited to the data collection process but also the process of disseminating the training results. The co-researchers with disabilities had a significantly crucial role in dissemination. Their presence and active participation in dissemination activities made the process of delivering messages more effective.

The co-researchers with disabilities represented the 'voices' of the informants with disabilities very well. This was due to the co-researchers with disabilities often sharing similar kinds of experiences with the informants with disabilities. Even during the interviews, the co-researchers with disabilities were already thinking about how to use the evidence generated to fortify advocacy work.

Consult with persons with disabilities on how research results can support advocacy efforts more broadly. And remember to jointly plan when doing a series of dissemination activities, so that the co-researchers with disabilities can participate in all decisions regarding the dissemination plan.

Based on these experiences, when you conduct dissemination activities, persons with disabilities must be involved from the time of planning the dissemination and the co-researchers with disabilities must be present as speakers at dissemination events.

Monitoring, Evaluation and Learning

Tips for Monitoring, Evaluation and Learning



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

- To ensure that the direction of the research is in line with the needs and preferences of the co-researchers with disabilities, it is essential to include persons with disabilities in the steering committee.



Create a feedback and complaints mechanism that persons with disabilities can easily and safely use.

- Ensure that persons with disabilities, whether members of the research team or informants can provide feedback, suggestions, and complaints through safe and easy formal and non-formal channels. Address the suggestions and feedback by consulting with them through group or individual meetings. Furthermore, ensure that the suggestions and feedback are acted upon accordingly.



Make sure the research allows for a reflective process and aids learning for everyone involved.

- Develop tools and methods to assist all research team members to reflect on their experiences, the lessons learned, and the work that was done throughout all stages of the research. The reflection tools and methods may be provided in various forms, for example, joint debriefing sessions or getting co-researchers with disabilities and research staff to write in learning diaries.



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

- Collect the results of the lessons learned and then disseminate them widely. Ensure that the public can easily access the results to support increased disability inclusion in research production. The results of the lessons learned also need to be published in various formats to ensure accessibility.

Monitoring, Evaluation and Learning Strategies

Monitoring capacity building results

In general, research projects differ from humanitarian response projects in terms of their interventions or activities. Implementers of humanitarian response projects or development projects always undertake a series of interventions to achieve the objectives of the project being developed. For example, an awareness activity on the practice of washing hands using soap is aimed at assisting to break the chain of disease. This kind of project requires a monitoring, evaluation and learning framework to help identify the success and impact of interventions as outlined in the planning document. Meanwhile, research projects generally do not include intervention activities, with the exception of action research.

Although iiiWASH was not an action research, it still used a monitoring, evaluation and learning framework, as the research process did include intervention activities, for example, building the capacity of the co-researchers with disabilities.

A monitoring, evaluation and learning framework was developed to monitor the contribution of the iiiWASH research in building the capacity of co-researchers with disabilities. Additionally, the general project monitoring tools continued to be used, such as annual and monthly planning.

The monitoring, evaluation and learning framework for the iiiWASH research was developed by adapting the three key inclusion areas of the WASH sector in the Humanitarian Inclusion Standards (HIS) for older people and persons with disabilities. These three key areas of inclusion include: (1) disaggregated data and information management; (2) addressing barriers; and (3) participation, strengthening capacity and ensuring safety and protection in providing feedback.

These three key areas of inclusion fit into the iiiWASH research framework through the outcome indicators.⁸

Monitoring research through a feedback and complaints mechanism

The iiiWASH research applied a number of strategies to create open and safe spaces for the co-researchers with disabilities to share their feedback, input and complaints. The OPDs had the opportunity to express their impressions, opinions, input, and criticisms of the process or activity content in all stages and activities throughout the research.

⁸ Example of the monitoring, evaluation and learning framework can be seen in Appendix 1.

Collecting feedback and complaints through various methods, such as:

- Training evaluation forms after each training.
- Learning diaries.⁹
- Directly through debriefing sessions and project evaluations.
- Directly in all joint activities.

Providing a variety of ways to collect feedback met two objectives: (1) identifying if anything needed to be improved in the process involving the co-researchers with disabilities in the research; and (2) seeing if anything in the research process itself needed to be improved, as shown in Examples of Practices 5.



Examples of Practices 5. How can feedback be used as the basis for improving the research process?

The partner OPDs experienced difficulties when the informants had problems understanding the interview questions. Moreover, many of the informants provided answers that did not relate to the questions. Based on this experience, consultation meetings were held with the OPDs to formulate strategies for asking questions and probing in ways that were easy for the informants to understand.

The OPDs assisted in identifying any potential challenges that arose during the interviews so that they could be discussed together and anticipated through practical strategies. This input improved the data collection issues encountered in the field.

“” Examples of Practices 5.

How can feedback be used as the basis for improving the research process?

Monitoring the research through the Steering Committee (SC)

Another strategy for monitoring the course of the research was the Steering Committee (SC) mechanism. The SC consisted of a group whose role was to supervise and provide input on the course of the research; ensure inclusion; and provide recommendations for adaptations, improving strategies, and for the research results.

⁹ Example of the learning diary format can be seen in Appendix 2

The committee members consisted of various academics from Indonesia and Australia, experts from the humanitarian and disaster response sector, the WASH sector, local governments, and inclusion activists. Committee membership was completely voluntary.

Persons with disabilities were also directly involved in the SC, with a representative of women with disabilities from the co-researchers with disabilities and a representative of men with disabilities from the Central Java Province Disaster Management Disability Inclusion Service Unit.

The SC members and the research team met regularly both online and offline to discuss the progress of the iiiWASH research process.

The SC team was established by first identifying a well-balanced composition of expertise that would bring benefits to the research, such as expertise in the areas of humanitarian response, WASH, research, and the inclusion of persons with disabilities and older people. Based on the identification of the expertise, experts in the relevant fields were then sought out and contacted.

The easiest way to find relevant experts was to take advantage of existing networks, and ask the experts if they were willing to provide support. The SC's Terms of Reference was shared with the experts at the time of contacting them, so they could learn about the SC and better understand its role. The SC's Terms of Reference at least outlined the involvement of the SC, how often meeting would be held, and information on other collaborative mechanisms. Based on this information, the SC could estimate whether it was able or unable to be involved in the research monitoring.

Lessons Learned from the Monitoring, Evaluation and Learning Strategies

Learning diaries need to be used: the purpose of writing in the learning diaries was to help the co-researchers with disabilities to reflect on the learning when participating in the various capacity building activities.

One section of the learning diary contained things that the co-researchers with disabilities felt still needed to be improved. This information made it possible to identify to what extent the training activities and facilitation had assisted the co-researchers with disabilities to take corrective steps and think about aspects of capacity building that may need to be addressed. Therefore, the learning diaries could serve as a mechanism for collecting feedback.

Based on these lessons learned, you need to utilise learning diaries as a part of participatory research with persons with disabilities.

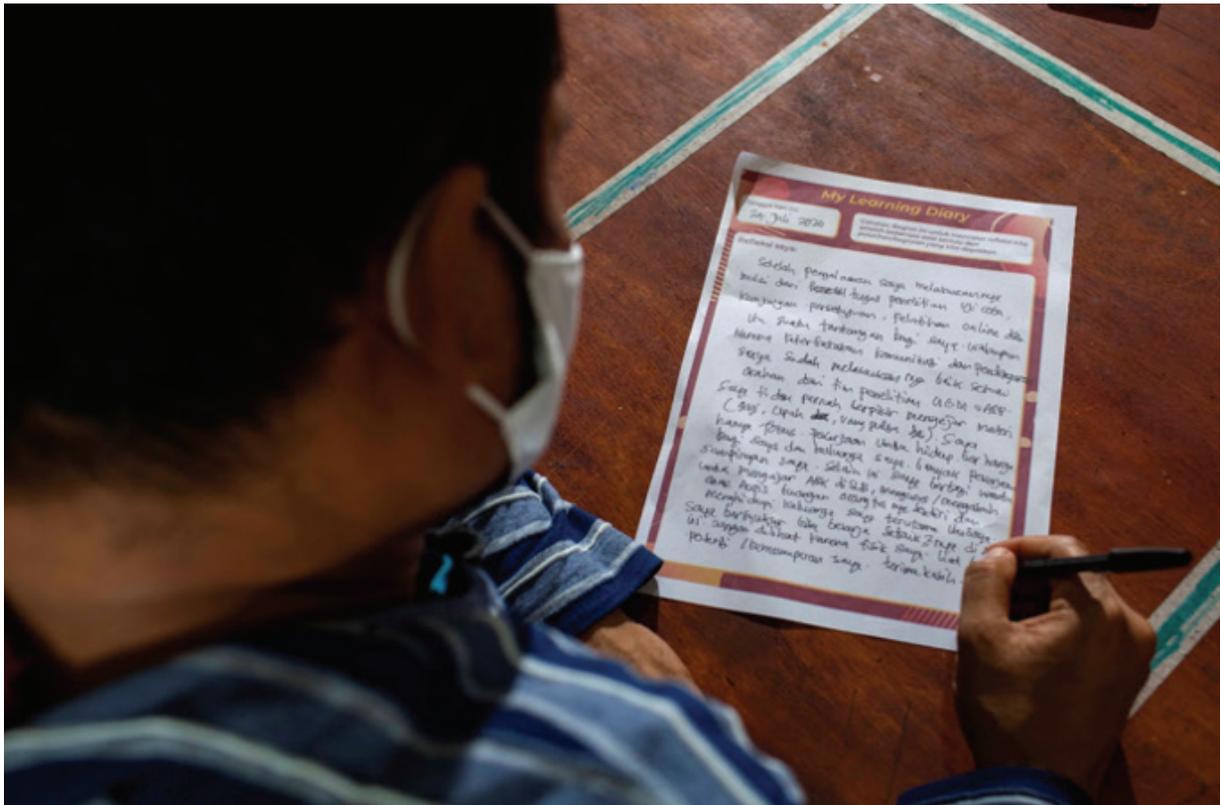


Photo 12.

Irmansyah, a co-researcher with disabilities is writing notes in his learning diary

It is necessary to ensure the presence of co-researchers with disabilities representatives in the SC:

the SC mechanism was very useful in monitoring and improving the research process and became a platform for the co-researchers with disabilities representatives to influence the research process in encouraging more meaningful participation and more equal decision making, as illustrated in Examples of Practices 6. If you use the SC mechanism to assist in monitoring the research, be sure to involve representatives of the co-researchers with disabilities.



Examples of Practices 6. How can the SC mechanism provide opportunities for co-researchers with disabilities to influence decision making?

In a meeting with the SC members and the research team, representatives of the co-researchers with disabilities put forward their assessment that the capacity building topics tended to focus only on data collection methods. They expressed that other research components, such as how to manage and analyse data were also important to the co-researchers with disabilities in order to gain a comprehensive overview of the course of the research.

This feedback was the basis for adjusting activities, and follow up of additional training on data management and analysis, including an introduction to coding techniques. Moreover, it also facilitated other activities that were able to support the role of the co-researchers with disabilities in the stages following data collection.

“” *Examples of Practices 6.*

How can the SC mechanism provide opportunities for co-researchers with disabilities to influence decision making?

Reflections on the Experience of Participatory Research

Co-researchers with Disabilities

The co-researchers with disabilities gained a variety of experiences, learning and benefits in the form of knowledge and skills through the series of research activities. These experiences also served to inspire their involvement in other research activities, and in advocating for WASH and more inclusive humanitarian responses. This section presents the impressions of the co-researchers with disabilities from their learning diaries.

Skilfully applying knowledge and skills

The co-researchers with disabilities declared that they learnt and acquired information in the training activities, and were able to put their knowledge and skills into practice in the interviews and in communicating with informants and local governments. They also confirmed that they were effective and felt fully confident in interactions with a variety of stakeholders and no longer considered research as something foreign or difficult.

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

“[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 the Dolo Selatan Cluster team.



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

“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 the Dolo Barat Cluster.



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Better understanding of applying research ethics

In the research process, the co-researchers with disabilities learnt the importance of respecting and valuing the rights of the research subjects and how to interact and deal with informants with different characteristics and from a variety of backgrounds. They also understood how to allow others to have their say.

Some of the OPDs said that they learnt how to listen better and not intervene or direct the informants' answers in the interviews. They also mastered how to phrase the interview questions more contextually, not to take offence with the informants, and simplify questions without jeopardising the meaning or quality.

The OPDs also learnt the importance of clearly conveying the objectives, scope and benefits of the research to the informants. They were able to avoid misunderstandings and deal with informants' expectations that were inconsistent with the research.

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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 the Dolo Selatan Cluster team.

“[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 the Dolo Selatan cluster.



“[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.

“[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 the Dolo Selatan cluster.



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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.

In fact, some of the co-researchers with disabilities stated that they intended to use the knowledge and skills they acquired in the iiiWASH research to conduct other research in the future and advocate for inclusive WASH in the community.

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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 the Sindue Cluster team.



“[I will] continue to learn and practice. Hopefully, I’ll get involved in other research. 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] 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 the Dolo Barat Cluster team.

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The co-researchers with disabilities shared reflections on how to use the knowledge and capacities they acquired in the iiiWASH research for broader collective benefits in the future. Overall, the OPDs participation in the research inspired their desire to become facilitators or activists for inclusive WASH issues in communities and their social environments.

They felt driven to introduce, share, and use their knowledge and capacity to assist disability groups, communities and local governments in accomplishing inclusive WASH. They were also motivated to collect more in-depth data and input related to inclusive WASH services from groups of persons with disabilities and older people.

More than six co-researchers with disabilities stated that they were interested in being involved in other research, for example, as researchers or data collectors. One of the co-researchers with disabilities expressed a desire to be involved in research with government and non-government organisations to seek truth and solutions to existing problems.

The co-researchers with disabilities aspired to learn more about research in general, particularly regarding issues pertaining to disability and older age. They even hoped to share their knowledge and skills as researchers and interviewers with their other colleagues with disabilities.

The reflection process highlights that the empowerment that the co-researchers with disabilities felt on a personal level has the potential to impact on a broader collective level for the benefit of other groups of persons with disabilities.

The range of reflections that the co-researchers with disabilities shared emphasises the fact that co-researching with persons with disabilities is not only about ensuring meaningful participation, but is also an empowering process with very visible benefits.

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“In the future, I want to conduct simple research using simple tools” – Samsinar, a co-researcher with disabilities from the Dolo Selatan Cluster team.

“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 the Sindue Cluster team.



“[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 the Sindue Cluster team.

“[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 the Dolo Barat cluster team.



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

“[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 the Dolo Selatan Cluster team.



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The ASB Research Team

The iiiWASH research process provided an opportunity to empower persons with disabilities who served as co-researchers. The empowerment experienced by the co-researchers with disabilities was evident in their accounts of their experiences, lessons learned, impressions, as well as observations of the OPDs participation during capacity building and data collection activities. The co-researchers with disabilities claimed they gained a number of benefits, namely increased knowledge and capacity on inclusive WASH, knowing how to conduct research and work as facilitators, interviewers and researchers.

Persons with disabilities were interested and able to participate in the iiiWASH research. Through intense communication with the OPDs and the OPDs' learning diaries, ASB ascertained that the co-researchers with disabilities could identify their respective areas of expertise and capacities, which assisted them in conducting the research.

In the reflection process, the co-researchers with disabilities were able to relay and share their experiences and collaborate with other research partners, whether they were in the same team or not, during the training sessions and data collection. The OPDs' ability to share their learning was an important component in ensuring that all members of the research team shared the same understanding in terms of data collection development. Furthermore, this also greatly assisted the research team in enriching their knowledge on inclusive strategies for involving co-researchers with disabilities.

Finally, in line with the reflections of the co-researchers with disabilities, ASB found that by being directly involved as research partners, persons with disabilities were able to see how the research results could be used once the interview process was completed. Research production is something that could significantly strengthen their advocacy work as it is evidence-based. Thus, co-researching with persons with disabilities is not only a positive and beneficial experience for the individuals with disabilities involved, but also for the broader disability movement.

The CHPM UGM Research Team

The iiiWASH research was an empowering process for the members of the OPDs with disabilities by involving them in every stage of the research. As opposed to being involved as research subjects, they served as the co-researchers. It was hoped that each process would further build the capacity of the OPDs, starting with developing the research plans, determining the research targets, trialling the research tools, collecting data, to presenting the research results.

The lessons learned in the process were related to the need to have sufficient preparation time and more detailed training materials. All training materials and meetings with the co-researchers with disabilities must always consider all the needs of the persons with disabilities involved.

Clearly, these aspects required more detailed preparation and time than was given. Considering that this research was also conducted amidst a pandemic, communication and coordination were also a challenge as it was mostly conducted via online meetings.

The cooperation and enthusiasm of the co-researchers with disabilities in every interaction and their capacity was outstanding. ASB's ability to facilitate the partnership between CHPM UGM and the OPDs was also excellent.

The lessons learned for future partnerships included the necessity for collaboration between partners to jointly establish an understanding of the research design and process at the outset of the collaboration stage. All stakeholders need to agree upon this and refer to it up until the last research phase to avoid challenges and changes in situations or conditions during the research and in writing up the research results.¹⁰

¹⁰ The reflections based on written testimonies from members of the CHPM UGM research team on 1 March 2021.

Conclusion

Research practices with persons with disabilities as co-researchers are extremely important in research on persons with disabilities, such as the iiiWASH research. Co-researching with persons with disabilities is a measure to uphold inclusive, participatory research, and is the first step in trying to break down the barriers between researchers and research subjects.

Involving persons with disabilities as co-researchers means that they have the opportunity to ensure that the research production is relevant to their own experiences as persons with disabilities. This is crucial in upholding one of the principles in the disability movement, namely 'nothing about us without us.'

These guidelines clearly show that the research partners, namely the persons with disabilities from the Working Group of Pasigala OPDs brought numerous benefits to the research process. They were able to quickly develop relationships with the informants with disabilities and they demonstrated an excellent understanding of the local context. Their involvement and the input they provided had a very significant role in striving to improve research processes and the quality of research results.

As an additional point, these guidelines also show how research can be of benefit to co-researchers with disabilities, as research is no longer perceived as a difficult process exclusively for experienced academics or researchers.

In the reflection process, the co-researchers with disabilities clearly depicted how research can be something inspirational and beneficial. The principle of reciprocity was a catalyst in empowering the co-researchers; persons with disabilities bring benefits to research production, and conversely, research production also provides benefits to persons with disabilities. It is precisely this principle that must be present in all participatory research with persons with disabilities.

Appendixes

Appendix 1. iiiWASH research monitoring, evaluation and learning framework

The Monitoring, Evaluation and Learning Framework adapts 3 key areas of inclusion in the WASH sector in the Humanitarian Inclusion Standards (HIS) for persons with disabilities and older people, namely managing disaggregated data and information; addressing barriers; participation, strengthening capacity and ensuring safety and protection in providing feedback. These 3 key areas of inclusion are outlined in the iiiWASH research framework through outcome indicators that are summarised in the following table:

Table 1. *The Monitoring, Evaluation and Learning Framework for co-researchers with disabilities.*

Outcome	Outcome indicators	Tools for measuring the outcome
1. The co-researchers with disabilities' knowledge on inclusive WASH and research activities increased	The number of co-researchers with disabilities involved in the training activities on inclusive WASH and the research processes and the quality of their involvement.	<ul style="list-style-type: none"> a. The initial and final assessment data from the Knowledge, Attitudes and Practices (KAP) Survey and the Survey on Knowledge, Behaviour and Practices of co-researchers with disabilities regarding Inclusive WASH and research skills. b. The Learning Diary that the co-researchers with disabilities used to reflect on learning related to what was implemented, new skills and knowledge learnt, their impressions and feelings on the activities, the things they felt were done well and those that still need to be improved, the progress or improvements they experienced, and lessons learned for future use. The learning diaries were in the form of printed sheets or recordings in audio form to facilitate all members of the OPDs. c. Activity attendance sheets disaggregated by sex, age group and disability. d. The results of the preliminary and final tests in each training session. e. ASB monitoring reports and photos of the training activities.

Outcome	Outcome indicators	Tools for measuring the outcome
<p>2. The capacity of the co-researchers with disabilities in inclusive WASH advocacy increased and they were able to utilise evidence from the research data collected.</p>	<p>The number of co-researchers with disabilities involved, the quality of their involvement, and their capacity in inclusive WASH advocacy to utilise the data and information they collect.</p>	<ul style="list-style-type: none"> a. The KAP Survey preliminary and final data on the experiences of the co-researchers with disabilities in data collection and advocacy on inclusive WASH. b. ASB observation reports. c. The Stories of Change that the co-researchers with disabilities personally experienced.
	<p>The number of co-researchers with disabilities involved and the quality of their participation in activities to support their understanding of inclusive WASH evidence collection.</p>	<ul style="list-style-type: none"> a. Activity attendance sheets disaggregated by sex, age group and disability. b. The preliminary and final test results. c. ASB monitoring reports and photos of activities.
	<p>The number of co-researchers with disabilities involved and the quality of their participation in conducting data collection.</p>	<ul style="list-style-type: none"> a. Activity attendance sheets disaggregated by sex, age group and disability. b. The results of the data collected by the co-researchers with disabilities. c. The list of co-researchers with disabilities who received an accommodation allowance for the data collection. d. ASB monitoring reports on data collection and photos of the activities.
	<p>The number of co-researchers with disabilities involved and the quality of their participation in facilitating community engagement.</p>	<ul style="list-style-type: none"> a. Activity attendance sheets disaggregated by sex, age group and disability. b. The list of co-researchers with disabilities who received an accommodation allowance for facilitating community engagement. c. ASB's monitoring reports on community engagement and photos of the activities.
	<p>The number and quality of advocacy meetings that the co-researchers with disabilities held for disseminating the iiiWASH research results.</p>	<ul style="list-style-type: none"> a. The list of the advocacy or dissemination of information meetings that the co-researchers with disabilities held.

Appendix 2. Learning Diary



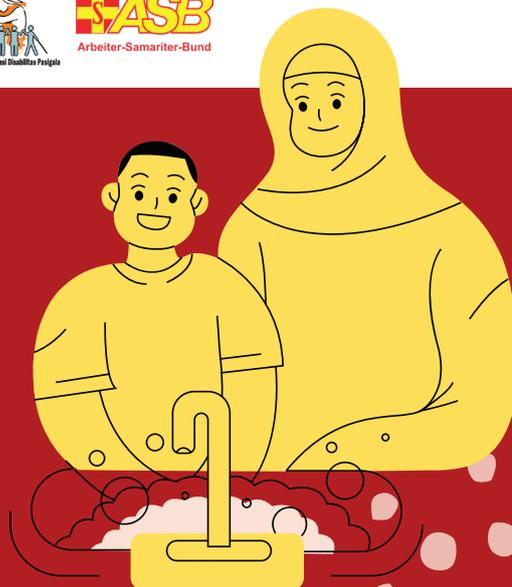
Humanitarian
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Inclusive WASH Learning Diary



Guidelines on Using the Learning Diary

Like its name, the learning journal, (hereinafter referred to as the learning diary) contains notes or a summary of what has been learned. The purpose of the diary is to assist us to think about and record our reflections on the learning opportunities that we have, in particular through our involvement in the Towards Inclusive WASH: Eliminating Barriers, Creating Opportunities research.

The diary is for recording our own personal learning. There is no 'right' or 'wrong' way of how we learn in a learning process. New things that impress or inspire us will be different from person to person. The point of this diary is that we record our learning, observe what is already working well and what still needs to be improved to become even better, and how we will use the information/knowledge/skills/techniques.

The learning diary is far more than just recording notes on 'what we did', as it helps us to critically reflect on what we have learned. The learning diary can show evidence of our self-development in terms of knowledge or skills. Moreover, the learning diary can assist us to reflect on how we can continue to increasingly contribute to the team, to organizations, and more broadly in society.

Following are some questions in the learning diary that are intended to assist us to reflect:

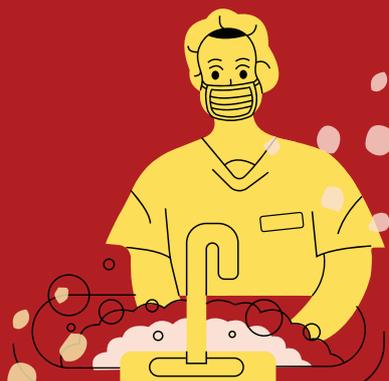
- What learning activity did I just do?
- What did I feel/think about the activity?
- Did I learn something new about myself in this activity?
- What did I learn? Did I acquire new skills/knowledge? If yes, what were they?
- What did I do well that I should continue doing?
- What do I need to improve in the future?
- If the activity was something that I had previously learned, have I made any progress? If yes, what it is?
- How can I apply this experience in the future?

Our writing does not need to be long and may also be written in point form. What is important is that it represents what we are thinking/feeling (and can be understood by others who may read the learning diary).

Ideally, we should write in the learning diary when we can still remember what it was that we learned/observed. Perhaps we may need some time to reflect and the end of the day after a training/activity may not be the best time for reflection as we will probably be feeling very tired. Therefore, there is a blank section in the learning diary.

It is hoped that we will come back to that section and fill it out a few days after the training/activity. In short, you can write in the learning diary at any time. However, it is good to always put aside some time to fill it out so that the learning points are not lost or forgotten and so that the others are able to learn from us.

Happy learning and happy writing!



My Learning Diary

Name:

What did I do in today's activity:

Today's date:

Something new that I learned from today's activity:

Name of activity:

My opinion/feeling about today's activity:

New skills/knowledge that I learned:

Things that I did well:

Things that I need to improve in the future:

I did not learn anything new but it turns out that I made progress, namely:

How will I use this knowledge/skill in the future:

My Learning Diary

Today's date:

Note: This section is for recording our reflections after a bit of time following a training/activity.

My reflections:

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