

# Promoting disability inclusion in sexual and reproductive health research and programming: Experiences from W-DARE



**W-DARE**   
Women with Disabilities taking Action  
on REproductive and sexual health



W-DARE (Women with Disabilities taking Action on Reproductive and sexual health) was a three year program of participatory action research that aimed to improve the sexual and reproductive health of women and girls with disabilities in the Philippines.

Conducted in partnership by the University of Melbourne (Australia) and De La Salle University (Philippines), with community partners WOWLEAP, PARE, Likhaan Center for Women’s Health, and the Center for Women’s Studies Foundation at the University of the Philippines.

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**Photo on front cover:** Sophia (Pia) C. Manlapaz collecting data during the household survey in District 2, Quezon City.

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### Philippines Advisory Group:

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- Prof. Carolyn Sobritchea (Vice President, UP Center for Women's Studies Foundation)
- Ms. Emmeline Verzosa (Executive Director, Philippine Commission on Women)
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- Ms. Pamela Godoy-Averion (UNFPA, Philippines Country Office)
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### International Advisory Group:

- Ms. Anne Harmer (Regional Program Coordinator, UNFPA) - Chair
- Prof. Nora Groce (Leonard Cheshire Disability & Inclusive Development Centre, University College London)
- Prof. Leslie Swartz (Department of Psychology, Stellenbosch University)
- Prof. Patricia O'Brien (Centre for Disability Studies, University of Sydney)
- Prof. Anne Kavanagh (Centre for Health and Society, University of Melbourne)
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## List of Abbreviations/Glossary of terms

Barangay	The smallest unit of local government in the Philippines
CRPD	United Nations Convention on the Rights of Persons with Disabilities
DOH	National Department of Health
DFAT	Australian Government's Department of Foreign Affairs and Trade
DHS	Department of Health Services
DPOs	Disabled People's Organisations
FGD	Focus Group Discussion
LC	Ligao City, Albay Province (WDARE rural research site)
LGU	Local Government Unit
MoU	Memorandum of Understanding
NCDA	Philippines National Council for Disability Affairs
NGO	Non-Government Organisation
PAG	Participatory Action Group
PAR	Participatory Action Research
PARE	People with disabilities Advocating for Rights and Empowerment
PDAO	Persons with Disability Affairs Office
QC	Quezon City, Metro Manila (WDARE urban research site)
RPRH Law	Responsible Parenthood and Reproductive Health Act
SDRC	Social Development Research Centre, De La Salle University
SRH	Sexual and reproductive health
UP	University of the Philippines
VAW	Violence against women
W-DARE	Women with disabilities taking Action on REproductive and sexual health
WHO	World Health Organisation
WOWLEAP	Women with Disabilities LEAP to Social and Economic Progress

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# Executive Summary

These guidelines provide information and resources to support the inclusion of women with disabilities in research, as well as policy, program and service development. These guidelines were developed as part of a three year program of participatory action research (PAR) that aimed to improve the sexual and reproductive health (SRH) of women and girls with disabilities in the Philippines, through improving access to SRH and protection from violence information and services. The program was conducted between April 2013 and March 2016 in two research sites: Quezon City (QC), Metro Manila and Ligao City (LC) in Albay Province, Bicol region.

Throughout the W-DARE project, women with disabilities and Disabled People's Organisations (DPOs) were involved across research activities in a range of roles; including as decision-makers, co-researchers, disability experts, program facilitators and participants.

There are a range of established benefits to actively engaging people with disabilities as researchers and research partners, and participatory research approaches that support and enable the participation of women with disabilities, are widely viewed as effective and appropriate ways of involving women with disabilities in research. However, actively engaging women with disabilities as decision-makers and members of the research team is a relatively unique approach in many places. This could be due to negative assumptions about the capacity of women with disabilities to conduct research, as well as a lack of knowledge and awareness amongst researchers and policy-makers about why they should engage women with disabilities in research, and how they can partner with women with disabilities and disabled people's organisations (DPOs) to design and implement research projects.

Based on the experience of designing, implementing and evaluating the W-DARE research program, the W-DARE team has the following recommendations for supporting disability inclusive SRH policy and programming:

- Work with women with disabilities themselves to build their capacity for meaningful involvement
- Bring agencies that can contribute to improving access to high quality SRH services together with women with disabilities
- Address structural and social factors that undermine access to SRH for women with disabilities
- Improve the availability of disability-related data
- Improve monitoring and compliance with existing legislation and policies
- Differentiate between the SRH needs of different women with disabilities
- Build capacity of the health, disability and welfare sectors

These guidelines aim to promote the active inclusion of women with disabilities in SRH research and programming in the Philippines and other similar settings, and are divided into five sections:

- **INTRODUCTION**
- **MODULE 1.** Disability Inclusive Research: what is it and why would you do it – this section provides information about the principles and ethics of involving people with disabilities in participatory research, as well as a range of tools to conduct disability inclusive research
- **MODULE 2.** Situation assessment: clarifying the situation before you begin – this section provides information and resources for conducting disability inclusive qualitative and quantitative data collection and analysis activities



Members of the W-DARE research team and participant at the 2nd W-DARE Rapid Assessment of Disability (RAD) Training Workshop, October 2013, Quezon City, Philippines.

- **MODULE 3.** Piloting interventions: towards a disability inclusive approach to sexual and reproductive health – this section provides information and resources to design, implement and evaluate interventions to improve SRH
- **REFERENCES**– this section includes a list of useful references about the importance of, and practical ways to, involve people with disabilities in research. Resources are listed with available hyperlinks throughout the manual.

We hope that this information will encourage you to involve women with disabilities as partners and stakeholders in future research programs.

These guidelines will have relevance for researchers, policy-makers, service providers and practitioners who would like to engage women and men with disabilities in efforts to strengthen disability inclusive SRH research, services, policy and programming.

The usefulness of these guidelines is not restricted to those conducting research about SRH. Much of the content of these guidelines will be of use to those wishing to involve women with disabilities in research, on any topic. These guidelines can be used in conjunction with other available guidelines on disability inclusion in research and programming, a list of which can be found at the back of these guidelines.

# Introduction

Many people with disabilities experience all forms of discrimination and exclusion from the social, cultural, political and economic life of their communities. Women with disabilities are acknowledged as experiencing unique and additional disadvantage because of intersectional discrimination associated with their gender and disability, resulting in a higher likelihood of experiencing exclusion compared with men with disability or women without disability [1-3]. This exclusion compromises a number of life outcomes for women with disabilities including education, employment, and attainment of health, including sexual and reproductive health (SRH).

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) has specific provisions that recognise the reproductive rights of persons with disability (Art. 23); the right of people with disabilities to access SRH information and services (Art. 25); and the specific need for empowerment of women with disabilities (Art. 6) [4]. In order for these rights to be achieved, women with disabilities need to be provided with age appropriate, accessible information on SRH, and to have recognition of their rights to have a sexual relationship, marry, establish a family, enjoy reproductive health, and physical integrity. [5, 6]. In low and middle-income countries, efforts to uphold these (and other) articles of the CRPD are hampered by a lack of data on the number of people living with disability and on their SRH needs and experiences [7, 8]. Evidence suggests women with disabilities have reduced access to health information, and experience barriers in accessing screening, prevention and care services resulting in greater unmet health needs, in particular in relation to SRH [1, 9].

Factors often undermining the SRH of women with disabilities are multifaceted. The restricted economic participation of women with disabilities reduces their ability to access health services, compounded by a lack of locally available services and costly, inaccessible transport [1, 6, 10]. Even when services are available, a need for greater understanding on how service providers and the broader

community can support the SRH of women with disabilities is required. Inaccurate and negative stereotypes circulate within community and health-care settings, including that women with disabilities are asexual, don't get married or have children, and therefore don't require SRH services [3, 5, 11, 12]. In addition service providers often lack appropriate equipment, accessible educational materials, and have not had training on providing SRH services for women with disabilities [1]. Furthermore, international development programs promoting access to SRH may inadvertently exclude women with disabilities as these programs are often not designed with due consideration of disability and the particular needs of women with disabilities [1, 7, 13].

An understanding of the benefits of disability inclusive research practice underpins the design of W-DARE. W-DARE is a participatory action research (PAR) project that collected extensive data about barriers to SRH services and information for women and girls with disability and went on to pilot interventions to improve demand for and supply of quality SRH services. Women with disabilities have been included as co-researchers and decision-makers throughout W-DARE, both because they have the right to be involved in research that affects their lives and because women with disabilities themselves have the best understanding of barriers to SRH and of what needs to change if access to SRH information and services is to improve.



Our experience with W-DARE suggests a number of key factors to consider when implementing disability inclusive participatory action research:

**Bringing people with disabilities together with service providers as co-researchers increases all parties' ability to understand each other's' experiences, priorities, constraints and capacities.**

**People with disabilities have the capacity to conduct research, and with training and ongoing support, deliver high quality research outcomes.**

**Strategic engagement with government throughout can result in significant local investment of resources.**

**It is important to work with both the disability sector and the women's movement to build understanding of the particular discrimination and disadvantage experienced by women with disabilities.**

**Many women with disabilities experience violence and this can undermine their ability to participate in all aspects of community life, including in research.**

**Particular strategies may be required to engage women with different types of disabilities , including women with psychosocial disability and/or intellectual disabilities.**

## Resources

Throughout these guidelines, you will find mention of many different resources either developed by the W-DARE research team or by others to support disability inclusive research practices.



The majority of W-DARE resources are freely available for download from the W-DARE blog: [www.wdare.wordpress.com](http://www.wdare.wordpress.com). Please click on the available hyperlinks throughout the manual, or visit the blog directly to look through the list of resources available.



We have also included links to other resources developed to support disability inclusive research. These resources are also listed throughout the manual and some are listed at the back of these guidelines.

# Module 1:

## Disability Inclusive Research – what is it and why would you do it

### Background

Historically, people with disabilities have been excluded from research, including research conducted to inform the development of policies and programs. This results in programs and services that fail to address the priorities and needs of people with disabilities and their communities [7, 13]. There is growing recognition however, that including people with disabilities as researchers and research partners can improve the relevance and effectiveness of research and subsequent services and programs [14-16].

Over the last 50 years, parallel to the growth of the disability rights movement, there has been a significant shift in how disability is understood, resulting in changes to how people with disabilities are involved in research [17]. Key disability models and how they influenced research approaches are summarised in Table 1.

Table 1. Disability models and implications for disability research

MODEL	IMPLICATIONS FOR DISABILITY RESEARCH
<p><b>Medical model of disability</b></p> <ul style="list-style-type: none"> <li>• <b>People are disabled by their impairment</b></li> <li>• <b>Disability is an ‘affliction’ that needs to be fixed</b></li> </ul>	<p>Traditional research approaches:</p> <ul style="list-style-type: none"> <li>• People with disabilities are viewed as research subjects and have no or little control over the research, or involvement in decision-making [18]</li> <li>• Can be viewed as exploitative – data extracted from people with disabilities who little or no control over how information is used and may see little change occur as a result [19].</li> </ul>
<p><b>Social model of disability</b></p>	<p>Inclusive research approaches:</p> <ul style="list-style-type: none"> <li>• Community members are enabled and encouraged to actively participate in research that has relevance to their lives [14].</li> <li>• Increasing use of participatory research approaches [20], underpinned by recognition and prioritisation of right people with disabilities to participate in research [21]</li> <li>• Development of emancipatory research approaches, developed by disability activists, that aim to shift control of research from external researchers to persons with disability [15].</li> </ul>
<p><b>Rights based models of disability</b></p> <ul style="list-style-type: none"> <li>• <b>Disability = impairment + barriers in society [4].</b></li> </ul>	<p>The right to participate in research:</p> <ul style="list-style-type: none"> <li>• Increased recognition of the rights of people with disabilities</li> <li>• Research approaches aim to facilitate empowerment and social change for people with disabilities; address power imbalances between external researchers and community members; build capacity of people with disabilities to conduct research; reflect that people with disabilities need to be respected by research community</li> </ul>

## What does disability inclusive research involve?

There is no one way of doing disability inclusive research, and there are many examples of different types of disability inclusive research projects. Each project will vary in relation to how, and the extent to which people with disabilities are involved. This includes projects generated by people with disabilities who identify the research priority and have control over the nature and direction of the research (often described as emancipatory research). Towards the other end of the spectrum of disability inclusive research, are projects initiated by external researchers who invite people with disabilities to be involved in research and where people with disabilities are supported to provide firsthand accounts of their views and experiences through the use of participatory methods.

The Centre for Applied Disability Research (CADR) review of current practice regarding including people with disabilities developed an infographic (Diagram 3) to describe the spectrum of approaches to including people with disabilities in research, from consultative and advisory at one end to co-researcher led at the other [22].

There are many different ways that external researchers can engage with people with disabilities and DPOs in research, and many different roles people with disabilities and DPOs can take throughout a research process. This depends on their interest, available resources and capacity and what is needed to achieve the aims and objectives of the research.

For example, people with disabilities and DPOs can be engaged in one or more of the following capacities:

- Research partners (decision-makers and co-researchers).
- Individuals and organisations have input into:
  - research aims and objectives.
  - research design;
  - development and drafting of research tools (question guides, surveys etc.);
- data collection and analysis (through conducting surveys, in-depth interviews, focus groups and using participatory research methods); presentation and dissemination of research findings; training and capacity building activities.

**Diagram 3: Spectrum of Models**



CADR, Inclusive Research: a review of current practice (2015), p.3.

- Members of advisory or steering committees for the research.
- Participants, who provide firsthand accounts of their perspectives and experiences. In some research projects, this may be supported by the use of participatory research methods.

Researchers have found that participatory and disability inclusive research approaches and methods are appropriate and effective for conducting research in partnership with people with disabilities [15]. There are clear and tangible benefits for researchers and participants, and for the research outcomes, when people with disabilities are actively involved in participatory research [23].

Conducting participatory research with people with disabilities however can bring with it certain challenges and the unique and additional barriers to participation in research that are often experienced by people with disabilities must be addressed. Facilitating the genuine and meaningful inclusion of people with disabilities requires additional time, budget, human resources, planning, flexibility, and willingness to adapt and tailor research processes [24]. It also requires external researchers to share control over, and ‘let go’ of power within, the research.

There were significant benefits to involving women with disabilities in W-DARE in this way. As with any research conducted by teams situated across different countries, there were also various challenges, and a need to balance varying expectations, expertise, priorities and modes of communications.

More information about the experience of implementing W-DARE can be found at ‘**Fact Sheet A. Benefits, challenges and lessons learnt about disability inclusive research**’ on page 40.

## How did we ensure the W-DARE was disability inclusive?

The W-DARE strived to ensure the research was centered on strategies to resource and facilitate the genuine inclusion of women with disabilities across the three years of activities, from the initial design phase through to dissemination.

This section includes an overview of W-DARE actions in relation to program design, facilitating participation and addressing barriers to involvement for women with disabilities, research management and governance, dissemination and utilisation of research findings and ethical considerations.

A summary of strategies to facilitate involvement of women with disabilities in research can be found in ‘**Fact Sheet B. Strategies for increasing the involvement of women with disabilities in research and program design**’ on page 41.

### Program design: involve women with disabilities from the very beginning

A key feature of disability inclusive research is the involvement of the disability community in identifying the research problem and designing the research project. Not only do women with disabilities have the right to be involved in research that affects their lives, but they themselves are best placed to understand barriers to SRH and what needs to change to improve access for women with disabilities to quality SRH information and services, including protection from violence.

Women with disabilities and DPOs were involved in W-DARE from the very beginning. The University of Melbourne partnered with local researchers who had established relationships with local DPOs. This enabled women with disabilities and their representative organisations to be involved in the early stages of developing the project proposal to ensure the research design was inclusive of women with disabilities and was relevant to the needs and priorities of women with disabilities. One of the first actions to be undertaken by the research team, was to conduct a research project needs assessment to identify how to build the capacity of the team to ensure the research was inclusive of women with disabilities.

The involvement of DPOs in identifying the research priorities and designing the research program helped to develop a sense of shared ownership of the research between the people with disabilities involved and the academic researchers. It also meant the research methodology was designed to be inclusive of the needs of people with disabilities and that the extra resources required to address barriers to participation for people with disabilities in W-DARE were considered and included in the budget and work plan that was approved by the funder.

Formalising research relationships with DPOs through establishing MoUs provided security for the DPOs involved in the project through ensuring that there was recognition of, and remuneration for, their role throughout the project.

### Participation: Facilitate the ongoing involvement of people with disabilities

The W-DARE participatory action research (PAR) methodology facilitated the inclusion of women with disabilities as decision-makers, co-researchers and participants across all research activities. The capacity of women with disabilities in

the role of co-researchers varied, from those with significant prior research experience and expertise and those with little or no research experience. The level of involvement also varied, depending on the requirements of each activity and the availability of the co-researchers. Some were involved on an ongoing basis as a member of the core research team; others were involved across one or more of the specific research activity.

Key actions to facilitate the involvement of people with disabilities in research:

- Formally contracting DPOs as project partners
- Including DPO representatives in regular decision-making and management meetings with the project manager and local academics.
- Giving DPOs responsibility for the recruitment of the co-researchers who were women and men with disability, including women and men with vision, mobility and physical impairments and women who are Deaf or hard of hearing.
- Build capacity and confidence of co-researchers and external researchers to undertake different research activities.
- Recognising and utilising the expertise and capacity of the women with disabilities involved in W-DARE throughout the project, including as co-facilitators and trainers during capacity development activities.
- Budget and plan for adequate resources to support the inclusion of women with disabilities
- Putting strategies in place to thoughtfully 'end' participation of community with disability, in order to ensure that individuals felt that their contribution was valued by the research team.

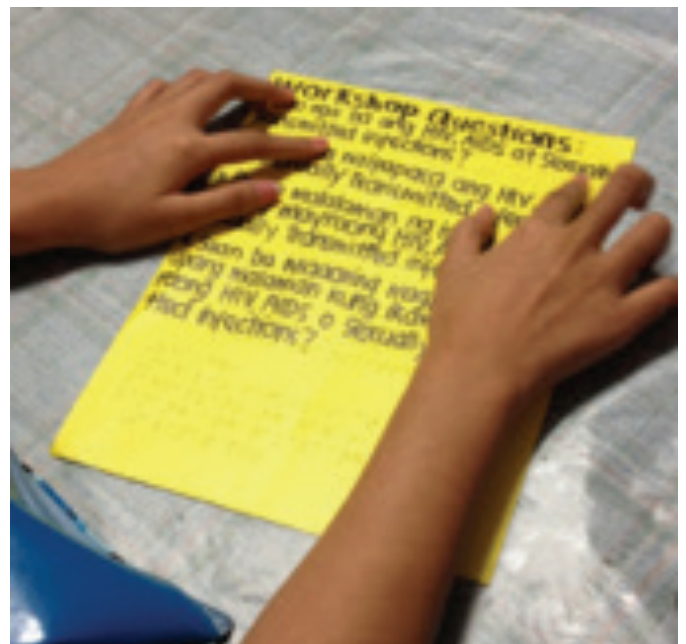
### **Accessibility: addressing barriers experienced by women with disabilities to participation in research**

There are a range of barriers experienced by people, and in particular women, with disability to participation in research. These include attitudinal, communication and environmental barriers. Ensuring additional time, and financial and human resources are adequately budgeted for to address these barriers is important to ensure that women with disabilities can be actively involved in research.

The W-DARE team identified a range of barriers (including attitudinal, physical/environmental, communication and language barriers) that could undermine the participation

of women with disabilities and implemented actions to address these barriers. An overview of the identified barriers and actions implemented by W-DARE can be found at '**Fact sheet C. Strategies implemented by the W-DARE to address participation barriers**' on page 43.

In addition, the W-DARE team also identified that women with different types of impairments (e.g. women who have mobility impairments, women who are blind and women who are Deaf) may experience different barriers to participation in research. As such, strategies may need to be tailored to address the needs of women with different types of disabilities. More information about how to address barriers to participation experienced by women with different types of impairments can be found at '**Fact sheet D. Strategies for addressing barriers to participation experienced by people with different types of impairment**' on page 44.



A participant with a visual impairment from Quezon City reads a braille translation of a resource on HIV and AIDS in Session 6

### **Research management and governance**

Disability inclusive PAR research projects with diverse research partners across different sectors, requires good management of partnerships, expectations, budgets, and logistics, as well as ensuring key stakeholders such as local governments are meaningfully engaged in the process.

Developing and maintaining positive relationships with diverse partners with varying levels of research expertise takes time, as does reaching a consensus on shared language and inclusive research methodology.

In relation to managing relationships with research partners, the W-DARE team found that an open and transparent management style, in which researchers and participant-researchers, including women with disabilities, were involved in decision-making processes, helped to build trusting relationships with various research partners and to improve the research process.

By definition, 'action' research relies on the ongoing process and findings to inform subsequent actions. This can make it more difficult in terms of management and planning, particularly when trying to ensure sufficient resources are available to support inclusion of co-researchers with disabilities.

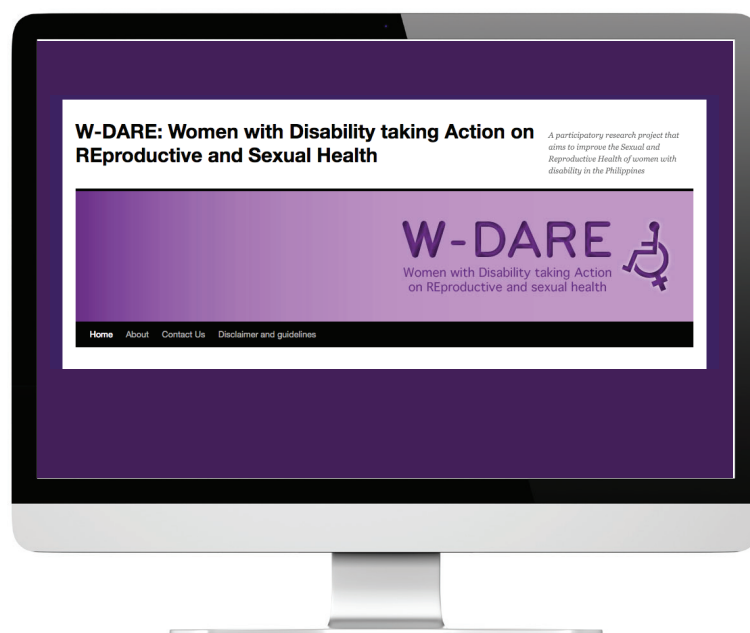
The W-DARE also established a local advisory committee, which met twice a year and provided oversight and guidance of the implementation of the W-DARE. The committee included representatives from several national stakeholders, including the peak body for people with disability (NCDA), the Philippine commission for women as well as representatives from government health departments and the W-DARE funders (DFAT and UNFPA).

## Dissemination and utilisation of research findings

Involving people with disabilities in decision-making about how research findings are analysed and shared and how participant's voices will be represented is an important part of disability inclusive research. This includes ensuring that people with disabilities and DPOs have ownership of the research findings and can use the findings to further their own objectives, including for advocacy. Actively involving people with disabilities in the dissemination of research findings, through their contribution as co-authors on publications, presenters or co-presenters at conferences and sectoral meetings, also has positive benefits for people with disabilities.

W-DARE co-researchers with disabilities have contributed to the development of papers and presentations including delivery at national conferences, co-authors of presentations at international conferences, co-authors on academic papers and community reports. This increases the visibility of the involvement of women with disabilities across the W-DARE and demonstrates disability inclusive research, recognises their contribution to the research project and continues to build their research capacity and progress their own careers.

Outputs documenting the findings of the W-DARE, including peer reviewed journal articles, community reports, fact sheets, case studies and women with disabilities' reflections on their experiences of involvement in W-DARE are available from the W-DARE blog: [www.wdare.wordpress.com](http://www.wdare.wordpress.com).



### Ethical considerations

Disability inclusive research aims to ensure that people with disabilities, about whom and for whom the research is designed, play a central role as researchers and as research participants; and the voice of people with disabilities is validated as data. However, people with disabilities may experience barriers to participation in research or may be reluctant to engage with research due to previous negative or exploitative research experiences.

Ethical disability inclusive research:

- Aims to provide tangible benefits to people with disabilities and their communities, whereby the potential benefits outweigh the risks involved in conducting the research
- Is owned by people with disabilities and their representative organisations
- Enables 'informed consent' by providing potential participants with the necessary information so that they can make an informed decision about whether or not to participate in the research
- Ensures the right to privacy for participants and confidentiality of information
- Provides appropriate support structures to manage effects of involvement for people with disabilities and other members of the research team
- Provides information about the research process, research tools, and research reports, in ways and in formats that are accessible to people with different types of impairments

To identify ethical issues that could predictably arise during, and as a result of, the W-DARE project, the research team conducted a risk assessment as a facilitated exercise as part of training for all researchers and participant-researchers on 'Research Ethics'. Involving women with different types of impairments in the risk assessment facilitated a more accurate understanding of the potential risks associated with conducting the research and the development of appropriate strategies to address these issues.

In particular, the risk assessment highlighted ethical issues associated with data collection, including in relation to informed consent, participant confidentiality and right to privacy, and how to respond to participants' disclosures of traumatic or illegal activities by all researchers and participant researchers involved in the team.

More information about these risks and the mechanisms put in place by the W-DARE team to address them can be found at '**Fact Sheet E. Ethical considerations during data collection**' on page 45.

The risk assessment formed the basis of the ethics applications submitted to ethics committees at the University of Melbourne and De La Salle University. These committees gave approval to conduct the research in the Philippines.

# Module 2:

## Situation assessment – clarifying the situation before you begin

### Introduction to Module 2

There is growing recognition of the need for contextual understanding of the lived experience of disability to support the design, implementation and monitoring of effective inclusive development programs [27, 28].

As highlighted in Module 1. Disability Inclusive Research, ensuring the participation of women, men, girls and boys with disability in designing, adapting and implementing a situation assessment is a key principle of disability inclusive practice. Having a clear understanding of what data you want to collect and why and how it will inform better disability inclusive services, policies and programs will help determine the kind of data collection activities required.

Responding to the sexual and reproductive health (SRH) needs of women with disabilities for example, requires context specific information on the lived experience of disability and how this intersects with sexual and reproductive health and access to appropriate information and services. Further information on determining appropriate disability inclusive data collection can be found in the following link:



Plan International and CBM-Nossal's Practice note: Collecting and using data on disability to inform inclusive development: [https://www.did4all.com.au/Resources/Plan-CBM-Nossal\\_Disability-Data-Collection-Practice-Note\\_2016Update.pdf](https://www.did4all.com.au/Resources/Plan-CBM-Nossal_Disability-Data-Collection-Practice-Note_2016Update.pdf)

This module describes Phase one of the W-DARE which involved the collection of quantitative and qualitative data to understand the lived experience of women with disabilities in the Philippines and their access to SRH information and services. Findings then informed pilot interventions aimed at improving access to quality SRH information and services. The steps outlined would be applicable to similar research in other contexts, or can be adapted for other disability related research.

The W-DARE community report provides more in-depth information about Phase 1 research activities and research findings that are covered briefly in this module:



W-DARE Community report: <https://wdare.files.wordpress.com/2015/06/w-dare-community-report.pdf>



## Understanding the contexts in which people with disabilities live

The lived experience of disability is influenced by the environmental and policy contexts of where people live. W-DARE conducted a number of processes to help understand the lived experiences of women with disabilities in the Philippines and how this influenced their access to quality SRH. These included:



### STAKEHOLDER ANALYSIS

Early identification and engagement of stakeholders who have influence over the environmental and policy contexts of disability and sexual and reproductive health is essential. Relevant stakeholders need to be informed as to why the research is being conducted and encouraged to engage with processes to support the research and longer-term strategies to improve the lives of people with disabilities. Stakeholders engaged in W-DARE included local and international experts in disability, gender and SRH, including local and national government representatives, representatives from the disability sector (especially those that had a focus on women with disabilities), academics, and service providers.



### POLICY ANALYSIS

Analysis of the laws and policies relevant to people with disabilities, women and children and SRH, and how these are implemented across the levels of government to influence access to services.



### CAPACITY BUILDING OF THE RESEARCH TEAM

Training workshops aimed to improve the capacity of project partners to conduct disability inclusive research, including quantitative and qualitative methods. Workshops also aimed to increase understanding of external researchers of the Philippines context, to engage with local priorities and sensitivities, and to adapt processes to ensure that they were culturally appropriate.



### AVAILABILITY OF SERVICES

Through mapping of all services relevant to SRH and disability within the area of interests. This information can also support the referral of participants requiring particular services.

## Quantitative data collection: Measuring disability prevalence and the inclusion of people with disabilities

There are a number of methods and tools which can be used to measure the prevalence of disability and disability inclusion. The tool you use and how you use will depend on the purpose and objectives of why you are collecting the data. Options include the Rapid Assessment of Disability (RAD), Washington Group Short Set of Questions on Disability and the World Health Organization's Model Disability Survey. W-DARE implemented a Rapid Assessment of Disability survey.

### The Rapid Assessment of Disability (RAD) toolkit

The RAD toolkit was developed by the Nossal Institute for Global Health and the Centre for Eye Research Australia at the University of Melbourne. The RAD is a population-based household survey designed to establish baseline information on the prevalence and effect of disability among adults (18 years or older) on well-being and access to community in comparison to people without disability [28].

The RAD questionnaire is interviewer administered and has two parts: the first part contains questions about the socio-economic characteristics of the household, which are administered to the head of the household; the second part is administered to individuals and contains sections on demographic information, self-assessment of functioning, well-being and access to the community.



The RAD toolkit (includes the SRH fieldwork manual in English, RAD Individual questionnaire, RAD Household questionnaire) <https://wordpress.com/post/wdare.wordpress.com/237>

### Women's Health Questionnaire

W-DARE developed a Women's Health Questionnaire to measure women's access to SRH services and information as part of the RAD household survey. The Women's Health Questionnaire was administered to all women identified as having functional limitation using the RAD, and to matched controls (matched on age and location). Matched controls were included to enable the team to compare access to SRH services for women with and without disability. Development of the Women's Health Questionnaire was informed by existing tools including the Philippines census questions, DHS surveys, and surveys developed by international agencies such as the WHO Multi country study on Women's Health and Domestic Violence against Women [29].



W-DARE Women's Health Questionnaire: [https://wdare.files.wordpress.com/2018/10/womens-health-questionnaire\\_philippines-adra\\_final.pdf](https://wdare.files.wordpress.com/2018/10/womens-health-questionnaire_philippines-adra_final.pdf)

### Training of research team

Field work teams included men and women with disabilities and representatives of project partner organisations. All team members undertook one week of training to understand the RAD tool and its ethical implementation. Field work teams were then supported and supervised by experienced SDRC and UP co-investigators.

### Pretesting

Both the RAD and Women's Health Questionnaires were translated and cognitively tested to make sure they were appropriate to the Philippines context. Local research teams conducted cognitive testing of the RAD and Women's Health Questionnaires in both Quezon City and Ligao City, including with respondents with a range of impairments. The purpose of this was to make sure that the questions could be easily understood by, and made sense to, all possible participants and to make sure that the questions were going to provide the most accurate information possible.



Ligao City RAD team preparing to visit a Barangay, December 2013.

### Sample and recruitment

The cross-sectional population-based survey used two-staged cluster random sampling. In the first stage of sampling, groups of puroks in Quezon City and barangays in Ligao City ('clusters') were randomly selected. Each cluster was divided into equal segments of houses estimated to provide 50 potential participants aged 18 years and above were identified. Mapping used by the National Statistics Office for the census and purok/barangay household lists were used to divide the clusters into segments and then one segment from each cluster was randomly selected for data collection.

### Quantitative data analysis

Statistical analyses were performed using SPSS. Descriptive analysis was conducted to determine the prevalence of disability. Both univariate and multivariate (binary logistic regression) analyses were undertaken to assess the

associations between socio-demographic characteristics and prevalence of disability. Disability (present or absent) as measured using the self-assessment of functioning section was the dependent variable. The independent variables were age of respondent, gender, education level, occupation and asset quintiles, and SRH outcomes. A two-day workshop with project partners and members of the household survey team was conducted to help contextualize the data and reflect on both the process and findings of the RAD survey.

More information about the W-DARE RAD survey methodology and findings can be found in the following article: "Rapid Assessment of disability in the Philippines: understanding prevalence, well-being, and access to the community for people with disabilities to inform the W-DARE project".



Rapid Assessment of disability in the Philippines: understanding prevalence, well-being, and access to the community for people with disabilities to inform the W-DARE project  
<https://pophealthmetrics.biomedcentral.com/articles/10.1186/s12963-016-0096-y>



For more information about the Washington Group Questions and the WHO Model Disability Survey visit:

- [Washington Group on Disability Statistics](#)
- [World Health Organization's Model Disability Survey](#)

## Qualitative data collection - understanding the lived experience of people with disabilities

The W-DARE team implemented several qualitative data collection activities to gain a deeper understanding of the situation of women with disabilities in relation to their SRH.

It is important to include the perspectives of women with different types of impairment, as well as different ages and socio-economic backgrounds. Qualitative methods such as focus group discussions and in-depth interviews are useful methods to gather this kind of data. To triangulate this information, it is also important to understand the perspective of other key stakeholders such as:

- Women without disabilities - in many contexts, women without disability also experience poor levels of access to services and it is important to understand what the similarities and differences are in terms of barriers and enablers to accessing SRH services between women with and without disabilities.
- Service providers – including service providers across various levels of government and non-government services, different types of services such as local health services providing family planning and MCH through to tertiary level hospitals, and violence prevention and protection services including stakeholders within the justice system.
- Policy makers and other key stakeholders – whose policies and programmes may directly or indirectly impact on the access to SRH services for women with disabilities.
- Family members of women with disabilities - including partners of women with disabilities, and where appropriate parents or carers of girls with disabilities, as family members and partners may influence a woman's access to SRH services.

Question guides for the different groups of participants were developed to increase understanding of the lived experience of disability, the SRH needs and experiences of women with disabilities (including exposure to violence), and the barriers and facilitators to accessing SRH services and information experienced by women with disabilities.

## Sample and recruitment

Participants for the in-depth interviews and focus group discussions were identified through the RAD survey and through the networks of the partner DPOs and non-government organisations (NGOs); through the staff and representatives of SRH service providers (government, non-government and Church-run) active in Quezon City and/or Ligao City; and through a snowball approach (in which participants identified other participants within their networks). All potential participants were provided with information about the research in the form of a plain language statement, and then informed consent was obtained. Services and information experienced by women with disabilities.

## Qualitative data analysis

A three-day in-country data analysis workshop with the qualitative data collection team was conducted to help identify key themes and develop an initial coding framework. The coding framework was used to categorise and allocate data for each theme and was used as a template for storing and managing data in NVivo version 10.2.1.

Pages 22 and 23 provide a snapshot of the findings from the Phase 1 quantitative and qualitative research activities.



Participants at an Introduction to Disability and Gender Inclusive Research workshop (Quezon City, August 2013)

Table 2. Overview of the Phase one W-DARE data collection activities

QUANTITATIVE	QUALITATIVE
<p><b>Rapid Assessment of Disability (RAD) Survey</b> with 3,059 adults (2287 adults in QC and 772 adults in LC).</p>	<p><b>42 in-depth interviews</b> with women and girls (aged 15 years and over) with disabilities</p>
<p><b>Women's Health Questionnaire</b> 253 women in total (137 women with disabilities identified as having a functional limitation during the RAD and 116 matched controls - women without disability from the same location and age group).</p>	<p><b>20 in-depth interviews</b> with SRH service providers</p> <p><b>8 focus group discussions</b> (partners and parents of women with disabilities, women without disabilities)</p>

# Key findings from Phase one of the W-DARE project

## Disability Prevalence

The **prevalence** of disability was

**7.14%** in Quezon City

**14.04%** in Ligao City



**Psychological distress** was the most commonly reported disability



Disability was found to **increase with age** and was similar in males and females.



People with **no education** or with **only some elementary education** were more likely to have disability compared to those with college or technical education.

## Wellbeing & Access to the Community

People with disabilities:



had poorer well-being when compared to people without disability



were more likely to report reduced access to health services, work, education, social and religious activities, and toilets



barriers to health services included cost of services, lack of information about services, negative attitudes, difficulty getting to facilities, and the absence of personal assistance).

## Access to SRH information, and SRH knowledge among women with disabilities

Mixed levels of knowledge across women with disabilities, in general however levels of **SRH knowledge were quite low** (particularly among women with intellectual disability and women who are Deaf or hard of hearing)



Disability and SRH were often reported to be **taboo topics**, with the sexual needs and desires of women with disabilities rarely discussed



**Mothers, sisters and friends** were the primary sources of SRH knowledge for women with disabilities

## Access to SRH services

Women with disabilities reported significant challenges accessing SRH services, including:

a range of **negative experiences** at health care facilities, including negative attitudes, prejudice, **discrimination and abuse** by health care providers

**limited capacity of services providers** to manage the SRH concerns of a woman with a disability (also acknowledged by service providers)



lack of local SRH services and limited accessible transport to get to what services were available



difficulty in accessing sign language interpreters



**financial barriers** including the cost of the actual service, and costs associated with accessing the service (e.g. public transport, medication)

## Right to healthy and fulfilling relationships

Women with disabilities reported:

instances where their **capacity to marry, have children and look after their children was questioned**, including having children being removed from their care



family disapproval of their choice of partner, often influenced by whether or not the partner also had a disability



the assumption (often held by their husbands family) that a woman with a disability could not be a good wife or take care of her husband

Service providers reported requests made by families of women with disabilities to **sterilize their female family members with a disability** to prevent pregnancies, including as a result of rape

## Agency and independence of women with disabilities



Women with disabilities reported varied levels of agency and empowerment in relation to their SRH.

Women with vision and mobility impairments, who were older, had higher levels of education and/or were married, demonstrated higher levels of independence and agency that those women who were younger, or had intellectual disability or were Deaf or hard of hearing.



Families of women with disabilities tended to be very (over)protective of their family members with disability, restricting their independence.

Conversely, some families were reported to hide their family members with a disability, because of the prejudice and discrimination often associated with disability. This has negative consequences for the health and wellbeing of women with disabilities.

## Community attitudes towards disability

### Women with disabilities reported:



experiences of **discrimination** from family members, health service providers (also confirmed by services providers who participated in the research), transport providers, educators, the law and justice sector, and members of the general public



discriminatory actions, including denial of service, derogatory remarks and abuse.

## Experiences of violence and abuse

### Women with disabilities reported:



common experiences of sexual and physical violence and abuse

being subject to a range of emotional and controlling behaviours as well as exploitation, neglect and maltreatment



abuse perpetrated by family members, partners and strangers

difficulty in coming forward and reporting abuse by family members and caregivers (a particular issue for women with intellectual disability or who were Deaf or hard of hearing)

not being believed by family members (when reporting abuse by other family members), compounding the trauma of the abuse and leading to family conflict

## Resilience of women with disabilities



It was also clear that many of the women and girls with disability involved in W-DARE were able to overcome substantial challenges, demonstrating resilience and strengths rarely acknowledged



Supportive family and social networks often facilitated women with disabilities being able to make informed choices about education, employment and personal relationships



Women with disabilities involved in W-DARE showed high levels of personal strength and resilience, which in some cases they attributed to their experiences of involvement in the W-DARE

## Acknowledging diverse lived experiences of disability by women with varied impairments

The W-DARE findings highlighted that whilst there are some common SRH experiences and needs shared amongst women with all types of impairments, that women with specific types of impairments can experience greater discrimination than others. For example, the W-DARE research findings indicate that women with psychosocial disability, women with intellectual disability and women who are Deaf or hard of hearing, experience higher levels of violence, prejudice, and discrimination, and can experience greater barriers to access of health services, than women without disability and women with other types of disability. This has implications for addressing barriers to access of SRH information and services, and for involving women with diverse impairments in disability inclusive research.

## Using findings to inform interventions

### Analysis workshop and prioritising of interventions

The W-DARE team worked with project partners to analyse the data generated in Phase One to generate ideas about pilot interventions to improve access to SRH. Activities and interventions were prioritised on the basis of need, feasibility, likely impact, stakeholder support and the available resources. The range of interventions developed reflects the need to address barriers and strengthen supports at a number of levels in order to improve access to quality SRH services, including protection from violence.

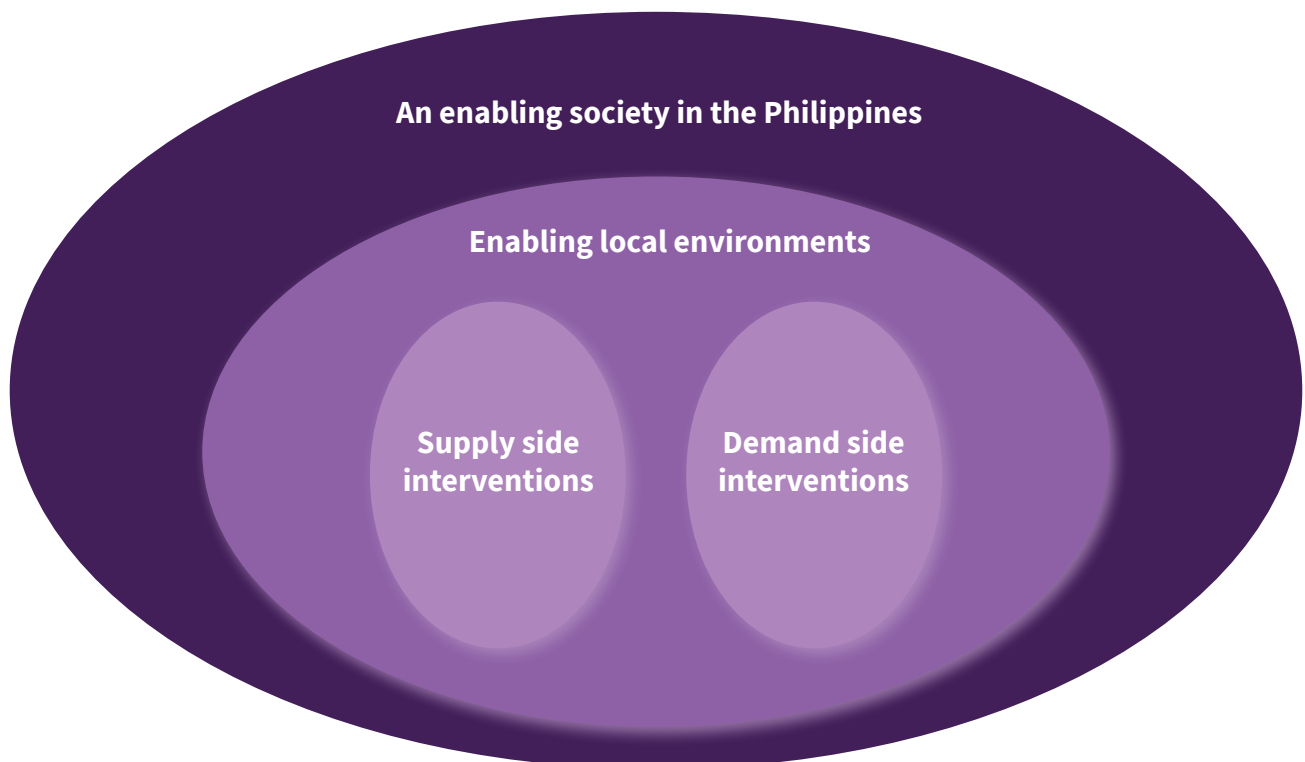
### Framework for interventions

In addition to working to increase supply of high quality SRH interventions to women with disabilities, and to increase demand for such services from women with disabilities, W-DARE findings highlight the importance of working with barangays and local government units to create enabling local environments. Delivery of SRH information and services

occurs in the wider social context, so it is also important to address prejudice and discrimination across all aspects of society in the Philippines.

In debating how to prioritise activities for support, the research team noted that the interlinked nature of these barriers to SRH meant that just working in one domain would be unlikely to increase access to SRH for women with disabilities. While the resources and scope of this action research project were limited, the decision was made to pilot activities in each of these four areas rather than prioritise one over others. The next module will provide an overview of the implementation and evaluation of several key pilot interventions implemented in Phase two of the W-DARE project.

Figure 1. A visual representation of the framework for interventions





# Module 3:

## Piloting interventions - towards a disability inclusive approach to sexual and reproductive health

### Introduction to Module 3

Phase one of W-DARE highlighted that to improve access to quality SRH for women with disabilities, targeted interventions needed to be developed and supported across a number of levels. For example, supporting women with disabilities to demand SRH information and services would not be appropriate if the capacity of service providers to supply quality SRH for women with disabilities was not strengthened. Service delivery therefore needs to be reinforced by local government structures which support disability inclusive SRH services. Similarly, one of the greatest barriers to inclusion is societal attitudes to disability; to really support disability inclusive SRH systems, W-DARE also needed to contribute to promoting positive attitudes toward women with disabilities.

Efforts to increase access to SRH for women with disabilities requires the sustained support of government agencies and the kind of structural change that can only be led by government, highlighting the need to resource continued engagement with government stakeholders. All interventions were therefore developed through the collaboration of the W-DARE team and project partners, DPOs, service providers and the Philippines Advisory Group and in consultation with relevant government agencies.

This module is divided into a number of sub-sections. Each section describes the processes and methods we implemented to pilot either a specific strategy, or a range of strategies to improve access and supply of SRH, key findings or factors to consider, and where applicable, the monitoring and evaluation frameworks used.

The sub sections are:

1. Demand-side intervention: Participatory Action Groups for women with disabilities and parents of children with disability
2. Supply-side intervention: Strengthening the capacity of services providers to deliver disability SRH services
3. Enabling local environments: Supporting local governance on disability-inclusive SRH
4. Building enabling societies: Media materials and other resources to address stigma and discrimination

### Demand-side intervention: Participatory Action Groups for women with disabilities and parents of children with disabilities

Findings from interviews and FGDs with women with disabilities in Phase one of W-DARE highlighted women with disabilities wanted more information about SRH and better support to access SRH services. To address this, the W-DARE team developed and implemented a pilot intervention focused on peer-facilitated Participatory Action Groups (PAGs) for women with disabilities.

#### **Aim: increase demand for quality SRH services and information for women with disabilities by:**

- increasing participants' SRH knowledge; awareness of their rights in relation to SRH and disability; and confidence to access and negotiate health services
- support development of individual and/or collective action plans to further promote demand for SRH within the women's communities, and
- facilitating the development of peer support amongst groups of women with disabilities

The findings also highlighted parents were often the source of SRH information for their family members with a disability. Yet parents themselves were often not equipped with an appropriate understanding of the rights of people with disabilities to SRH. To respond to this, a separate peer-facilitated PAG for parents of children with disability

was also implemented with the specific aim of increasing understanding of parents of children with disability about how to support family members with a disability in attaining quality SRH throughout their life course.

### The PAG intervention

The PAG intervention consisted of supporting a series of ten peer-facilitated meetings for six groups of women with disabilities (participatory action groups or PAGs) and one group of parents of children with disability. The PAG meetings were held approximately every fortnight over a twenty-week period, with each meeting lasting for half a day to a full day. All meetings were participatory, strengths-based and comprised a combination of structured activities and open discussion, with a focus on key factors relevant to SRH needs and rights, but also allowed plenty of time for fun activities and opportunities for social interactions.

### Key elements of the PAG intervention included:

**Stakeholder consultations** - ongoing consultations with the W-DARE team including co-researchers with disability to further developed the ideas and methodologies for the PAG intervention and determine the logistical support needed for implementation.

**Development of a PAG Training manual** - A draft PAG manual was developed, which outlined a number of topics related to disability and SRH to be utilized by the different groups to develop materials and content for each of the ten PAG sessions. PAG Facilitators then adapted each session to make it as relevant as possible for the PAG participants.

**PAG facilitator recruitment and training** - Local research team members with disabilities were recruited into the role as PAG facilitators. Additional PAG facilitators were recruited through the networks of the DPO partners, with the aim of building the capacity of women with less experience of research and group facilitation. A four day workshop was conducted to build the capacity of facilitators to plan and implement the PAG sessions.



Detailed information about the PAG sessions can be found in the W-DARE Participatory Action Group (PAG) Guide for facilitators, available here: <https://wdare.files.wordpress.com/2018/10/w-dare-pag-session-guide-for-facilitators.pdf>

### Recruitment of the PAG participants

The PAG participants were recruited through the networks of the facilitators, the W-DARE local research team and partners, and through the Persons with Disability Affairs Office (PDAO) in each research site. When identifying potential participants, disability, age and geographical location were all taken into consideration. Women were broadly grouped in relation to type of disability to allow for appropriate communication, but also as women with different types of disability often experience SRH differently.

The age range of participants was 18 to 35 years of age. Parents of children with disabilities were also recruited through local partners for the PAG for parents.

### Logistical considerations

There were a number of logistics required to support the PAG intervention which need to be considered when determining the cost and feasibility of similar interventions.

- **Allowance** - All participants were given a small allowance to support their travel and childcare costs or time away from work due to participating in the PAG sessions.
- **Location** - Meeting venues needed to be physically accessible (including accessible bathroom facilities), allow for confidentiality of the participants and ideally were in a central location.
- **Transport** - where required, an accessible van and driver was hired to pick up and return women from their homes to the PAG venue.
- **Additional assistance** - support staff were engaged to help care for children of women who did not have childcare alternatives and to provide additional support to women where required
- **Resource persons** - organisations and individuals with expertise in SRH content and service delivery (including W-DARE partner Likhaan) were engaged to support sessions relating to HIV and STIs, family planning, and safety planning for women at risk of violence and abuse. Some of these sessions were held offsite (at health clinics or violence protection offices) which helped participants to become familiar with these services.

### Ongoing support for the PAG facilitators

A local research team member was engaged in the role as the PAG Coordinator to support the implementation of the intervention and providing ongoing support and mentoring for the PAG facilitators and participants, including referral and follow-up for women requiring additional support, such as in relation to experience of abuse.

### Action planning:

Each group was encouraged and supported to develop an individual or collective action plan. The aim of the action planning activity was two-fold. Firstly, it provided an opportunity for the groups to draw on their acquired knowledge and ideas and build their capacity to collectively plan and implement activities that would help sustain

the PAG process and impact. Secondly, it was hoped the action plans would help facilitate awareness of SRH and disability for other women with disabilities and the broader community.

### Monitoring and Evaluation

Monitoring and evaluation of the PAGs was conducted through a range of evaluation activities. The purpose of this was to ensure that changes in PAG participants' knowledge and attitudes over time could be recorded, and to make sure that the perspectives of a wide range of people involved in the PAGs could also be captured.

Table 3. Overview of PAG Monitoring and Evaluation activities

TIMING	GROUP	DATA SOURCE	AIM
Pre and post intervention	PAG participants	Quantitative – RAD survey and SRH knowledge questionnaire	To measure baseline levels and subsequent changes in functioning, well-being and participation in community, as well as participants SRH knowledge and understanding.
Pre and post intervention	Parents of children with disability	Knowledge, attitudes and practice survey	To assess changes on knowledge, attitudes and practices around SRH and disability.
After each session	PAG facilitators	Documentation	To record the content covered, any issues arising, reflections on process and monitor support/referral requirements of participants.
Mid-intervention	PAG coordinator and facilitators	Interim monitoring workshop	To document any changes observed by PAG facilitators, and identify any negative impacts to be mitigated.
End of intervention	PAG participants	Stories of change: Qualitative interviews about individual change, group discussions to prioritise collective change	To identify most significant change at individual and group levels as a result of participating in the PAG intervention
6 months post intervention	PAG participants	Follow-up interviews (with selected participants from each group)	To examine whether change that participants originally described has been sustained

### Key findings from the PAG intervention

Analysis of the women's stories highlighted a range of important changes in women's lives that participants attributed to their participation in the PAGs. Whilst there were differences in how each PAG collectively prioritised these changes, common themes to emerge across the groups include enhanced self-confidence; increased knowledge on the rights of people with disabilities; increased knowledge on protection from violence for women and children with disabilities; increased access to SRH services including protection from violence; sustained social inclusion; and increased participation in communities.

More information about the process of implementing the PAG intervention and the evaluation findings can be found in the **“Freedom to go where I want”: improving access to sexual and reproductive health for women with disability in the Philippines** publication: <https://www.tandfonline.com/doi/abs/10.1080/09688080.2017.1319732>

### PAG for parents of children with disabilities

The two facilitators of the PAG parent group and four participants were interviewed. After the PAG intervention, participants of the PAG for parents identified the most important changes as increased self-confidence to parent and increased confidence in the capacity of their children with disabilities; increased knowledge on the rights of children with disabilities and on the importance of protecting children with disabilities from violence and abuse.

These changes were confirmed by the interview participants as being sustained after the PAG intervention had finished and had also enabled dissemination of information to other parents of children with disabilities in their communities. Learning about the laws which should protect children with disability from abuse helped participants to try and address cases of abuse and neglect within their communities. All the parents emphasized that the positive changes gained through participation in the PAG had been sustained.

When asked what they would have changed about the PAG intervention, the PAG parents reported the need to conduct the PAG for other parents and to increase the coverage of the intervention. Overwhelming though, the greatest need reported was the need for resources and support for parents, children and the communities to protect children with disabilities from sexual abuse and violence.

## Supply-side interventions: Building the capacity of SRH providers to improve access for women with disabilities

Whilst efforts to improve demand for SRH information and services by women with disabilities were clustered within one priority intervention (PAGs for women with disabilities as discussed in the previous module), in order to improve the supply of disability inclusive SRH services, the project supported a range of interventions involving close collaboration with the National Department of Health and the City Health Offices in the two LGUs where W-DARE was focused.

The overall aims of W-DARE supply-side interventions were to:

- increase SRH and violence service provider awareness of disability and sensitivity to the specific needs of women with disabilities;
- enhance service providers' communication and other skills required to provide services to women with disabilities;
- provide guidance as to what would be required for a facility or service to become disability inclusive and accessible; and
- strengthen existing practices and referral pathways for women experiencing violence to ensure that they are inclusive of women with disabilities.

An important approach taken in all of the supply side capacity building workshops was the involvement of women with disabilities in the development and delivery of content.

Examples of their input included:

- speaking to the lived experience of women with disabilities and the SRH needs;
- conducting mock consultations with service providers to enhance understanding on how to provide services for women with disabilities;
- accompanying service providers through accessibility audits of facilities; and
- providing guidance on appropriate communication with women with different types of impairment.

As this module provides an overview of multiple supply-side interventions, information about processes and implementation are written specific to each intervention, instead of in relation to the development of the overarching program of supply-side interventions as a whole.

In relation to monitoring and evaluation, many service providers and government officials participated in both 'Supply-side interventions' and 'Interventions to support enabling local environments'. As it was not possible to determine if changes were attributable to a particular workshop or from exposure to multiple activities, evaluation findings are reported together at the end of Module 4.

### Overview of supply-side interventions

#### Disability and gender sensitisation workshops

W-DARE supported disability and gender sensitisation workshops in Quezon City and Albay Province. In order to build capacity across different sectors and levels of governments to delivery disability-inclusive SRH services, the W-DARE project team delivered training workshops for health service providers at different levels, from senior doctors and nurses, violence protection workers, police,

social workers, to barangay health workers, and government officials from agencies such as the Philippines Commission on Women, the National Council for Disability Affairs, and the Department of Social Welfare and Development.

These workshops aimed to raise participants' awareness of the rights of women with disabilities; the strengths and contributions made by women with disabilities and the challenges they face in accessing SRH services and information. These workshops were co-facilitated by women with different types of disabilities who were able to ensure discussion of potential service responses is realistic and informed by their experiences. Women with disabilities worked with participants to develop strategies for improving communications with women with disabilities (including basic sign language skills) and for adapting examination and other procedures.



Women with disabilities and project partners co-facilitating training of doctors and other clinicians (April 2015)

As a part of the disability and gender sensitisation workshops, participants (service providers and government officials) were supported to:

- Develop action plans – Participants were tasked with identifying concrete steps they could take in their own services, facilities and workplaces to increase accessibility for women with disabilities. Action plans included a variety of steps and strategies, including developing relationships and liaising with DPOs; offering outreach services; modifying health and other facilities; and training other staff around the SRH needs of women with disabilities. Participants were encouraged to identify locally available resources, such as each local government’s Gender and Development budget, to support these local action plans.
- Conduct accessibility audits of selected health facilities – Accessibility audits of selected facilities were conducted using a ‘disability walk through’ tool developed by the W-DARE team. This process involved health facility managers working with women with different kinds of disabilities to use a check-list when ‘walking through’ a health facility, to assess all kinds of accessibility at different points in a client’s use of a facility, including entrance, reception, findings a service, passages and transit areas, waiting rooms, toilets and consulting suites. The tool includes reviewing the physical accessibility of buildings; accessibility of information, technology and communication systems of services; and accessibility of surrounding infrastructure and transport (meaningful to help understand barriers to accessing services in the immediate context).

#### **Tools for conducting accessibility audits: Disability ‘walk through’ assessment checklist**



W-DARE Service provider training package:  
<https://wdare.files.wordpress.com/2018/09/w-dare-service-provider-training-package1.pdf>

#### **Contribution to Department of Health (DOH) training and resources**

Consultations and engagement with The Department of Health (DOH) highlighted a need for extensive capacity building around disability inclusion to be conducted at multiple levels of the department. As such, the W-DARE team developed and delivered training modules for the DOH disability inclusion training and developed a toolkit for health managers on disability inclusive facilities. The toolkit included training materials and audit tools on disability inclusion within SRH services and systems.

#### **Strengthening disability inclusive violence and responsive services**

Data collected in the first phase of W-DARE confirmed that many women with disabilities in the Philippines have experienced violence. The Philippines has a well-developed national policy framework in response to violence against women, including guidelines for local level services [30] and referral pathways for women who have experienced violence [31]. However data generated through W-DARE make clear that existing services and resources in the community, such as the Violence Against Women (VAW) Desks at barangay level or the Women’s and Children’s Protection Units (located in DOH Hospitals) are not always accessible for women with disabilities.

W-DARE worked closely with the Department of Health, the Ligao and Quezon City Health Offices and with barangays (the smallest unit of local government) to improve violence response services. This included conducting a review of national guidelines for referral of women experiencing violence to identify barriers at each step for women with disabilities; developing a resource for service providers with guidance on how to address these barriers and conducting a series of workshops with health workers and government representatives in QC and LC to identify how current violence referral pathways are enacted and how these can be made more inclusive of women with disabilities and to develop strategies to strengthen responses to violence against women and girls with disabilities.

These workshops considered:

- the physical accessibility of local services such as VAW Desks and Women and Children’s Protection Units (of both the building but also equipment such as examination couches);
- the ability of personnel to communicate with women with different types of impairments (including women who are Deaf or who have intellectual disability);
- and the availability of adapted information resources (for example, large print, easy language or pictorial materials).

These workshops have generated discussion of how to address other barriers to violence response services experienced by women with disabilities (including transport and financial barriers, and dependence on perpetrators including for housing) and on what kind of data can and should be collected by services. Violence response services do not collect information about whether their clients have an impairment and whether they have particular support needs in relation to impairment, which means service providers do not necessarily know what adaptations they may need to make to provide a disability inclusive service.

There are challenges associated with disaggregating data to assess service utilisation by women with disabilities, with violence service providers not being trained to identify disability and existing tools for population use inadequately capturing some types of disability (such as psychosocial disability). However service providers’ inquiries about support needs are essential if their efforts to ensure women’s safety are to be effective for women with disabilities.

The W-DARE experience of implanting interventions to address disability inclusive violence response and prevention services suggests a range of important considerations for researchers, practitioners, and policymakers seeking to increase disability inclusion in responses to violence against women. These considerations and more information about the W-DARE interventions to improve violence responses for women and girls with disability can be found in the **“Building capacity for a disability-inclusive response to violence against women and girls: experiences from the W-DARE project in the Philippines”** publication, available here: <https://minerva-access.unimelb.edu.au/bitstream/handle/11343/112312/Final%20draft.pdf?sequence=1>

## Building local government capacity to contribute to inclusive local environments

To strengthen the capacity building and increased awareness of service providers and government officials to provide disability inclusive SRH information and services developed through participation in ‘supply-side interventions’, participants were invited to participate in other W-DARE activities that further aimed to build local government capacity to contribute to inclusive local environments.

In addition to building local government capacity, this activity also supported efforts to ensure all W-DARE interventions incorporated intra-government communication and coordination and to strengthen communication, collaboration and coordination between government agencies, non-government organisations and DPOs.

### Peer to peer knowledge exchanges

Peer-to-peer knowledge exchanges between local government departments are a valuable way to strengthen capacity and motivation for local level disability inclusive policy and programming. Knowledge exchanges also create opportunities to build awareness of important issues related to development research and programming, which can then support greater ownership of issues and contribute to locally developed and sustainable solutions.



Planning and preparation for peer to peer exchanges was informed by the following resource: The art of knowledge exchange: World Bank Institute: The Art of Knowledge Exchange: A Results-Focused Planning Guide for Development Practitioners 2013. [Available here](#)

The W-DARE supported knowledge exchange visits between LGU personnel in Quezon City and Ligao City. Representatives from each of the Persons with Disability Affairs Offices (PDAO), City Health Offices, and Social Welfare and Development Departments participated in the exchanges.

Exchange visits included site visits to local SRH and general health services partnering with W-DARE and local Violence Against Women and Children Protection units. This allowed participants to gain a better understanding of existing barriers to health services, such as those created by the physical

environment and surrounding infrastructure, and to discuss with service providers what services are doing to try and improve access for women with disabilities within existing contexts. Examples shared by service providers included working with local PDAOs to get a better understanding of their communities and to identify women with disabilities within their catchment who may require SRH services; increasing outreach services for women not able to get to facilities; and promoting flexibility within service provision at facilities.

#### Monitoring and Evaluation - ‘Supply-side interventions’ and ‘Interventions to support an enabling local environment’

The effectiveness of capacity building efforts with service providers and policy-makers was assessed in multiple ways. Similarly to the evaluation of the PAG intervention, evaluation data was collected both before and immediately after participation in an intervention, and also 6 – 9 months after the intervention to assess sustained changes and outcomes as a result of participation in W-DARE.



Quezon City LGU personnel visit the Ligao City Health Office (February 2015)

Table 4. Monitoring and evaluation data sources for ‘supply-side’ and ‘enabling local environment’ interventions

TIMING	GROUP	DATA SOURCE	AIM
Pre and post intervention	Participants (service providers and policy makers)	Quantitative – pre and post training questionnaires	To assess changes in knowledge and attitudes amongst
6-9 months post intervention	Participants (service providers and policy makers)	Qualitative individual in-depth interviews	To assess changes in practices or services offered.



# Findings from supply side interventions

Key outcomes attributed to W-DARE interventions that aimed to improve service provider and policy-maker capacity to provide disability inclusive SRH information and services includes:

Strengthened relationships between **Disabled People's Organisations and women's health service providers**, with DPO representatives now included in policy and practice consultations and advocacy efforts and inclusion of DPO representatives in LGU/barangay decision making forums.



Strengthened relationships between **Disabled People's Organisations and a range of government departments** relevant to improved access to SRH services



Policy makers and service providers recognising the **capacities of women with disabilities**, and their right to be included in **decision making** that effects their lives



Service providers having increased knowledge about the SRH needs of women with disabilities, and increased skills and strategies to communicate with and provide services to women with disabilities



LGUs making new budgetary allocations in support of disability inclusion efforts (e.g. to ensure facilities were physically accessible);



Concrete changes in services and service provider practice, including:

- **staff from physically inaccessible facilities** conducting mobile outreach clinics;
- **successful advocacy efforts** to ensure that a new facility in Quezon City is fully accessible;
- **budgeting for adaptive equipment** (e.g. height adjustable examination couches);
- **establishment of referral pathways** from general health services to community-based rehab and other disability-specific services; and
- **changes to referral practices** for women with disabilities experiencing violence, to increase and improve access to violence response services

# Key messages relating to efforts to build capacity of health services and local governments to provide disability-inclusive SRH information and services



When service providers have had minimal exposure to people with disabilities and little training in the area, basic disability sensitisation can have a substantial impact on service providers' attitudes and practices. Disability sensitisation activities are most effective when (trained) people with disabilities lead these activities themselves.



The resources required to increase the accessibility of physical facilities and equipment needs to be included in local government budgeting, and therefore will take time to mobilise. Strategies for increasing accessibility in the meantime must be priorities.



Expanding disability sensitisation efforts to include engineers and other personnel responsible for health facility standards, construction and accreditation would strengthen efforts to ensure that health facilities (current and planned) are fully accessible.



Health facilities and service providers require ongoing support to develop strategies for monitoring the uptake and use of SRH and other services by people with disabilities. Extensive collaboration between national, provincial and local government health offices will be required to ensure that strategies are feasible, sustainable and generate data that is useful for improving practice.



Forums that bring together health and violence service providers with women with disabilities can generate innovative solutions to practical service barriers.

## Building enabling societies: addressing prejudice and discrimination

### Overview of the intervention:

In addition to addressing barriers that effect the supply and demand of SRH services, and working to improve capacity of local government to deliver disability-inclusive SRH services, our research team members with disabilities emphasised the importance of long-term efforts to address disability-based prejudice and discrimination in the Philippines. Widespread ignorance, prejudice and discrimination are likely to undermine efforts to address demand for and supply of violence prevention and response services to women with disabilities.

During participatory analysis of the W-DARE data, women with disabilities highlighted the over-riding impact of prejudice and discrimination in their lives. Our partners felt that specific efforts to increase demand for, and supply of, high quality health and violence response services were essential, but that they may have limited impact in the wider context of negative community attitudes and active discrimination.

The time and budget available to the W-DARE team for this particular activity was limited, but all researchers and partners agreed that it was important to at least begin the process of addressing disability-based prejudice and discrimination in the Philippines. Given this is not an issue unique to the Philippines, the team also felt that our initial efforts may catalyse anti-discrimination activities in similar settings in the region.

As a contribution towards an ‘enabling society’ in the Philippines, W-DARE developed a series of short films that intended to increase public awareness of the rights and capacities of women with disabilities, and to reduce prejudice, discrimination and violence towards people with disabilities. These short films featured the personal stories of women with disabilities, involved in the W-DARE project as PAG participants, who were invited to talk about their

experiences in relation to sexual and reproductive health, their rights and capacities as women and parents with disability, and the impact of prejudice and discrimination on people with disabilities.

The W-DARE research team engaged a consultant to collaborate with the W-DARE Principal Investigator and other members of the research team in the design and production of the short films. The consultant also conducted a one-day media training workshop with W-DARE partners in Quezon City, including the National Council on Disability Affairs. The objective of this workshop is to build capacity of people with disabilities to confidently articulate their perspectives on camera.

The footage included dialogue in Tagalog and the final films were subtitled in English to increase accessibility to both Filipino and international audiences.



W-DARE advocacy videos: <https://www.youtube.com/channel/UCQV2jJ7bossdjtYJfvXXsg>

# Translating inclusive research into inclusive SRH policy and programming:

## Recommendations from W-DARE

The Philippines has a strong legislative framework protecting the rights of women (including the Magna Carta of Women) and the rights of people with disabilities (for example, the Magna Carta for Disabled Persons). The Responsible Parenthood and Reproductive Health Act (RA No. 10354) also provides a legislative mandate protecting the right of women with disabilities to access the full range of SRH information, services and commodities on an equal basis with women without disabilities. The challenge is to ensure the rights enshrined in legislation are a reality for women with disabilities in the Philippines. Recommendations on how to support disability inclusive SRH policy and programming are highlighted below. Whilst some of these recommendations are specific to the Philippines context, they will have relevance to effort disability inclusive SRH policy and programming across all settings.

### Key recommendations to support disability inclusive SRH policy and programming:

#### Work with women with disabilities themselves to build their capacity for meaningful involvement.

Women with disabilities can be powerful advocates for inclusive responses to their own SRH needs and priorities. However, to do so they need confidence, knowledge, skills and ongoing support. Women need opportunities to collaborate in SRH research, as well as in leadership roles in SRH programs, and to develop the networks that underpin successful advocacy.

To support this, policy and programmers should:

- Provide gender sensitivity training to existing DPOs to promote representation and inclusion of women with disabilities within DPOs and across their activities
- Support women with disabilities and their families to access existing DPOs
- Provide 'start up' resourcing and mentoring of peer support groups for women with disabilities and their families where DPOs do not exist.

- Ensure women with disabilities and their representative organisations are meaningfully included in any research that is relevant to their lives or to the lives of women more broadly.

#### Bring agencies that can contribute to improving access to high quality SRH services together with women with disabilities.

Women with disabilities advocating for increased access to SRH services and information need forums where they can connect with those policy-makers and government officials who have the power to bring about change. It is important that health, transport, social welfare and development, and gender and development personnel have the opportunity to work with women with disabilities to plan and implement inclusive services. Examples include:

- Ensuring Persons with Disability Affairs Offices are represented on interagency committees responsible for prevention of violence against women and children
- Instigating consultative processes where local DPOs are able to meet with health, social welfare, gender, transport, police and other authorities to provide input about the needs and experiences of women and men with disabilities
- Service providers working with DPOs to develop local responses to, and advocacy about, disability-based and gender-based prejudice and discrimination.

#### Address structural and social factors that undermine access to SRH for women with disabilities.

The SRH of women with disabilities is shaped by wider social contexts of disability-based and gender-based discrimination. Women with disabilities may be disadvantaged by social norms, prejudiced beliefs, and widespread lack of awareness about the rights of people with disabilities. Structural initiatives, including health facilities, transport providers and social protection programs developing inclusive policies and activities, can help address some of the intersecting disadvantage experienced by women with disabilities.

### **Improve the availability of disability-related data**

Accurate disability-related data that is consistent and comparable will enable health services and health policy-makers to understand and forecast the resources required to support women with disabilities to access SRH information and services. Recommendations around increasing the availability of disability-related data include:

- Increase accuracy of prevalence estimates by using consistent and comparable tools, e.g. using the Washington Group Short Set of disability questions in the census and other national and sub-national data sources.
- Develop an agreed approach to disaggregation of service usage data by disability (in the Philippines this could be by recording whether clients have a PWD card or not, or by asking all clients to respond to a short set of questions about functional limitation, such as the Washington Group Short Set).

### **Improve monitoring and compliance with existing legislation and policies**

It was widely reported across research activities that many SRH facilities are physically inaccessible to women with different types of disabilities; economic barriers (cost of services, accessible transport and sign language interpreters) undermine access to SRH; and, SRH information and services are often not available to women with disabilities in accessible formats including braille, sign language and large print.

Recommendations to improve the monitoring and compliance of legislation and policies include:

- Regular accessibility audits of all health facilities to assess different domains of accessibility (e.g. physical access, lighting and signage, communication, adapted equipment)
- Ensure funding is available and used to undertake works required to ensure health facilities are compliant with the Accessibility Law (BP 344)
- Work with DPOs to conduct 'mystery client' visits to health facilities, where women with disabilities can assess compliance with policies for people holding PWD cards; compliance with the RPRH Law (RA 10354) that requires women with disabilities be offered comprehensive SRH information and services; and the attitudes of service providers and other facility personnel

- Undertake advocacy to ensure breaches of existing legislation and policies are promptly addressed and/or penalised.

### **Differentiate between the SRH needs of different women with disabilities**

The SRH of women with disabilities is shaped by wider social contexts of disability-based and gender-based discrimination. Women with disabilities may be disadvantaged by social norms, prejudiced beliefs, and widespread lack of awareness about the rights of people with disabilities. Changes are required to health, transport, and social protection programs, to ensure they are inclusive of all women with disabilities and address some the intersecting disadvantages experienced by women with disabilities.

Policy-makers and programmers need to recognise that some women with disabilities have been particularly excluded from SRH information and services and are particularly vulnerable to violence (e.g. women who are Deaf, women with intellectual or psychosocial disabilities) and therefore need targeted responses to ensure they are included in all SRH policy and programming.

### **Build capacity of the health, disability, and social welfare sectors**

The role that health service providers play in facilitating or undermining access to SRH services for women with disabilities was highlighted across research activities and pilot interventions.

It is therefore important to:

- Integrate disability and gender sensitisation into the initial training and ongoing professional development of SRH service providers and service providers responsible for responding to family and other forms of gender-based violence
- Build the knowledge and skills of frontline staff to enable them to communicate with women with disabilities seeking SRH information and care.

For more information on the W-DARE recommendations for inclusive SRH policy and programming, please visit the following W-DARE policy briefs: <https://wordpress.com/post/wdare.wordpress.com/245>

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## Fact Sheet A. Key benefits, challenges and lessons learnt from the W-DARE

IMPACT	DESCRIPTION
<b>BENEFITS</b>	<ul style="list-style-type: none"> <li>• <b>DATA:</b> More accurate, relevant and higher quality data, resulting in more effective and appropriate policies and programs.</li> <li>• <b>RESEARCHERS:</b> Increased awareness of disability inclusion and recognition of the capacity of people with disabilities to conduct research.</li> <li>• <b>PEOPLE WITH DISABILITIES:</b> Promotes empowerment, self-confidence, greater research capacity and expertise, knowledge and awareness of factors relevant to their own lives.</li> <li>• <b>DPOs and DISABILITY SECTOR:</b> Strengthened research capacity and expertise at organisational and sectoral levels.</li> <li>• <b>COMMUNITY/SOCIETY:</b> Positive role modeling of people with disabilities to overcome negative stereotypes and encourage more people with disabilities and their communities to participate in research.</li> </ul>
<b>CHALLENGES</b>	<ul style="list-style-type: none"> <li>• <b>ATTITUDINAL BARRIERS:</b> need to address negative attitudes about people with disabilities and their capacity to conduct research</li> <li>• <b>PHYSICAL/ENVIRONMENTAL BARRIERS:</b> which impact on participation in research need to be considered and addressed, such as ensuring accessible meeting spaces and provision of accessible transport to enable participation in field work</li> <li>• <b>COMMUNICATION BARRIERS:</b> information needs to be provided in a variety of accessible formats, for example braille, through sign language interpreters, easy-to-understand, and other inclusive methods</li> <li>• <b>TIME AND RESOURCES:</b> additional resources are often required to facilitate the meaningful inclusion of people with disabilities in research and address identified barriers to research.</li> <li>• <b>RESEARCH EXPECTATIONS:</b> Different expectations of the research and what will be done with the research findings between academic and disability focused research partners need to be understood and managed</li> <li>• <b>RESEARCH RELATIONSHIPS:</b> Establishing and managing trusting partnerships between external researchers and people with disabilities</li> </ul>
<b>LESSONS LEARNT</b>	<ul style="list-style-type: none"> <li>• <b>SELF-DETERMINATION:</b> Ensure people with disabilities are able to determine their participation in research, including whether or not to participate and the scope of their participation.</li> <li>• <b>PROGRAM DESIGN:</b> Consider the needs of people with disabilities (including additional resources and modifications required to address barriers to participation) when developing budgets and during all phases of the research.</li> <li>• <b>CONTROL OF RESEARCH:</b> Share control of the research with participants and maximise the possible participation of people with disabilities as researchers and decision-makers through all stages of research.</li> <li>• <b>RESEARCH PROCESSES:</b> Tailor and modify research processes to facilitate the genuine inclusion of people with disabilities – consider impairment type and level of functioning of co-researcher with different types of impairment.</li> <li>• <b>DISSEMINATION OF RESEARCH FINDINGS:</b> Include participants in decision-making about how research findings are analysed and shared and how participant’s voices will be represented.</li> </ul>



## Fact Sheet B. Strategies for increasing involvement of women with disabilities in research

INCLUSION PRINCIPLES	ACTIONS
<b>RESEARCH AIMS AND OBJECTIVES</b>	
<p><b>Research must provide tangible benefits to people with disabilities, and work toward greater inclusion of people with disabilities in the community.</b></p>	<ul style="list-style-type: none"> <li>• Research aims to improve outcomes for people with disabilities and their communities.</li> <li>• Ensure that DPOs and representative organisations can use research findings to help achieve their own aims and objectives.</li> </ul>
<b>PROGRAM DESIGN</b>	
<p><b>People with disabilities should be involved in identifying the research problem and methods for conducting the research.</b></p>	<ul style="list-style-type: none"> <li>• Consult with, and listen to, people with disabilities about their ideas for research: including strengths to draw on and barriers to be addressed to promote their participation in how the research is conducted.</li> </ul>
<b>OWNERSHIP</b>	
<p><b>People with disabilities and DPOs have a degree of ownership over research design, implementation and evaluation, and dissemination and use of research findings.</b></p>	<ul style="list-style-type: none"> <li>• Involve people with disabilities in all levels of decision-making from the outset.</li> <li>• Ensure research decision-making processes are open and transparent.</li> </ul>
<b>PARTICIPATION</b>	
<p><b>Ensure that people with disabilities are included as active participants throughout the research as decision-makers, advisors, researchers, trainers etc.</b></p>	<ul style="list-style-type: none"> <li>• Establish and formalize partnerships with DPOs and representative organisations from the outset.</li> <li>• Allow people with disabilities to negotiate their own participation in research, including remuneration, scope of involvement and capacity development needs.</li> <li>• Involve DPOs or representative organisations in all decision-making regarding the involvement of people with disabilities in research.</li> <li>• Establish ongoing practices that support inclusive research such as capacity building, clear expectations and responsibilities, policies and procedures.</li> </ul>
<b>ETHICS</b>	
<p><b>Researchers must apply processes of ethics approval that ensure that people with disabilities are included in research as active and willing participants. This includes harm minimisation, ownership and informed consent.</b></p>	<ul style="list-style-type: none"> <li>• Seek ethical approval to conduct research (if applicable).</li> <li>• Conduct disability inclusive research ethics training with all team members.</li> <li>• Conduct a risk assessment to ascertain risks and their probability, and whether the risks outweigh benefits to participants.</li> <li>• Develop and adapt informed consent processes (Plain Language Statements and informed consent forms) to ensure people with different impairments can provide informed and free consent.</li> </ul>

## DISABILITY AWARENESS

**Researchers and other stakeholders are aware of disability and its implications, and of the importance of including people with disabilities in research.**

**Research is conducted in a culture of inclusion.**

- Provide disability inclusion training to all involved in research which is facilitated in collaboration with people with disabilities and their representative organisations.
- Maximise opportunities for people with disabilities to be ‘visible’ in the community when involved in research (e.g. data collection, consultations, presentations etc.).

## STRENGTHS BASED APPROACH

**Utilise a ‘strengths based approach’ that recognises the contribution that people with disabilities can make to research, and builds on their existing strengths.**

- Identify and highlight the strengths of people with disabilities and DPOs involved in the research and provide opportunities for them to contribute and build on these strengths.

## COMPREHENSIVE ACCESSIBILITY

**Barriers to participation in research for people with disabilities are addressed.**

**Information about the research process, research tools, and research reports are provided in formats that are accessible.**

**Recognise the diversity within the disability community and the impact of age, gender, socio-economic status, education, geographic location and impairment type on the opportunities of a person with a disability to participate in research.**

- Tailor recruitment methods to most effectively reach different groups of people with disabilities.
- Provide appropriate remuneration for participation (salary for participant-researchers, cover travel expenses and payment time for participants).
- Conduct a disability needs assessment and plan for inclusion when applying for funding and designing program budgets and work plans.
- Adapt existing participatory research approaches and methods to ensure they are accessible for people with disabilities.
- Refer to “Fact Sheet D. Strategies for addressing barriers to participation experienced by people with different types of impairments”.

## DISSEMINATION OF RESEARCH FINDINGS

**People with disabilities have opportunity to contribute to the development and drafting of research outputs, and are involved in their dissemination.**

**Voices of people with disabilities are visible in research findings.**

- Involve DPOs in the development of a dissemination plan for sharing research outputs.
- Store research findings and outputs in a shared and accessible space, such as a dropbox folder
- Involve people with disabilities in the interpretation and analysis of research findings (to facilitate accurate representation of participant voice).
- Ensure opportunities for co-production and delivery of publication, presentations and written reports etc.
- Acknowledge people with disabilities and their contribution to the research in all research outputs.

## Fact Sheet C. Strategies implemented by the W-DARE to address participation barriers

BARRIER	W-DARE ACTIONS
<p><b>Attitudinal barriers</b></p> <ul style="list-style-type: none"> <li>Prejudice and discrimination about gender and disability = incorrect assumption that women with disabilities aren't capable of conducting research</li> </ul>	<p><b>Actions:</b></p> <ul style="list-style-type: none"> <li>Disability inclusive research training, co-facilitated by women with disabilities was conducted to increase awareness of the rights of people with disabilities including in regard to participating in research, and how to address identified participation barriers, (attendants: external researchers and academics)</li> <li>Promoting people with disabilities in research activities also helped to shift negative attitudes about people with disabilities held by community members and other researchers.</li> </ul>
<p><b>Physical/environmental barriers</b></p> <ul style="list-style-type: none"> <li>Barriers to access within the built environment, such as a flight of stairs instead of a ramp or inaccessible toilets, directly affect the ability of people with disabilities to participate in research.</li> </ul>	<p><b>Actions:</b></p> <ul style="list-style-type: none"> <li>Make sure that all research activities (such as training sessions, workshops and meetings) were held in accessible venues</li> <li>Ensure accessible transport was made available to support women with disabilities to participate in research activities;</li> <li>Resourcing personal assistants, support staff and childcare to better enable women with disabilities to participate in activities.</li> </ul>
<p><b>Communication barriers:</b></p> <ul style="list-style-type: none"> <li>Often, information is not provided in accessible formats for people with different impairments, such as people with vision impairments and those who are Deaf or hard of hearing, restricting their ability to fully participate in research.</li> </ul>	<p><b>Actions:</b></p> <ul style="list-style-type: none"> <li>Ensure that sign language interpreters were present during W-DARE events and to assist during data collection activities;</li> <li>Modify research tools and workshop materials to ensure that they were accessible for women with different types of impairments, e.g. easy-to-understand information about the research,</li> <li>Provide written information in advance to participants with vision impairment to enable time to access documents through screen reading software and providing detailed explanations of any visual aids used in presentations or training sessions.</li> </ul>
<p><b>Language barriers (women with disabilities and others local researchers):</b></p> <ul style="list-style-type: none"> <li>A key challenge of DI research is developing a 'shared language' that is equally accessible to all those involved in the project, regardless of their research capacity or expertise or native language</li> </ul>	<p><b>Actions:</b></p> <ul style="list-style-type: none"> <li>Trainings were conducted in Tagalog where possible,</li> <li>Tagalog translations were made available when training sessions were conducted in English;</li> <li>Provide research tools and training materials were written in accessible language for all involved.</li> </ul>

## Fact Sheet D. Strategies for addressing barriers to participation experienced by people with different types of impairment.

IMPAIRMENT	PARTICIPATION REQUIREMENTS	STRATEGIES
<b>ALL</b>	<ul style="list-style-type: none"> <li>• May experience prejudice and discrimination because of their disability.</li> <li>• May have limited or negative previous research experience and/or limited research capacity.</li> </ul>	<ul style="list-style-type: none"> <li>• Implement disability inclusion and sensitisation training with all team members.</li> <li>• Discuss capacity needs and research expertise with disability partners</li> </ul>
<b>VISION</b>	<ul style="list-style-type: none"> <li>• May not be able to see/read text (or smaller font) in presentations, question guides, other research materials.</li> <li>• May be unable to see visual prompts including gestures, photos and pictures.</li> <li>• May require assistance to: <ul style="list-style-type: none"> <li>o Travel to and from research activities</li> <li>o Access facilities within buildings (such as toilets)</li> <li>o Navigate environments during fieldwork</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• Offer tactile and aural prompts, such as hearing questions or feeling objects associated with question and answer</li> <li>• Use large font and high contrast in text and pictures.</li> <li>• Offer braille translation of materials</li> <li>• Offer to provide research materials electronically in advance (for use with screen readers or conversion into audio files if participants have access to computer/software).</li> <li>• Offer to reimburse personal assistants for their travel to accompany the person to and from research activities</li> <li>• Offer to have personal assistants in attendance during research activities.</li> </ul>
<b>PHYSICAL</b>	<ul style="list-style-type: none"> <li>• May experience difficulty in travelling from place to place (workshop activities, field sites etc.).</li> <li>• May have difficulty navigating certain terrains and environments (e.g. rocky, steep or narrow roads and pathways).</li> <li>• May experience difficulty entering and accessing venues (including bathroom facilities etc.).</li> </ul>	<ul style="list-style-type: none"> <li>• Hold meetings in accessible venues (e.g. ramps at entry way, doors wide enough to fit wheelchairs, lifts to upper levels, accessible toilets).</li> <li>• Offer to reimburse participants to take a taxi (if accessible) or arrange to collect and drop off participants to and from research activities.</li> </ul>
<b>HEARING</b>	<ul style="list-style-type: none"> <li>• May be unable to hear or have difficulty hearing instructions/questions that are spoken.</li> <li>• May not have developed a spoken language (or have limited spoken language).</li> <li>• May not have had an opportunity to learn sign language (or have limited or very localised sign system).</li> </ul>	<ul style="list-style-type: none"> <li>• Use visual prompts (text, pictures, symbols etc. slides during presentations)</li> <li>• May require a sign language interpreter. for communication during research activities, including data collection.</li> <li>• Offer to provide video recording equipment to film data collection activities.</li> <li>• Use text rather than written instructions.</li> </ul>
<b>PSYCHOSOCIAL</b>	<ul style="list-style-type: none"> <li>• May have lack of focus or limited attention span.</li> <li>• May have behavioural issues that affect their interaction.</li> <li>• May experience distress or be upset during research activities.</li> </ul>	<ul style="list-style-type: none"> <li>• Have a support person available to provide comfort and support should the person become aggravated or distressed.</li> <li>• Strategies for other impairment groups may be useful.</li> </ul>

## Fact Sheet D. Ethical considerations during data collection

### “Sexual and Reproductive Health of women with disability in the Philippines”

#### What do we mean by ‘ethics’?

All human interaction, including the interaction involved in human research (in particular, between the researcher and the research participant), has ethical dimensions. However, ‘ethical conduct’ involves more than just doing the right thing. It involves acting in the right spirit, out of respect and concern for other humans.

#### Ethically good human research requires the following:

- participants are accorded the respect and protection that is due to them;
- the research is of benefit and the benefit of the research justifies any risk of harm or discomfort to research participants;
- is conducted with integrity to a high quality; and
- is accessible to participants (especially the research findings and outcomes).

There two major aspects of ethics in research: procedural ethics, which usually involves seeking approval from a relevant ethics committee to undertake research involving humans; and ‘ethics in practice’ relate to the everyday ethical issues that arise when undertaking research. Ethical issues consider the ethical obligations a researcher has toward a research participant in terms of interacting with him or her in a humane, non-exploitative way while at the same time being mindful of one’s role as a researcher.

When faced with these issues, researchers experience ‘ethically important moments’, for example: when a research participant states that he or she does not want to be assigned a pseudonym in the writing up of the research but wants to have his or her real name reported or when interviewing participants about a sensitive issue, such as experiences of violence, where the researcher has to decide how far to probe a participant about a difficult and distressing experience.

Research may lead to harms, discomforts and/or inconveniences for research participants, researchers and/or others. This fact sheet is designed to provide you with information regarding possible harms associated with research in general and in relation to this research project, and what strategies are in place to manage those harms, to assist in preparing you for the possibility of ‘ethically important moments’.

#### What are some of the possible harms associated with research?

A risk is a potential for harm, discomfort or inconvenience. It involves the likelihood that a harm (or discomfort or inconvenience) will occur; and the severity of the harm, including its consequences. One key aspect of ethically good human research is preventing harm. You can think about the harm that researchers might do at several levels:

- harm to the individuals in the study; and
- harm to the study population, or the whole community.

Possible harms associated with field research at an **individual level** may include:

- Loss of reputation or exposure to discrimination, if confidentiality is breached
- Emotional distress
- Fear
- Discomfort, embarrassment or shame
- Causing offence
- Leaving people with unanswered questions



Possible harms associated with field research at a **group or community level** may include:

- Disempowerment
- Adding to negative stereotypes
- Disappointment, people feeling let down or misled
- Community feeling drained, overburdened by questions
- Loss of resources (such as time, energy, food and income)
- Reinforcing and/or perpetuating the “status quo”
- Legitimising the interests and agenda of powerful groups with a stake in the community

But “to do no harm” is not enough. Researchers should also aim to:

- Leave the community having earned their respect for how the research was conducted (which also prevents potential harms to the research ‘sector’ as a whole)
- Ensure that those who were studied “get” at least as much from the process as you do
- Ensure that the research process (including dissemination of results) contributes to development of health-enabling community contexts – which requires building capacity on a range of levels, including capacity to conduct research

### **What are some of the potential risks specific to this project?**

Prior to commencing this project, a risk assessment was undertaken to identify any risks; gauge their probability and severity; assess the extent to which they can be minimised; determine whether they are justified by the potential benefits of the research; and determine how they can be managed. Several potential risks to research participants and researchers were assessed:

- **The primary risk to participants is a psychological one.** Participants may feel a range of apprehensions, such as feeling offended if questioning is felt to be intrusive, patronising or insensitive to their religious beliefs; they may anticipate adverse judgments of their perspectives on SRH, or discrediting of their experiences; and they may feel anxious that the stigma often experienced by persons with disability may be compounded by discussion of their sexual and reproductive health. Participants who discuss their personal experiences in relation to SRH (including exposure to violence) may find this distressing. An interview on sensitive topics such as experiences with SRH services, experiences of violence and their relationship with disability can provoke emotional distress when such experiences are recalled.
- Participants may also be sensitive to issues of disclosure, confidentiality and judgment **between participants in a focus group discussion.** There is a risk that participants may disclose sensitive information that was shared by other participants during focus group discussions. Participants may also be concerned about members of the data collection team (field workers) and/or researchers breaching their confidentiality.
- Even when capable of giving consent, persons with intellectual disability, cognitive impairment and/or communication impairments, may be more than usually vulnerable to discomfort and/or stress as a result of their participation in this research.
- **Research on sensitive issues can be psychologically challenging for researchers.** Training of all persons involved in data collection and analysis will include strategies for managing stress and anxiety, and for maintaining safety (for example, fieldworkers conducting the household survey will work in teams of three to minimise risks associated with entering households). Should team members experience stress and/or anxiety associated with the Program, they will be encouraged to utilise the counselling and support services available through the University of Melbourne and De La Salle University.

It is felt that the benefits of this research justify the potential risks to participants. This research project has been developed in response to the lack of evidence as to what strategies may be effective in increasing access to sexual and reproductive health (SRH) programs for women with disability. The poor access to SRH programs for women with disability poses a very real and ongoing risk to women’s health, greater than the risks associated with participation in this research.

### How will these risks be managed?

A number of strategies have been put in place to minimize these potential risks to participants and researchers, including:

- All data collectors will be provided with **intensive training**, including four day training on disability and gender inclusive research; one week training for interviewers and two week training for all members of the field work team involved in the household survey. These trainings will incorporate strategies for minimizing and appropriately responding to participant distress, informed by guidelines developed by the World Health Organisation.
- All research assistants, qualitative interviewers, field supervisors and field workers (data collectors in the household survey) **are experienced, local persons**. Local research assistants contracted by SDRC are academic staff with extensive relevant experience; qualitative interviewers and field supervisors (with and without disability) have graduate qualifications and social research experience; field workers (with and without disability) have experience with household surveys or other data collection activities. Recruitment of experienced researchers will facilitate the conduct of high-quality research.
- The research project has been carefully designed to ensure that the most appropriate research methods have been selected to answer different research questions within this research project. For example:
  - o The **household survey**, where the setting of the interview may be less private or controlled, will focus on disability prevalence and access to services and information (rather than attempting to collect quantitative data on experiences of violence for example).
  - o The more sensitive research questions (the experiences of women with disability in relation to SRH and violence) will be explored through **in-depth interviews** conducted by experienced interviewers, and in more controlled circumstances than is possible in a household survey.
- All persons involved in data collection and analysis will be required to sign a **non-disclosure statement** to protect participants' privacy and confidentiality.
- **Plain language statements for any focus group discussions** will emphasise the importance of participants maintaining confidentiality and protecting the privacy of other participants. The introduction at the beginning of each focus group discussion will reinforce the importance of maintaining confidentiality amongst participants.
- All participants will be reminded that **participation in the study is voluntary** and participants will be free to terminate a household survey leave, a focus group discussion or interview and withdraw data collected at any time.
- All **research tools and processes have been reviewed and tested** to ensure their appropriateness to, and inclusivity of, persons with intellectual disability, cognitive impairment and/or communication impairments.
- There are some risks associated with the fact that the **research is undertaken and managed across multiple sites**. The Philippines-based research partners have extensive experience in the implementation of projects being implemented at multiple sites in collaboration with researchers overseas, and in the day-to-day monitoring of research activities. In addition, very regular Skype and email contact between University of Melbourne and DLSU researchers will be maintained throughout the duration of the project. Advisory Group members in the Philippines will also support the ongoing monitoring of project activities in country.
- Participants in interviews and focus group discussions will be offered the opportunity for a **one-to-one debrief with a member of the research team** (to discuss how participants found the experience of involvement, or to answer further questions about the research) if this is requested. Prior to the household survey, field workers and field supervisors will be advised on how to respond to concerns that participants may raise in relation to the survey, and will be provided with written information to distribute to all participants about how to access the range of counseling, health and referral services available in Quezon City and Ligao City. This written information outlining the range and contact details of local services will be provided to all participants.
- Potential participants will be provided with **written information** both about the Program overall and about the specific project (household survey, interview or focus group discussion) that they are being invited to participate in in the form of a plain language statement (PLS). Each of these PLSs will be tailored to the requirements of the specific data collection activity.

## List of other disability inclusive research and programming resources and guidelines

Smith-Merry, J. (2017) Research to Action Guide on Inclusive Research. Centre for Applied Disability Research. Available at [www.cadr.org.au](http://www.cadr.org.au)

CBM, 2012. Inclusion Made Easy. A quick guide to disability in development. Available from: <https://www.cbm.org/Inclusion-Made-Easy-329091.php>

Leonard Cheshire Disability and Inclusive Development Centre, 2013. Research Toolkit for Disabled People's Organisations: How to undertake and use applied research. Available from: <https://www.leonardcheshire.org/about-us/publications/latest-publications-download/research-toolkit-for-disabled-peoples>

Nind, M. and Vinha, H. Practical considerations in doing research inclusively and doing it well: Lessons for inclusive researchers. Available from: [http://eprints.ncrm.ac.uk/3187/1/Nind\\_practical\\_considerations\\_in\\_doing\\_research\\_inclusively.pdf](http://eprints.ncrm.ac.uk/3187/1/Nind_practical_considerations_in_doing_research_inclusively.pdf)

Centre for Disability Studies, 2016. Disability Inclusive Research Principles. Available from: <https://cds.org.au/wp-content/uploads/2018/04/Inclusive-Research-Principles.pdf>

Autism CRC, 2014. Inclusive Research Practice Guidelines and Checklists for Autism Spectrum Research. Available from: <https://www.autismcrc.com.au/sites/default/files/inline-files/Inclusive%20research%20practice%20guides%20and%20checklists%20-%20Final%20report.pdf>

Jenkin, E et al. 2015. Inclusive practice for research with children with a disability: a guide. Available from: [http://www.voicesofchildrenwithdisability.com/wp-content/uploads/2015/03/DEA-Inclusive-Practice-Research\\_ACCESSIBLE.pdf](http://www.voicesofchildrenwithdisability.com/wp-content/uploads/2015/03/DEA-Inclusive-Practice-Research_ACCESSIBLE.pdf)