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A summary of initial findings and pilot interventions
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Photo on front cover: Sophia (Pia) C. Manlapaz collecting data during the household survey in District 2, Quezon City.

Photo on back cover: Rowena Rivera (Weng) meets with young people who are Deaf in Ligao City.
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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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Evidence from across a range of settings suggests women with disability have reduced access to health information and experience barriers in accessing screening, prevention and care services, which results in greater unmet health needs, particularly in relation to sexual and reproductive health (MacLachlan & Swartz 2009; WHO and UNFPA 2009). Studies also show women with disability are two to four times more likely to experience physical and sexual violence than women without disability (Takamine 2004; Stubbs 2009; Spratt 2013; Astbury and Walji 2014). In addition to being a grave violation of their rights, violence against women with disability also undermines their health and sexual and reproductive health (SRH) in particular.

The Philippines Statistics Authority estimate that 3.1% of the population over the age of five has a disability (PSA 2015). The Philippines is a signatory to the United Nations Convention on the Rights of Persons with Disabilities (CRPD) and the national Magna Carta for Persons with Disability upholds the rights of women with disability. However, studies suggest that Filipina women with disability continue to experience high rates of human rights violations, including violence and abuse (DPRI 2009). Disabled People’s Organisations (DPOs) in the Philippines advocate that the barriers to comprehensive SRH services and information experienced by women with disability need to be addressed, however little research has been conducted in the area in the Philippines and little is known about the role service providers can play in improving access and in the development of inclusive services. It is also unclear how best to support women with disability to take action to improve their access to SRH.

In 2012 researchers from the Nossal Institute for Global Health and the Centre for Health Equity at the University of Melbourne developed a new research collaboration with the Social Development Research Center (SDRC) at De La Salle University, Manila. The collaboration developed a proposal for research about how access to SRH services and information could be improved for women and girls with disability, which was subsequently funded by the Australian Government through the Australian Development Research Awards Scheme under an award titled Sexual and Reproductive Health of Women with Disability in the Philippines: Building evidence for action. Funding was also provided by the UNFPA Philippines Country Office. This report shares findings from the first phase of the resultant project, W-DARE (Women with Disability taking Action on REproductive and sexual health).

**Research design**

W-DARE is a three-year participatory action research project led by researchers from the Nossal Institute for Global Health and the Centre for Health Equity at the University of Melbourne and the Social Development Research Center (SDRC) at De La Salle University in Manila. Project partners include local DPOs WOWLEAP and PARE; the national non-profit women’s health service provider Likhaan Center for Women’s Health; and the Center for Women’s Studies at the University of the Philippines. W-DARE is being implemented in Quezon City in Metro Manila and in Ligao City in Albay Province, and women with disability and SRH service providers are involved across all stages of the research.

The aim of the research is to improve access to quality sexual and reproductive health (SRH) programs, including protection from violence, for women with disability in the Philippines.

W-DARE comprises three distinct research phases. In line with the participatory action research approach, the findings from each phase inform the design and activities of the next phase. A mix of quantitative and qualitative data was collected in Phase 1 (April 2013 to June 2014) to inform the development of pilot interventions aimed at improving access to SRH for women with disability in Phase 2 (which will run until late 2015).

Quantitative data were collected to measure disability prevalence, well-being, access to community, and access to and knowledge of SRH programs. Data were collected using the:

- Rapid Assessment of Disability (RAD) Questionnaire that was administered to 3,051 adults (2,287 adults in Quezon City and 772 adults in Ligao City).
- Women’s Health Questionnaire that was administered to 253 women (137 women who were identified as having a functional limitation during the RAD and 116 matched controls, i.e. women without disability from the same location and age group).

Qualitative data were collected to understand the SRH needs and experiences of women with disability, why women with disability access SRH programs, and the challenges that they may face in doing so. Qualitative data collection activities included:

- 37 in-depth interviews with women and girls (aged 15 years and over) with disability
- 20 in-depth interviews with SRH service providers
- 8 focus group discussions (with partners and parents of women with disability, women without disability, and SRH service providers).
Key Findings from Phase 1

Disability prevalence
The RAD questionnaire was used to determine disability prevalence. The prevalence of disability was 7.14% in Quezon City, and 14.04% in Ligao City. Psychological distress was the most commonly reported disability. Overall, 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 and access to the community
Responses to the RAD showed people with disability had poorer well-being when compared to people without disability. They were also more likely to report reduced access to health services, work, education, social and religious activities, and toilets. Reported barriers included cost of services, lack of information about services, negative attitudes, difficulty getting to facilities, and the absence of personal assistance.

Access to SRH services
In the Women’s Health Questionnaire, women were asked about their awareness of and access to SRH information and services. The number of women completing the Women’s Health Questionnaire was relatively small and not statistically significant difference in access to SRH services was found between women with and without disability. However in the in-depth interviews with women and girls with disability, women reported significant challenges accessing SRH services. Women reported a range of negative experiences at health care facilities, including negative attitudes, prejudice, discrimination and abuse by health care providers. Women with disability and service providers also reported service providers had limited capacity to manage the SRH concerns of a woman with a disability. Other barriers to health services for women with disability included a lack of local SRH services, lack of accessible transport, and difficulty in accessing sign language interpreters. Financial barriers related to both the cost of the actual service, and associated costs with accessing the service, such as the cost of transport and the cost of medication were commonly reported.

Access to SRH information, and SRH knowledge among women with disability
While there were mixed levels of knowledge across women with disability interviewed, levels of SRH knowledge were mostly quite low, particularly among specific impairment groups, such as women with intellectual disability and women who are Deaf or hard of hearing. Both disability and SRH were often reported to be taboo topics, with the sexual needs and desires of women with disability rarely discussed. Mothers, sisters and friends were the primary sources of SRH knowledge for women with disability.

Agency and independence of women with disability
Women with disability 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 disability 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 disability.

Right to healthy and fulfilling relationships
Women with disability reported instances where their capacity to marry, have children and look after their children was questioned, and in some cases their right to do so was taken away from them. This included reports by women with disability who had children removed from their care, and reports by service providers of requests made by families of women with disability to sterilize their female family members with a disability. Some women with disability also reported family disapproval of their choice of partner (although approval was sometimes influenced by whether or not the partner also had a disability), and that their husband’s family did not think a woman with a disability could be a good wife or take care of her husband.

Community attitudes towards disability
Women with disability reported experiences of discrimination from health service providers, transport providers, educators, the law and justice sector, and members of the general public. The negative and stigmatising attitudes held by some members of the community were made evident in a range of discriminatory actions, including denial of service, derogatory remarks and abuse. Some women also experienced discrimination from members of their own families. Interviews with SRH service providers confirmed that some health professionals hold discriminatory attitudes, often arising from a complete lack of awareness about disability.
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Experiences of violence and abuse

Reports of sexual and physical violence and abuse against women with disability were common. Women with disability were subject to a range of emotional and controlling behaviours as well as exploitation, neglect and maltreatment. Abuse was frequently perpetrated by family members and partners, but also by strangers. Women with disability reported difficulty in coming forward and reporting abuse by family members and caregivers. When women with disability did report abuse by a relative to another family member there were instances where they were not believed, further compounding the trauma of the abuse and leading to family conflict. It was particularly difficult for women with intellectual disability or who were Deaf or hard of hearing to report abuse.

Strength of women with disability

Women with disability described a number of factors undermining their SRH, but 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 disability being able to make informed choices about education, employment and personal relationships. Women with disability 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 project.

Phase 2 – developing pilot interventions

The W-DARE research team and partner organisations have used the key findings from Phase 1 outlined above to design and implement interventions to address barriers to SRH services and information for women with disability. These interventions are being piloted in Quezon City, Ligao City and, in some instances, the wider Bicol region. Interventions include ‘supply-side’ and ‘demand-side’ activities, to address factors that were identified as inhibiting the provision of high quality SRH information and services to women with disability, and to women with disability seeking SRH services. Findings from Phase 1 emphasise the importance of an inclusive and enabling local environment, so W-DARE have also developed interventions to increase the awareness, skills and networks of Local Government Unit (LGU) personnel in Quezon City and Ligao City, in relation to disability. Women and girls with disability described the challenges they face in maintaining SRH in a wider context characterised by negative community attitudes and disability-based discrimination. Therefore, W-DARE will support activities aimed at increasing public awareness of the rights and capacities of women with disability, and to decrease stigma and discrimination. Interventions currently being developed, implemented and evaluated include:

Demand side interventions

• Peer-facilitated Participatory Action Groups (PAGs) for women with disability: a strengths-based intervention designed to enhance knowledge of SRH, improve demand for quality SRH services and develop networks of peer support among women with disability. W-DARE supports PAGs for women with a range of impairments to meet regularly in Quezon City and in Ligao City.

• W-DARE also supports a peer-facilitated PAG for parents of children and young people with disability to equip parents with knowledge and skills to support their children and young adults to maintain SRH.

Supply side interventions

• A series of sensitisation and training workshops for SRH service providers and for service providers working in response to violence against women and children. These trainings aim to increase participants’ awareness of the needs and rights of women with disability, and to build skills in communicating with and providing services to women with disability. A number of trainings have been conducted with service providers from different levels, with additional trainings planned.

• Ongoing provision of support to the national training program currently being implemented by the Department of Health to increase disability inclusion in primary health care settings, with a focus on ensuring inclusion of SRH, violence prevention, and gender sensitivity in the program.

• W-DARE is working with women with disability, and the management and clinical staff at a number of health facilities (at different levels, from barangay health centres to training hospitals) to develop and document disability-inclusive and accessible ‘model SRH facilities’.
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- Development of guidelines and resources for health facilities to increase disability inclusion and accessibility of SRH services and violence prevention and response services, and to strengthen current referral practices to ensure that they are responsive to the needs of women with disability.

**Interventions to strengthen enabling local environments**

- Exchange visits between LGU staff across the two research sites, to share experiences of efforts to ensure that SRH and violence prevention and response services are disability inclusive. Staff from the two LGUs’ Persons with Disability Affairs Offices, City Health Offices, and City Social Welfare and Development Officers are involved.

**Interventions to support an inclusive wider society**

- The project will support women with disability to share their experiences and perspectives in relation to the SRH, rights and capacities of women with disability through photography and a public photography exhibition later in 2015.

- W-DARE will also support the development of short videos that can be used to increase public awareness about the rights and capacities of women with disability, and to reduce prejudice and discrimination towards people with disability.

Documentation, monitoring and evaluation, and formal research about the interventions have commenced. Phase 3 (November 2015 – March 2016) will draw on the evaluation of these initiatives to develop guidelines for gender-sensitive disability inclusion in relation to SRH in the Philippines. The guidelines may also be useful to the wider health sector, and will be disseminated to service providers, policy makers, women with disability, and the wider community.

**Conclusion**

This report summarises initial findings of a disability-inclusive, participatory action research project conducted in Quezon City in Metro Manila and Ligao City in Albay province, involving women with disability and SRH service providers across all stages of the research. Researchers in the Philippines and Australia are leading the project, in partnership with Philippines-based DPOs, SRH providers and other academic institutions.

The international collaboration has strengthened the rigor of the research, and ensured that our approach is informed by local and international expertise on gender, disability, SRH and protection from violence. Our local partners and advisory group have ensured that the research has remained culturally and contextually appropriate for the Philippines. The local women with disability and the DPOs involved in W-DARE have provided valuable insights, expertise, networks and experience throughout.

Our initial findings highlight the considerable challenges faced by women and girls with disability to maintain their SRH, including barriers to accessing SRH information and services, denial of women’s capacity and rights to marriage and motherhood, and high rates of violence and abuse of women and girls with disability. Families of women with disability can play a key role in facilitating positive SRH outcomes for women with disability, but where there is discrimination and abuse can also undermine the SRH of women with disability. Families often act as ‘gatekeepers’ to community for women with disability, controlling access to the wider world, including relevant health and support services. Pervasive and underlying prejudice and discrimination towards women with disability has a considerable negative impact on the SRH of women with disability, informing the behaviour and attitudes of SRH service providers, families, partners and carers of women with disability, and members of the community towards the SRH of women with disability.

W-DARE has begun implementing a range of interventions, targeting barriers to SRH information and services, including services providing protection from violence, for women with disability. Evaluation of these initiatives will inform the development of disability-inclusive, gender-sensitive guidelines for the provision of SRH services to women with disability in the Philippines, and will have relevance to the wider health sector, and to other settings in the Asia Pacific region.
1. Introduction

This report presents initial findings from W-DARE, an innovative participatory action research project being implemented in collaboration by researchers from Australia and the Philippines, working in partnership with local Disabled People’s Organisations (DPOs), health service providers, and local government departments in Quezon City in Metro Manila and Ligao City in Albay province, Philippines.

W-DARE aims to improve the sexual and reproductive health (SRH) of women and girls with disability in the Philippines by increasing their access to quality SRH information and services. To do this the W-DARE team has collected extensive local data to better understand the SRH needs and experiences of women and girls with disability in the Philippines, including their experiences of SRH services. The data collected also documents the factors that prevent women with disability accessing comprehensive SRH services and information. Based on this evidence, the project is now supporting a range of pilot interventions aimed at improving access to SRH information and services for women and girls with disability, with a focus on Quezon City and Ligao City.

What do we mean by disability?

Disability is an evolving concept. The language of disability has changed significantly over the last century, reflecting changing political positions and the conception and growth of the global disability rights movement. Different disciplines and communities have various understandings of what disability means, and use different terms to describe disability and people with disability.

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) is the first international legally binding recognition of the rights of people with disability, and forms the basis of disability laws and policies in many countries, including the Philippines. The Preamble of the CRPD notes that:

“Disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others” (UN 2006)

This reflects that it is not only an individual’s impairment (be it physical, sensory, psycho-social or intellectual) that limits or prevents their participation in society. Barriers in a person's environment, such as physical barriers that inhibit access to certain buildings, or attitudinal barriers that lead to discrimination by family members and others, are ‘disabling’ – but are also often factors that can be changed. This understanding underpins the design of W-DARE and is the rationale for piloting interventions to address attitudinal, environmental and other barriers to SRH services and information for women and girls with disability.

The sexual and reproductive health of women with disability

An estimated 15 percent of the world’s population, or 1 billion people, live with disability (WHO and World Bank 2011). Women with disability have greater unmet health needs than women without disability, and reduced access to health information, screening, prevention, and care services (MacLachlan & Swartz 2009; WHO and UNFPA 2009). In particular, women with disability have minimal access to SRH programs (WHO and UNFPA 2009). They have often been excluded from development activities promoting access to SRH information and services because having a disability is falsely associated with being asexual (Groce, Poul et al. 2012); because SRH services are often not appropriate for, or accessible to, women with disability (Maxwell
2007; Dune 2012); and because there are limited accurate data on the prevalence of disability, and on the SRH experiences and needs of women with disability available to inform disability inclusive SRH activities (WHO and UNFPA 2009).

A range of factors undermines the SRH of women with disability. These include direct factors (environmental barriers, service costs, lack of accessible transportation, lack of services, care-givers assuming women with disability do not need SRH information or services) and in-direct factors (lack of education and access to economic resources, limited agency, lack of awareness of rights) (Mall and Swartz 2012). The limited economic participation and independence of women with disability reduces their ability to access basic services of all kinds, including SRH services (Mall and Swartz 2012). Across the world, women with disability face challenges to their right to SRH information; stigma and discrimination from service providers; and barriers associated with local attitudes towards disability, women and SRH (Maxwell 2007; WHO and UNFPA 2009; Mall and Swartz 2012). In addition, women with disability are two to three times more likely to be victims of physical and sexual abuse than women without disability (Jin-Ding, Lan-Ping et al. 2010; Hughes, Bellis et al. 2012), further compromising their health overall and SRH specifically (Foster and Sandel 2010; Astubury and Walji 2013).

Article 32 of the UN Convention on the Rights of Persons with Disabilities (CRPD) emphasises the importance of including people with disability in development. The CRPD has specific provisions related to recognition of reproductive rights (Article 23); access of people with disabilities to SRH information and services (Article 25); and the rights and empowerment of women (Article 6) (UN 2006). For the freedoms set out in the CRPD to be achieved, women with disability need to be provided with age appropriate, accessible information on SRH, and have their rights to be involved in a sexual relationship, marry, establish a family, enjoy reproductive health, and to physical integrity recognised (Jin-Ding, Lan-Ping et al. 2010). However efforts to uphold elements of the CRPD throughout Asia and the Pacific are hampered by the lack of context specific data about the prevalence of disability and about women’s experiences in relation to SRH and protection from violence (including women's expressed needs, priorities and perceptions of services).

### The context for women with disability in the Philippines

The Philippines Statistics Authority estimate that 3.1% of the population over the age of five has a disability and that just under half of all people with disability are women (PSA 2015). However, it is thought that the real number of people with disability might actually be much higher in some areas due to underreporting. In the Philippines pervasive cultural misconceptions and prejudices about disability, and beliefs about the roles and responsibilities of women, work to disempower women with disability and increase their vulnerability to discrimination and abuse (Zayas 2013).

It is known that at least one in five women in the Philippines, aged 15 – 49 experiences physical violence (National Statistics Office 2009) and this number is thought to be much higher for women with disability due to their increased vulnerability. Whilst SRH and other issues important to women with disability in the Philippines are largely under-researched, some studies have been conducted. Research conducted by DPRI and PARE highlight that women with disability, especially those with low and middle socio-economic status, are more likely to experience human rights violations than any other demographic group in the Philippines (DPRI 2009; PARE 2012). Others have found that women and girls with disability are particularly vulnerable to discrimination and abuse, often as a result of being ‘overprotected’ by their families and excluded from participation in the community. Evidence suggests that deaf women and girls are particularly vulnerable to discrimination and abuse (PARE 2012).

In 2012, UNFPA supported a literature review in relation to the SRH (and protection from violence) of women with disability in the Philippines (PARE 2012). Findings suggest that agencies and services providers have little awareness of the SRH experiences of women with disability in the Philippines, limited capacity in relation to disability and SRH, and that very limited data is available (including accurate information on the prevalence of disability) to inform disability inclusive SRH activities in the country. The review identified an urgent need for further research to inform the development of disability inclusive health service policy and practice guidelines by relevant government agencies in the Philippines. W-DARE was designed in response to this research gap, and aims to contribute to the evidence available to policy makers in the Philippines.
Participatory Action Research

As the name implies, participatory action research involves community members’ participation – to have a part or share in something; and action – the bringing about an alteration – using research as a tool (Kidd and Kral 2005). Participatory action research responds to practical and pressing community issues, engages with people in collaborative relationships, draws on many ways of knowing, is strongly values-oriented, and is a fluid process that cannot be pre-determined but changes and develops as knowledge is acquired (Reason 2006).

Since the early 1970s participatory action research has increasingly been used in a wide range of settings, but particularly in contexts of poverty, inequality and exclusion (Vaughan 2014). Participatory action research practices recognise that research methods should support overall aims of empowerment and social justice and aim to shift the alignment of power within the research process through the participation of research beneficiaries and subjects (Walmsley and Johnson 2003). In recent years, participatory action research approaches have become widely accepted in disability research as they aim to appropriately access and represent the views and experiences of people with disabilities, and reflect that people with disability need to be treated with respect by the research community (Walmsley and Johnson 2003).

It was important to the W-DARE partners that the project increased knowledge about the barriers to SRH for women with disability in the Philippines, from women’s own perspective. The research team also believed that it was critical to respond to the question of ‘what to do about it’, if the project was going to make a difference to the SRH of women with disability. As such, we designed a participatory action research project that engages women with disability and other local stakeholders across all phases of the research, and includes the piloting of interventions. The W-DARE team includes formally trained researchers (academics), disability inclusive development specialists, SRH service providers and women with disability. The project has supported a range of capacity building activities, including sensitisation workshops, research methods training, and mentoring. This has built the capacity of women with disability and other local stakeholders to be meaningfully involved in the planning and design of the project; data collection and analysis; and development, planning and implementation of interventions to address barriers to health service access for women with disability. The capacity building activities have also increased the ability of the external researchers to meaningfully engage with the historical, cultural, political and social context of the Philippines.
W-DARE research phases

The W-DARE project comprises three distinct phases. In line with the participatory action research approach, the findings from each phase inform the design and activities of the next phase. For example, research findings from data collection in Phase 1 have informed the types of interventions which are implemented in Phase 2. Evaluation of Phase 2 interventions will inform the development of guidelines for the provision of SRH information and services to women with disability in the Philippines in Phase 3.

- Phase 1 (April 2013 – June 2014) involved the collection of quantitative data on disability prevalence and access to community (through the Rapid Assessment of Disability household survey), and women’s access to SRH programs. Qualitative data was collected from women and girls with disability about their SRH needs and experiences, and their experiences accessing SRH programs, as well as from service providers, and the husbands or partners and families of women and girls with disability.

- Phase 2 (July 2014 – October 2015) involves the design and implementation of a range of interventions to increase access to SRH services and information for women with disability. These involve working directly with service providers, and women with disability and their communities, to address service barriers on a number of levels.

- Phase 3 (November 2015 – March 2016) focuses on evaluation of these interventions and development of guidelines for gender-sensitive disability inclusion in relation to SRH specifically and across the health sector more broadly in the Philippines. The guidelines will be developed and disseminated to service providers, policy makers, women with disability, and the wider community.

This report summarises findings from Phase 1 and outlines the range of interventions developed in Phase 2.

Research sites

W-DARE is being carried out in District 2 in Quezon City, Metro Manila, and in Ligao City (a rural district in Albay Province, Bicol Region). These locations were selected to provide data on the experience of women with disability from across a range of socioeconomic groups and those living in diverse settings (including households in rural communities and in highly urbanised cities, including in informal settlements).

District 2 is the largest in Quezon City (QC) and is one of the most densely populated districts in the Philippines, with an estimated population of 635,967 (National Statistics Office 2012). It includes households from both extremes of the socio-economic spectrum, but overall is relatively disadvantaged with many informal settler families living in the district. Ligao City (LC) is a rural and semi-urban district in Albay Province, approximately one hour from the Provincial Capital Legazpi. Running from the foot of Mt. Mayon to the coast in the southwest, the district has a population of 104,914 (National Statistics Office 2012).
2. Research Design

Methods

Training and capacity building

The research design in Phase 1 included a range of capacity development activities to ensure that research partner organisations and representatives had the skills and confidence to be active in the W-DARE research. Training workshops aimed to improve the capacity of project partners to conduct disability inclusive research using quantitative and qualitative methods, and to ensure that all individuals and partner organisations had a shared understanding of the aims and objectives of the research as well as the ethical considerations associated with data collection. Workshops also aimed to increase the ability of external researchers to understand the Philippines context, to engage with local priorities and sensitivities, and to adapt processes to ensure that they are appropriate for the Philippines. Individual workshops were conducted in each research site, as well as trainings that brought representatives from both research sites together. Capacity building workshops prior to data collection included:

- Introduction to disability and gender inclusive research (QC)
- Introduction to disability and gender inclusive research (LC)
- Qualitative research methods training (participants from both QC and LC)
- Rapid Assessment of Disability training (participants from both QC and LC)
- Consolidation of research methods training workshop (QC)
- Consolidation of research methods training workshop (LC)

Researchers from Australia and from the Philippines facilitated the research training workshops. Partners report that these training activities contributed to their knowledge and skills to undertake disability-inclusive research. Women with disability described the development of new practical skills, and academic partners described increased awareness of the needs and capacities of women with disability.

“\textit{I have been involved in the women’s movement as a researcher for many years, and I am ashamed to say that I never really thought about women with disability}” (Academic partner)

“\textit{It has been a steep learning curve for me, I never worked alongside women with disability before. I mean I was really surprised, they can really do it}” (Academic partner)

In addition, much of the capacity development that research partners and the research team describe has emerged through the collaborative implementation of project activities – learning by doing. The data collection teams included women and men with disability, representatives from partner organisations, representatives from the Persons with Disability Affairs Offices in Quezon City and Ligao City, and academic researchers.
2. Research Design

Data collection – Household survey

Tools

The Rapid Assessment of Disability (RAD) Questionnaire developed by the Nossal Institute for Global Health and the Centre for Eye Research Australia at the University of Melbourne is a population-based household survey designed to identify people with disability, and measure well-being and access to community for people with disability. 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 a questionnaire administered to each individual in the household and contains sections on demographic information, self-assessment of functioning, well-being and access to the community. The second section of the RAD uses questions on self-reported functional difficulty across similar domains as the Washington Group on Disability Statistics as a measure of disability. These include questions about vision, hearing, communication and mobility; about gross motor, fine motor, cognitive and psycho-social functioning; and about self-reported difficulty associated with appearance and psychological wellbeing. The questionnaire also has sections designed to capture aspects of wellbeing and access to the community for respondents who report functional difficulty and their matched controls (people without disability matched for age and gender), to allow for comparisons between people with and without disability. The RAD was conducted in District 2 of QC and in LC.

W-DARE developed an additional Women’s Health Questionnaire to measure women’s access to SRH services and information during the 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 WHO and UNFPA.

Permission to conduct the household survey was sought from respective barangay kapitans at each research site, and fieldwork teams were accompanied by local barangay health workers. Field work teams included men and women with disability and representatives of project partner organisations, and were 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. As the RAD had been originally developed for use across a range of settings, and the Women’s Health Questionnaire was based on international surveys, it was necessary to ensure that the questions were relevant and appropriate for the Philippines context. Local research teams (including persons with and without disability) conducted cognitive testing of the RAD and Women’s Health Questionnaires in both QC and LC, 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.
2. Research Design

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 QC and barangays in LC (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.

One segment from each cluster was randomly selected for data collection. Within the selected segment, the survey team visited all households door-to-door. Where possible, survey teams were accompanied by the local barangay health worker. The head of household was informed about the study and invited to complete the first part of the RAD (about household socio-economic characteristics). All individuals living in the household and aged 18 years and above were provided with translated information about the project in the form of a plain language statement and invited to complete the individual questionnaire. Interested persons were asked to provide informed consent (written or verbal, as appropriate). If an eligible household member was absent, at least two return visits were made to the household in an attempt to minimise recruitment bias associated with the timing of data collection. The survey teams had access to sign language interpreters to facilitate recruitment of any Deaf potential participants. Door-to-door visits continued in each segment until 50 people aged 18 years and above had been recruited. Women who were identified as having functional limitation through the RAD were asked to also complete the Women’s Health Questionnaire, as were matched controls (women without disability from approximately the same location and age group).

A sample size of 2920 was estimated using the most recent estimate of disability prevalence at the time of this study, i.e. a disability prevalence of 5% in the population, a 95% confidence level, sampling error of 20%, an estimated design effect of 1.6, and a non-response rate of 40%.

Data collection - In depth interviews and focus group discussions

Qualitative data were collected through in-depth interviews with women and girls with disability (aged 15 years and above), in-depth interviews with SRH service providers, and focus group discussions with women without disability and with parents and partners of women with disability. Question guides were developed to increase understanding of the lived experience of disability, the SRH needs and experiences of women with disability (including exposure to violence), and the barriers and facilitators to accessing SRH services and information experienced by women with disability. Question guides were also developed to explore the perspectives of service providers in relation to SRH and the provision of SRH services to women with disability, and the perceptions and experiences of family members and partners of women with disability.

Dona, a community based rehab worker, collecting household survey data (Ligao City, December 2013)
Sample and recruitment

Women identified as having a functional impairment during the RAD, and their partners and carers, were provided with written information about the in-depth interviews and focus group discussion, along with a verbal explanation of what participation would entail. A member of the research team then contacted those RAD respondents who wished to participate in the qualitative research activities at a later stage. Participants for the in-depth interviews and focus group discussions were also identified through the membership and networks of 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.

Recruitment for the qualitative data collection activities continued until theoretical saturation within the data was achieved, i.e. when new information no longer appeared during interviews and discussions, but rather the commentary from later participants began to reiterate issues that had already been highlighted by earlier participants.

Thirty-seven in-depth interviews were conducted with women and girls who had a range of impairments. All interviews with women with disability were conducted by another woman with disability (except for interviews with women with intellectual disability which were conducted by a SDRC-based psychologist researcher). The aim of these interviews was to explore the SRH-related needs and experiences of women with disability (including girls aged 15 years and above), including any experiences of violence, and to examine barriers and facilitators to women with disability accessing appropriate services.

Eight focus group discussions (FGDs) were held with husbands, partners, families and carers of women with disability, and with women without disability, to describe the perceptions and experiences of partners and carers of women with disability, in relation to the SRH-related needs of women with disability and to increase understanding of barriers and facilitators to all women accessing SRH programs, and how these may differ from women with disability. Discussions were facilitated by SDRC co-investigators.

Twenty in-depth interviews were conducted with SRH service providers to describe the knowledge, attitudes and practices of SRH service providers in relation to the SRH-related needs of women with disability; to increase understanding of service provider perceptions of the SRH needs of women with disability; and to explore factors influencing provision of and access to SRH services. These interviews were conducted by SDRC co-investigators and a representative from Likhaan Center for Women’s Health.

Consistent with usual practice in Philippines, study participants were not offered any payment or incentives (this is discouraged by local governments in particular). However respondents to the quantitative questionnaires were offered refreshments during participation and participants in qualitative interviews and FGDs were offered refreshments and reimbursement of any transport costs associated with attending the group discussion or interview.

Table 1. Overview of all data collection activities

<table>
<thead>
<tr>
<th>Activities to generate quantitative data</th>
<th>Activities to generate qualitative data</th>
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<tbody>
<tr>
<td>Rapid Assessment of Disability (RAD) Questionnaire with 3,059 adults (2287 adults in QC and 772 adults in LC).</td>
<td>37 in-depth interviews with women and girls (aged 15 years and over) with disability</td>
</tr>
<tr>
<td>Women’s Health Questionnaire 253 women in total (137 women with disability identified as having a functional limitation during the RAD and 116 matched controls - women without disability from the same location and age group).</td>
<td>20 in-depth interviews with SRH service providers</td>
</tr>
<tr>
<td>8 focus group discussions (partners and parents of women with disability, women without disability)</td>
<td>20 in-depth interviews with SRH service providers</td>
</tr>
</tbody>
</table>
2. Research Design

Data analysis

Data from the household survey was entered into a custom built Access database that ensured high data quality by restricting what could be entered. Double data entry of around 100 randomly selected surveys was performed to confirm quality of data entry. 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. In February 2014 we facilitated a two-day workshop with project partners and members of the household survey team to introduce participants to the principles of quantitative analysis; elicit participant feedback on our early analysis, including contextualisation of the data; and to reflect on the RAD process.

Interviews and focus group discussions were audio-recorded with participants’ permission and transcribed and where necessary translated from Tagalog to English. Documentation of interviews that had been translated included the Tagalog transcription and the English translation side-by-side to facilitate quality checking of the translation by SDRC co-investigators. Data analysis was thematic and data driven (Braun and Clarke 2006), and drew upon the expertise and insights of co-investigators and W-DARE partners. In February 2014 we facilitated a three-day data analysis workshop with the qualitative data collection team. Participants read and re-read the transcripts, identifying the key themes raised in the interviews and focus group discussions. An initial coding framework was collaboratively developed by workshop participants and refined by the research team following the workshop. 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.

Understanding inclusive research processes

In addition to the data collected by the W-DARE team to inform the development of SRH interventions a PhD student, Ms. Liz Gill-Atkinson, has been conducting research with women with disability and others involved in collecting the data described above. Liz’s PhD focuses on understanding what women with disability think about, and want from, research that affects their lives. She is working with women with disability and others to explore their perspectives on the participatory research processes involved in W-DARE, the impacts of their participation, and their experiences of participation. This research will contribute to our understanding of ‘what works’ in participatory research and will strengthen research practices as they relate to women with disability. Findings from this highly valuable addition to W-DARE will be available in late 2016.

Ethics approval

Ethics approval for the W-DARE program was obtained from the University of Melbourne Health Sciences Human Ethics Sub Committee and the De La Salle University Ethics Committee in August 2013.
3. Findings

Disability prevalence, wellbeing and access to the community

A total of 3,059 adults over the age of 18 completed the RAD survey, 2,287 persons in District 2 of Quezon City (32.1% male, 67.9% female) and 772 in Ligao City (44.7% male and 55.3% female). A total of 253 women completed the SRH questionnaire (137 women with disability and 116 women without disability). There were a number of differences between participants in Quezon City and Ligao City. Participants in Quezon City were more likely to be younger, have a higher level of education, but also be more likely to be unemployed and dependent on their families. In Quezon City 65% of participants were under 45 years old compared to 59% in Ligao City, 37% had a college or technical education compared to 14% in Ligao City, and 48% were unemployed compared to 37% in Ligao City.

<table>
<thead>
<tr>
<th>Functioning categories</th>
<th>QC (N=2287) Prevalence (95%CI)</th>
<th>LC (N=772) Prevalence (95%CI)</th>
<th>Total (N=3059) Prevalence (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sensory/physical/</td>
<td>6.29 (5.35,7.3)</td>
<td>12.88 (10.45,15.78)</td>
<td>6.56 (5.65, 7.60)</td>
</tr>
<tr>
<td>cognitive/communication</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Psychological distress</td>
<td>2.51 (1.94, 3.24)</td>
<td>5.27 (3.84, 7.20)</td>
<td>2.62 (2.07, 3.32)</td>
</tr>
<tr>
<td>Overall functional</td>
<td>7.15 (6.15,8.29)</td>
<td>14.04 (11.52,17.0)</td>
<td>7.43(6.47,8.52)</td>
</tr>
<tr>
<td>limitation</td>
<td></td>
<td></td>
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</tbody>
</table>

The prevalence of disability (Table 2) was 7.14% in Quezon City, and 14.04% in Ligao City. There could be a number of reasons why the prevalence was found to be so different in the two research sites. One likely reason is that respondents in Ligao City were older and disability is known to increase with age. In Quezon City, the population was younger and working (or had moved to Quezon City seeking work). In some of the parts of Quezon City that were randomly selected for inclusion in the survey, the environment is particularly challenging. The terrain is hilly, with very narrow pathways between houses built close together in informal settlements. The environment in these barangays is very difficult to navigate for people with mobility impairments (as was found by our data collection team) and potentially other kinds of disability. Therefore families with a member with a disability may self-select to live elsewhere, which would also contribute to the lower prevalence in this particular district of Quezon City.

Psychological distress was the most commonly reported disability. A significant proportion of people with sensory/physical/cognitive/communication functional limitations (65% in Quezon City and 78% in Ligao City) also reported psychological distress. In Quezon City, difficulty using hands and fingers, and difficulty remembering and concentrating, were also commonly reported. In Ligao, difficulty seeing and difficulty moving outside the house were the most commonly reported difficulties after psychological distress. Overall, disability was found to increase with age, and was similar in males and females.
3. Findings

Having a disability was associated with having had no education or only some elementary education, with those with college or technical education less likely to report disability. Researchers in other settings have also found this negative association between disability and education (access and attainment) (WHO and WB 2011). In contrast to what has been found elsewhere, prevalence of disability was similar among the different wealth quintiles in our survey. This may be because clusters randomly selected for inclusion in the study had similar low socio-economic status, and that there was insufficient heterogeneity in the sample to detect an association between disability and poverty. While there are affluent parts of District 2 in Quezon City, these are relatively few and were not randomly selected.

Wellbeing and access to the community

Wellbeing was measured by sixteen survey items related to quality of life and activity limitation. People with disability reported poorer wellbeing when compared to people without disability. People with disability also reported less access to different domains in the community compared to their gender and age matched controls. They were more likely to report reduced access to health services, work, education, social and religious activities, and toilets. Reported barriers to health services in particular included cost of services, lack of information, negative attitudes, difficulty getting to facilities, and the absence of personal assistants.
3. Findings

Access to sexual and reproductive health information and services

Research findings regarding access to SRH information and services for women with disability were obtained through responses to the Women’s Health Questionnaire, the in-depth interviews with women with disability and SRH service providers, and the focus group discussions. In the questionnaire, women were asked about their awareness of and access to SRH information and services.

Women with disability responding to the questionnaire were more likely to have been pregnant and to have had multiple pregnancies, than women without disability. No statistically significant difference was found between access to SRH information and services for women with and without disability, however it should be noted that the sample of women completing the questionnaire was relatively small (with the overall household survey powered to accurately measure disability prevalence rather than potential difference in access to SRH services). Trends that were observed included that women with disability were less likely to access pre- and post-natal care than women without disability, and were less likely to know where to go for an STI or HIV test.

While analysis of the quantitative data didn’t find a statistically significant difference in the awareness of and access to SRH services for women with and without disability, analysis of the qualitative data suggests that women with disability often have difficulty accessing services and information.

**Limited access to SRH information**

Disability and SRH were often described as taboo topics, with the sexuality of women with disability rarely discussed. Women with disability who were single or unmarried, or living in rural areas, could remember very few occasions on which SRH had been raised. Some women had not heard the terms ‘sexual’ or ‘reproductive.’ Unsurprisingly, then, interviews with women with disability revealed that many women had limited SRH knowledge, with some participants describing the confusion that they experienced in relation to puberty – one woman thought she was pregnant when she first started menstruating.

In addition to reporting limited access to SRH information, some women with disability had incomplete awareness of how and when to access SRH services and were, in many cases, unaware of their sexual and reproductive rights. Knowledge in relation to SRH was mixed across the women and girls with disability interviewed, however it was clear that there were women with specific types of impairment (such as women who were Deaf or hard of hearing and women with intellectual disabilities) who had particularly low levels of SRH knowledge. A number of the Deaf women interviewed reported having had no education about SRH at all, and were unaware of where they could access information about topics such as puberty, menstruation, safe sex, contraception and pregnancy.

“When I met my husband we had our first child by accident, and we didn’t know anything about SRH” (Woman who is Deaf, LC)

Women with disability reported learning about sexuality and SRH through their personal networks (family and friends), the media and occasionally through formal education provided in schools. However, little was reported about the content and quality of SRH information provided. Mothers were predominantly reported as the source of information on SRH, but the focus of this information was on menstruation and “how to act like a lady”.

“I mean, you barely find disabled women who are open to talk about these things. Of course, sometimes, when you’re married it’ll be okay to talk about sexual and reproductive health concerns, but when you are single, some aren’t that open” (Woman with mobility impairment, QC)

Women with disability reported a range of barriers to accessing sexuality education and information. These included miscommunication of concepts; limited community and educator awareness about the sexual rights of women with disability; and the reluctance of parents, carers, teachers and social workers to discuss sex and sexuality with young women with disability. For women who are Deaf or hard of hearing, limited availability of sign language interpreters was also a barrier to accessing sexuality information.

**Challenges accessing SRH services**

In the in-depth interviews, women with disability and SRH service providers described a range of factors undermining access to SRH services for women with disability. Both women with disability and service providers described how limited availability of SRH services in some local communities, and a lack of accessible transport, made it difficult for women to access the services that they needed. This was particularly true for women in rural barangays in Ligao, but there are also limited local services in some parts of Quezon City.
3. Findings

“First, the facilities are not accessible by the PWDs. Second, the front liners are not able to handle the needs of PWDs especially to the Deaf and to those with intellectual disabilities, and also the distance of health centre and health facility in the areas. The health centres are far and the transport is not accessible” (Government representative, QC)

Even when services were available, they were often physically inaccessible to women with disability. Some women with mobility impairments, in particular wheelchair users, reported instances where they were not able to physically access a service that they had gone to seeking SRH care.

“Even if the service provider has good intentions, but he is on the 5th floor, what good is it then?” (Woman with mobility impairment, QC)

“Going to the clinic, then the door is so small, you can’t get in” (Woman with mobility impairment, QC)

Another major barrier for women with disability was the lack of accessible transport to get to and from SRH services. Roads surrounding health services are often very busy with traffic and there are few safe, accessible places to cross. Transport service providers are not always helpful to their customers with disability:

“How many times have I been asked to get out of the bus because I am being a hindrance. You’re on a wheelchair and they make you go down EDSA!” (Woman with mobility impairment, QC)

Financial barriers to accessing health services were commonly reported by women with disability and their families. The cost of the actual SRH service, and in particular costs associated with transport and medication, prevented women accessing care. Most of the women with disability interviewed were unable to afford private health care.

“The services were really hard to come by. It’s not like the ones the rich people get. They just lay there, and they get everything they need. If you’re poor and you have a disability, your suffering is doubled” (Woman with mobility impairment, QC)

“Of course you want to avail the government services so you won’t spend much, but it’s hard... they don’t pay attention to your needs” (Woman with mobility impairment, QC)

In some instances, women would then seek care for their SRH needs from alternative providers in an attempt to save money. However treatment of SRH issues outside mainstream health services sometimes led to poor health outcomes and greater costs to women in the long run.

“I thought it would be ok for me to rely on traditional healers so I could save money financially, but it was a big mistake” (Woman with mobility impairment, QC)
3. Findings

The cost of accessing sign language interpreters (and their limited availability) was another barrier to services for women who are Deaf and hard of hearing.

“No, I don’t have access to any of that. I couldn’t afford an interpreter and I do not have access to sexual reproductive services or information because it is not provided in sign language” (Woman who is Deaf, LC)

**Barriers to supply of high quality SRH services**

In addition to the financial barriers raised by women with disability, service providers also highlighted the limited financial, human and material resources available to provide appropriate services for women with disability. Service providers noted that there were often multiple structural barriers to service provision, combining to reduce access to SRH for women with disability.

“In terms of the availability of supplies; because sometimes we lack supplies, and this becomes a problem. We have medical supplies, but there are times that they are depleted, they are not enough” (Service Provider, LC FGD)

Many service providers perceived that the disadvantage of women with disability in the Philippines was not only caused by their impairment, but was due to the intersection of discrimination based on gender, disability and poor socio-economic status. Service providers highlighted the conservative socio-political context in the Philippines as a factor undermining access to SRH for all women, including women with disability. Participants described how their ability to provide SRH services could be hampered by the socio-religious stance of the director or manager of the service in which they worked.

“We do family planning advocacy. In the past we had a problem, because sometimes, it depends on the department head. But, we are okay this year. The previous years when we had a different head we weren’t, because [they were] pro-life”. (Nurse, LC)

Service providers also highlighted the need for more accurate data to inform the provision of SRH services to women with disability. Service providers felt that they did not have sufficient information about the SRH needs and experience of women with disability, and were unaware of how many women with disability lived in their local area or how many women with disability actually used their services. Participants emphasised that it was difficult to compete with other government sectors for funding, or to advocate for more resources to increase disability inclusion in their service, without evidence to draw upon.

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**Poor experiences of sexual and reproductive health services**

Women with disability described a range of barriers that they needed to overcome in order to access SRH services. If they were, in the end, able to access services, many of the women with disability we interviewed reported poor experiences. Often these experiences related to the negative attitudes of service providers and other staff at health facilities towards people with disability. Women reported that some service providers seemed reluctant to provide them SRH services at all.

““At the emergency room the doctor told me ‘We have no doctor available’. He is a doctor and the one assigned in the emergency room. ‘We have no available doctor here. Do you want [points] to help you in your delivery?’ It was like he wants the janitor to do the delivery” (Women with mobility impairment, QC)

The judgmental attitudes of some service providers in relation to the sexual activity of women with disability was clear in women’s descriptions of their treatment in SRH settings. Women with disability described being scolded by service providers, with some service providers (in many cases falsely) believing that a woman’s disability would be passed on to potential children or that women with disability could not raise children and therefore should not be having sex.

“I went to the doctor when I was pregnant to have a checkup. They would ask me why I got myself pregnant when I am like this” (Woman with mobility impairment, LC)
A number of service providers were clearly uncomfortable talking about disability and people with disability, and were unclear of what terms were considered appropriate. Service providers’ attempts to avoid offending or disempowering people with disability through inappropriate language revealed their uneasiness and confusion when talking about disability.

“It’s very disempowering if you say limitation, impairment. That’s why we use the word mentally challenged, with special concerns. Because the language itself would make them more of a loser” (Participant in service provider FGD, QC)

Service providers also struggled with what they perceived to be the contradictory positions of acknowledging that people with disability should be prioritised to receive health services, and not wanting to ‘discriminate’ between people with and without disability for fear that this would be received as patronising.

“It's not specific because we treat everyone as a regular client whether it’s women, young girls, young women or young people. So it's not exclusive for PWD because they might think that they’re not like the others” (Participant in service provider FGD, QC)

A number of service providers, including those in senior management roles in government services, stated that while people with disability may be ‘prioritised’ (the Magna Carta for Persons with Disability requires prioritisation) they will not receive any additional consideration. While this position was framed as inclusive and non-discriminatory, it does not recognise the additional barriers women with disability face in accessing services, and that additional measures are therefore needed to increase equity of access. Other service providers noted that in reality prioritisation was difficult, as admission and reception staff were untrained in how to identify women with disability and had no tools that they could use to do so.

**Service provider understanding of the SRH needs and rights of women with disability**

Service providers often linked the right to, and need for, SRH services with marital status. One participant suggested that as women with disability in her catchment were married they would not need family planning services; conversely another stated that women with disability did not have a need for SRH services as they did not marry. In addition to marital status, experiences of abuse were also linked to the right of women with disability to access SRH services. For example, one participant reported that women with disability, especially women with intellectual disability, did not have a need for family planning unless they experienced abuse.

“Yes, they need medical health service but regarding family planning services, they wouldn’t really get married except if they are abused and get pregnant” (Nurse, QC)

Few service providers acknowledged that women with disability are equally likely to have sexual desire and experiences as women without disability, and therefore require SRH services as standard practice.

“But sometimes, they’re not innocent about sex already so it becomes their need. Even though they have disability, they’re still human” (Participant in service provider FGD, QC)

While service providers did not report denying access to services for women with disability, their poor understanding of the SRH needs of women with disability undermines both their ability to provide services and the health-seeking behaviour of women with disability.

**Capacity of service providers**

Women with disability reported that many SRH service providers had limited awareness of disability issues. Service providers themselves often felt that they lacked the capacity to provide appropriate SRH services to women with disability, stating that they had had no training in the area. Some suggested that it was not really their role to treat women with disability and felt that specialist care was required.

A number of participants noted that when service providers had limited training in how to meet the needs of women with disability, or held negative attitudes towards them, clinicians could be uncomfortable treating women with disability and behave inappropriately. Descriptions of inappropriate behaviour included reports of verbal abuse.
3. Findings

“As a service provider, instead of treating them [woman with disability] with a calm voice, it rises. They would usually shout at the patient. In the first place, he doesn’t know what are the things to ask. Instead of asking questions with reproductive intent, he might ask, “Why do you want to be pregnant?”” (Participant in service provider FGD, QC)

Participants reported that communication difficulties were a specific barrier to service providers delivering SRH services to women with disability. Participants described the way that communication difficulties caused service providers to become frustrated, directly resulting in poor clinical management of women with disability.

“I referred her [a woman with psychosocial disability] to ER in a nearby hospital and she was not given a good treatment. She was shouted at because she’s not answering. See, [the doctor] didn’t give her a favourable treatment because she’s not answering. For me, because the patient is already bleeding, they should not have asked questions; they should’ve treated the complications when we rushed her there” (Participant in service provider FGD, QC)

Service providers reported having particular difficulty understanding the needs of, and communicating information to, women who are Deaf or hard of hearing and women with intellectual disability. Trained sign language interpreters were rarely available to assist service providers, who instead relied on family members. Service providers also highlighted the additional time that may be required to communicate with women with disability, and noted that this was difficult in under-resourced workplaces.

“My husband’s parents were against it [their marriage] because they said that there are many normal women, why did he have to choose me?” (Woman with mobility impairment, LC)

Interviews with women with disability suggested that there was considerable ignorance and fear among some members of the general public with regard to disability. This not only undermined the rights of women with disability, it had a significant impact on some interviewees’ confidence and sense of themselves.

“I have also experienced being looked at like I have some contagious disease” (Woman with mobility impairment, QC)

Experiences of violence and abuse

Women with disability frequently reported violence and abuse. Women and girls reported sexual violence, physical violence, and being victim of a range of controlling and emotional behaviours. In addition to their own experiences of violence and abuse, many women with disability recounted experiences of violence by other women and girls with disability within their networks.

“My husband’s parents were against it [their marriage] because they said that there are many normal women, why did he have to choose me?” (Woman with mobility impairment, LC)

“Many [girls with disability] get abused, they turn women into maids… be in the house, wash dishes, wash the clothes, that’s the only thing they must do… They abuse the rights of the girls to live normally” (Woman with mobility impairment, QC)

Other factors undermining sexual and reproductive health for women with disability

Women with disability reported dealing with prejudice and discrimination on a daily basis, from the general public, family members, transport providers and health service providers. This undermined access to and participation in community in a range of ways, including undermining women’s maintenance of SRH. Negative community attitudes undermined women’s ability to achieve the SRH rights described in the UN CRPD (including the right to be involved in a sexual relationship, marry and establish a family) in very concrete ways.
Women reported abuse perpetrated by family members and partners, as well as persons outside their household. There were also reports of neglect and maltreatment. Interviewees described the difficulty women with disability had in coming forward and reporting abuse by partners or other people that they were dependent upon.

“My mom hits me sometimes because she gets irritated from me. She is fond of pinching me, for example at my breasts… another form of abuse I consider the most is my dad rejecting me, because he left us for his other family… he can’t accept that I have disability. He says they don’t have that kind of genetic abnormality in his bloodline” (Young woman with mobility impairment, QC)

“Instead of talking, always, he’ll hurt me. That’s how he dealt with our situation. He’ll beat me just to emphasise that I stop talking” (Deaf woman, QC)

Several service providers raised concerns about women with disability being sexually abused when family members (particularly mothers) were away from the home for work. However the concern often related to family or service provider anxiety about avoiding pregnancy as a result of abuse, rather than the abuse itself. Service providers recognised, and were concerned about, the additional stress families may experience if their family member with a disability became pregnant. However the right of women with disability to live safely in their own homes was rarely directly raised.

“There was one family who had a mentally retarded child so they came in to ask what they should do with their child who has no supervision the whole day because they are working. They say ‘Doc, how’s this? Someone might take advantage of the child or violate her, what if she gets pregnant? Can she be put on family planning?’” (Doctor, QC)

A number of participants highlighted that women and girls with disability were particularly at risk of sexual abuse by male relatives within the home. However in discussing the abuse, service providers often framed disability as “the problem”, rather than the perpetrator’s criminal behaviour.

“Sometimes there is incest … sometimes it is the brother who gets the sister pregnant; if not the brother, the father …. they take advantage of the weakness of the woman … it normally happens to them – in many cases, disability is the problem. Often, there are more of those with disability than those who are normal without disability” (Participant in service provider FGD, LC)

While there is no evidence it is common, some young women with disability described abuse by service providers themselves (both government and traditional providers). This would no doubt discourage women with disability from accessing health services and trusting health professionals in future, with negative consequences for their SRH.

“He asked to undress because he said its part of, he’ll massage my back. Because he said that is where my eyes had a problem. Of course I undressed and then he touched me on my breasts. He said it was part of the massage. Then suddenly he did this, in front. I said ‘why?’ and he said, I was still a maiden ‘It’s treatment.’” (Young blind woman, LC)

As a result of experiencing abuse and violence, or hearing accounts from other women with disability about violence and abuse, some women with disability reported a fear of men, family conflict (especially when the perpetrator was a family member) and negative impacts on their children. When reporting incidents of violence and abuse to family members, often they were not believed, further compounding the trauma of abuse.

“After she told me her story I felt fear and was mindful of men around me. I have a feeling of hesitation with my doctors, like I don’t want them to check or even touch me” (Woman with a mobility impairment, QC)

“One time he [stepfather] wanted to do it but I restrained him. I was angry at him and told him I will tell my mum about it. That’s when my mum and I had a fight and I blurted it all out. I thought it will be okay but it wasn’t because my mum gave me the cold shoulder and didn’t believe me immediately” (Young women with mobility impairment, QC)
Agency and independence of women with disability

The agency and independence of women with disability, in general and specifically in relation to sex, SRH and sexual relationships, appears to be influenced by impairment type, age, education and marital status. Women with vision and mobility impairments, and women who were older, had higher levels of education and/or were married, demonstrated higher levels of independence and control over decision-making.

“I usually make the decisions [about family planning]. Because my husband wants a big family, if possible he wants five to ten children cause he finds it lively. While me, I can’t take care of the kids, raising them was already a challenge. So I decided that I can only have two to three kids” (Woman with mobility impairment, LC)

Families of women with disability tended to be quite protective of their female family members with a disability (in particular women with intellectual disabilities). While the motivation for this was generally positive it was unclear whether this then undermined the ability of women with disability to access information about sexuality and sexual health, and make informed decisions about their SRH and sexual rights.

Right to healthy and fulfilling relationships and roles

Parents and other family members of women with disability were sometimes conflicted in relation to their daughters’ relationships. Family members wanted their daughter with disability to be happy and were usually supportive of the choices women with disability made, but were fearful that women could be abused by their partners and were concerned about how women with disability would be able to raise children. Parents and carers of people with disability mentioned not wanting their children to marry another person with a disability because they were concerned about the couple’s ability to look after their children. Other parents were very negative about their daughter’s right to form relationships and/or marry at all.

“They say that I won’t be able to find a husband because I am stupid and that I am deaf” (Woman who is Deaf, QC)

A number of the women with disability who were interviewed described how their husband’s families had responded negatively to their son’s choice of partner, questioning why he would choose a woman with a disability over an able-bodied woman. Parents-in-law questioned the capacity of the woman with disability and her partner (especially when the partner also has a disability) to take care of each other without assistance.

“Before, my husband’s parents want us to live with them after our wedding. They want us to live under their control. But we refused. How can we learn? They said we will not survive. It will be difficult for us because we’re both blind they said. But we refused” (Woman with a visual impairment, QC)

Women with disability who had children were often subject to questioning over their capacity as a mother and were told they were not sufficiently capable to take care of their children. While many women with disability did report difficulty in juggling the demands of motherhood and work, especially when they had little support from their families, this is also likely the experience of mothers without disability.

Some service providers reported that families of women with disability had requested tubal ligation for their daughter to prevent pregnancy. Service providers recognised that sterilisation of women with disability without their consent was a violation of women’s rights. However, they felt the practice was still sometimes justified in order to ease the burden on families and the strain on social services.

“So those are the young women I handle, abused and with impairment. Especially if the impairment is cognitive, it’s very hard. Every time she comes to you, she’s pregnant. And it came to a point that the family doesn’t want to accept the child. And what they suggested is to ligate this woman because her first two children are already with the family and this is the third, which will be given to them. And they cannot afford to have another baby. But we said, we don’t have the right to do that. But the relatives cannot understand it... But because of her inability to decide for her welfare, it was her mother and her relatives that decided for her... So you can see that we also have some ethical issues” (Participant in service provider FGD, QC)
The role of families in supporting women with disability access SRH services

A number of participants discussed the key role that families play in either supporting or preventing access to SRH services. Service providers described families as, at times, acting as gatekeepers to SRH information and services and in particular to preventative programs. Several service providers noted how the prejudice often associated with disability in the Philippines sometimes led to people “hiding” family members with a disability, with clear negative impacts on their health and well-being.

“The obstacle has to do with the relative of the woman with disability. Because sometimes, they are hesitant or do not allow the woman with disability to go out of the house. They try to keep them inside the house, because they are ashamed if other people would know they have a relative who has a disability” (Participant in service provider FGD, LC)

Family members often acted as intermediaries between women with disability and service providers, with service providers communicating with relatives rather than a woman with disability herself. In some instances this was because sign language interpreters were unavailable, or because service providers did not have sufficient skills to communicate with a woman with a communication or cognitive impairment. However, in other cases the rationale for communication through a relative was unclear.

“If it’s a physical challenge, that’s no problem but if, let’s say, a mental challenge – you need to explain, be ready to understand, you need to explain to the parents. Another thing, it is difficult to communicate with the deaf and mute…. When the blind come to the centre, they are usually accompanied so you can communicate directly with the companion” (Nurse, QC)

Few service providers reflected on how communication through a family member might inhibit a woman with disability seeking SRH services, or how this may render help-seeking for violence or abuse impossible if a family member was the perpetrator.

Strength of women with disability

We have discussed the considerable challenges that women with disability face in this report. However it was also clear that many women with disability are strong and are overcome these difficulties to make an important contribution to their families and communities, and maintain health including SRH. Education and support from family seemed to enhance resilience and where this support was present, women were able to articulate their rights and describe how they achieved these rights. A small number of women reported being aware of policies and programs that have the potential to support access to SRH services such as the Reproductive Health Law and the Persons With Disability ID card. Building on the strengths of these women with disability and developing the capacity of others, will be a major focus of the interventions supported by W-DARE.
Interviews conducted during Liz’s PhD research demonstrate that when women with disability have strong social networks and support from friends and family, that they are able to participate fully in community life. This includes economic participation, but also being involved in advocacy and research initiatives such as W-DARE. Many of the women with disability involved in W-DARE had already made a significant contribution to, or were leaders in, the disability sector in the Philippines. Other women with disability involved in W-DARE reported enhanced personal strength and individual agency, as a direct result of their involvement in project.

“One thing that I have got is that I have developed my self-confidence, before I tended to be shy and even the thought of talking to persons made me feel nervous… now I realise ‘oh I can do it’ and I am more sure of myself” (Woman with a mobility impairment, QC)

Women with disability reported increased self-confidence, and pride in themselves and their families (for supporting their choices) because of their participation in the research project. For some women with disability the experience of doing the same work, and working alongside, researchers without disability was a powerful validation of their lived experience and expertise. Women with disability found particular strength in their increased knowledge and awareness about SRH, and a desire to use their newly acquired skills and knowledge and ‘give back’ to the disability community.

“After I learned SRH I wanted to go back to the particular community and help them… share with them my knowledge of SRH now after I have learnt it” (Woman who is Deaf, QC)

The women with disability involved in collecting the data presented in this report described the research fieldwork as leading to rewarding interactions with community members and meetings with “people from all walks of life” that they would not otherwise have met. Meeting and becoming friends with others involved in W-DARE, learning from peers, and being able to help other researchers who did not have a disability, were also reported to be positive and strengthening experiences.

It is clear that participation in community life (including involvement in research that has relevance to their lives) can build on the existing personal strengths and agency of women with disability. The W-DARE interventions described below will draw on the strengths and expertise of all our project partners, including women with disability.
The W-DARE team worked with project partners to analyse the data generated in the first phase of the project, generate ideas about interventions that could be piloted to address some of the barriers to SRH that were identified, and to prioritise which interventions should be supported. Activities and interventions were prioritised on the basis of need, feasibility, likely impact, stakeholder support and the resources available. 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, for women with disability.

Throughout the project, but particularly in Phase 2, the W-DARE team has invested considerable resources in engaging with government on a number of levels, including the national Department of Health and the National Council on Disability Affairs, Provincial and City Health Offices, Persons with Disability Affairs Offices, and Department of Social Welfare and Development at different levels. We recognise that efforts to increase access to SRH for women with disability requires the sustained support of government agencies and the kind of structural change that can only be led by government.

All interventions have been developed through the collaboration of the W-DARE team and project partners, in consultation with relevant government agencies, DPOs, service providers and the Philippines Advisory Group. Activities are being implemented at both sites and include a particular focus on documentation and monitoring and evaluation. Evaluation of pilot interventions will support the development of guidelines for improving disability inclusion in SRH services in the Philippines. We anticipate that they will also have relevance for strengthening disability inclusion across the health sector in the Philippines and the wider region.

Framework for interventions

Analysis of the data generated in the first phase of the project highlighted that there were barriers to SRH for women with disability on a number of levels:

- SRH services were often physically inaccessible to women with disability, and access was further undermined by the prejudicial attitudes of some service providers and the limited capacity of service providers to deliver SRH and violence prevention services to women with disability. This undermines supply of services.
- Women with disability and their families had limited knowledge about SRH, about SRH services, and about their rights. Families sometimes restricted provision of information about SRH to women with disability. This undermines demand for services.
- Local government units need to manage a range of competing priorities and demands across diverse sectors. LGUs may have strengths in particular areas (such as provision of disability services such as rehabilitation) but less experience in others (such as provision of high quality SRH services), and have limited opportunities to learn from how other governments do things. This undermines their ability to coordinate and foster a supportive local environment for disability inclusive SRH.
- Women with disability continue to face prejudice and discrimination from families, service providers, and the wider public. This undermines their confidence and sense of themselves as valuable members of the community, and reduces women’s help and health seeking behaviours. Prejudice and discrimination also undermine a disability-inclusive and enabling 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 disability. While the resources and scope of this action research project are limited, we decided to pilot activities in each of these four areas rather than prioritise one over others. This necessarily means the scale of activities are limited, but we hope will provide a demonstration of how things could be done on a larger scale and inform guidelines for disability inclusive SRH relevant to a range of sectors.
Pilot interventions

A range of pilot interventions and activities are currently being supported by W-DARE. They include activities across the four domains outlined above.

**Demand side interventions**

The project is supporting a number of peer-facilitated Participatory Action Groups (PAGs) for women with disability and one for parents of children with disability. The PAGs are small groups of participants that meet fortnightly to discuss different aspects of SRH. PAGs have been organised to meet the needs of women with different types of impairment (for example, a group of women who are Deaf meet together, groups of women with mobility impairment meet together) and are being supported in both Quezon City and Ligao. All meetings are participatory, strengths-based and comprise a combination of structured activities and open discussion, with a focus on key factors relevant to women’s SRH needs and rights. The research team has developed a manual to support the peer facilitators and provided them with training prior to the groups commencing. All peer facilitators have access to ongoing support and mentoring by an experienced researcher and community organiser, who coordinates the PAG processes including monitoring and evaluation.

The aim of the PAGs is to increase demand for quality SRH services for women with disability by:

- increasing participants’ SRH knowledge
- increasing participants’ awareness of their rights in relation to SRH and disability
- increasing understanding of parents of children with disability about how to support family members with a disability to access services
- increasing participants’ confidence to access and negotiate health services, and
- facilitating the development of peer support amongst groups of women with disability and a group of parents of children with disability.

Qualitative and quantitative data collected at the commencement of the group process will be compared with data collected at the intervention’s completion, and at 3 to 4 months after completion, to evaluate the effectiveness of the intervention in contributing to change.

**Figure 2: A visual representation of the framework for interventions**

- An enabling society (working to increase public awareness of the rights and capacities of women with disability, decrease S&D, advocacy for appropriate policy and resourcing)
- ‘Supply side’ interventions (working with health facilities, SRH service providers, and those responding to violence)
- ‘Demand side’ interventions (working with women with disability, their families and carers to increase awareness, and uptake of SRH services)
- Enabling local environments (working with local communities, organisations and governments to create a supportive environment for interventions)
Supply side interventions

The project is supporting a range of activities that collectively aim to improve the supply of disability inclusive SRH services. This has involved close collaboration with the national Department of Health and the City Health Offices in the two LGUs where W-DARE is focused. Activities aim to increase SRH and violence service provider awareness of disability and sensitivity to the specific needs of women with disability; enhance service providers’ communication and other skills required to provide services to women with disability; 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 disability. Specific activities include:

- development and delivery of modules for the Department of Health’s (DOH) disability inclusion training
- facilitating disability and gender sensitisation workshops for service providers in Quezon City and Albay Province
- supporting the development of a toolkit for health managers on disability inclusive facilities
- conducting training workshops for health service providers at different levels, from senior doctors to barangay health workers
- facilitating workshops to develop strategies to strengthen responses to violence against women and girls with disability.

Interventions to develop an enabling local environment

The project has supported exchange visits between LGU personnel in Quezon City and Ligao City. Representatives from the Persons with Disability Affairs Offices, City Health Offices, and Social Welfare and Development Departments have participated in these exchanges. The exchange visits aim to increase participants’ exposure to different approaches to delivering SRH and disability services through local government mechanisms, facilitate sharing of experiences by local government peers, and encourage innovation and problems solving to gain support for enabling local environments for disability inclusion. Documentation of the exchange visit process will include follow up with participants over time to monitor their ability to incorporate new ideas into local practice.
Enabling society interventions

Data generated in the first phase of the project clarified the pervasive impact of prejudice and discrimination on the day-to-day lives, and consequently SRH, of women with disability. Therefore W-DARE will support activities aimed at increasing community understanding of the impact of discrimination and violence against women with disability; increasing recognition of the strengths and capacities of women with disability; and increasing awareness of the rights of people with disability in the Philippines, including the right to form sexual relationships, marry and have children. These activities will be supported in the second half of 2015 and may include the development of short promotional video and/or a photography exhibition developed by women with disability. W-DARE will work in close collaboration with our partner DPOs and with the National Council on Disability Affairs in the development of these activities.

Monitoring and evaluation

Implementation of these activities is ongoing – most of the interventions have begun at the present time (May 2015), with some to commence in coming months. Interventions and activities are being closely documented, with monitoring and evaluation of the effectiveness of specific activities to inform the drafting of overall guidelines generated by W-DARE. These guidelines will focus on strategies for increasing access to SRH services and information for women with disability in the Philippines, and will be available in 2016.
5. Conclusion

This short report summarises initial findings from the three-year participatory action research project W-DARE. Data generated in the first year of the project suggest a range of barriers to quality SRH services and information for women with disability in the Philippines. W-DARE have developed a range of small pilot interventions in response to these barriers, with the aim of demonstrating what can be done to increase access to SRH for women and girls with disability. This report outlines the framework for these interventions, noting that changes are required in relation to the supply of SRH services; the demand for SRH services; in coordination and support at the level of local communities and local government; and in attitudes and understanding at the level of the wider society. Guidelines informed by evaluation of our pilot interventions will be made available in 2016.

The challenges that women with disability in the Philippines face in accessing SRH services include physical, financial and attitudinal barriers; low levels of awareness in relation to SRH and rights; violence and abuse; and prejudice and discrimination. However the many women with disability that we have worked with over the last two years also demonstrate considerable strength and agency in managing their own health and advocating for the health and rights of other women with disability. The W-DARE team, a partnership between women with disability and their representative organisations, dedicated SRH service providers and advocates, and academic researchers in the Philippines and Australia, are committed to building on women's strengths, sharing their stories and supporting their efforts to achieve sexual and reproductive health. The Philippines has ratified the UN Convention on the Rights of Persons with Disabilities and has passed legislation to protect the rights of people with disability including their right to SRH and protection from violence. As is clear from the findings summarised in this report, much remains to be done to enable Filipina women with disability to realise these rights.
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