

A Situational Analysis of the Sexual and Reproductive Health of Women with Disabilities

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List of Acronyms

AIDS	Acquired Immune Deficiency Syndrome
CBR	Community-based rehabilitation
CEDAW	Convention on the Elimination of all forms of Discrimination against Women
CRPD	Convention on the Rights of Persons with Disabilities
DPO	Disabled Peoples Organization
DWNRO	Disabled Womens Network of Resources Organization
ECOSOC	United Nations Economic and Social Council
ESCAP	Economic and Social Council of the Asia-Pacific
GBV	Gender based violence
GPDD	Global Partnership for Disability and Development
HIV	Human Immunodeficiency virus
ICW	International Community of Women with HIV/AIDS
IDP	Internally displaced person
IO	International organization
IRC	International Rescue Committee
NCKK	National Council of Churches of Kenya
NGO	Non-governmental organization
MDG	Millennium Development Goals
RH	Reproductive Health
SGBV	Sexual and gender based violence
SHIA	Swedish Handicap International Aid Foundation
SRH	Sexual and reproductive health
STI	Sexually transmitted infection
UN	United Nations
UNFPA	United Nations Population Fund
WHO	World Health Organization
WWDA	Women with Disabilities Australia

Background

UNFPA's corporate frameworks reflect its commitment to the Convention on the Rights of Persons with Disabilities, the first global human rights treaty to address sexual and reproductive health of persons with disabilities. The Fund's Strategic Plan 2008-2011, which provides the overall direction for UNFPA support to countries in the three interrelated focus areas of population and development, reproductive health and gender equality, places a special focus on marginalized groups and makes an explicit reference to women with disabilities. In line with articles 23 and 25 of the Convention, the Strategic Plan provides guidance to UNFPA staff to ensure that persons with disabilities participate in the design, implementation, monitoring and evaluation of culturally- and gender-sensitive policies and programmes that contribute to the achievement of the Millennium Development Goals, particularly MDGs 1, 2, 3, 5 and 6.

At the country level, UNFPA provides technical support for the incorporation of the disability perspective into health policies, programmes and national development frameworks, while advocating for the participation of persons with disabilities in decision-making processes. At the same time, the Fund works to support capacity building and education efforts, as well as positive media involvement to ensure adequate quality of care and response, particularly for young persons living with disabilities.

There is the need to develop a corporate strategy to strengthen UNFPA's understanding of the population and development, reproductive health and gender equality issues of persons with disabilities, more particularly women and girls, and establish a stronger framework for UNFPA's work on persons with disabilities.

To this end, a working paper has been developed describing the main sexual and reproductive health issues women with disabilities face in order to provide solid factual basis for that strategy. Accordingly, UNFPA will utilize the working paper to advise countries on policy and programming on the SRH and rights of women with disabilities. The methodology employed to identify the main issues that women and girls with disabilities may face in relation to their sexual and reproductive health consisted of interviews and meetings with experts, literature reviews and the collection of analytical information on the SRH and rights of women with disabilities through the lens of country-case studies.

I. Introduction

The World Health Organization (WHO) estimates that 10 percent of any given population has a disability, with a higher incidence for post-conflict countries.¹ Most persons with disabilities, approximately 80 percent, live in developing countries. The United Nations estimates that this percentage may be higher, and 25 percent of the world's population may be living with a disability.² *UNFPA Emerging Issues, Sexual and Reproductive Health of Persons with Disabilities*, Article 1 defines persons with disabilities as "...those who have long-term physical, mental, intellectual, or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others". Despite the large number of persons living with disabilities worldwide it was only in 2006 that the Convention on the Rights of Persons with Disabilities (CRPD) was adopted and subsequently entered into force in 2008.³ Women and girls with disabilities have compounding risk factors for violence, injury or abuse, challenges in accessing health services, discrimination, maltreatment, and exploitation.⁴ Health infrastructure of most developing countries neglects the needs of persons with disabilities, thus the situation for women with disabilities is dire in this context.⁵ Access to sexual and reproductive health services (SRH) for women with disabilities is not only a human right, but it will also help the international community to meet the Millennium Development Goals (MDGs), specifically MDG 3, to promote gender equality and empower women, MDG 5, to improve maternal health, and MDG 6, to combat HIV/AIDS, malaria and other diseases. With the 2015 deadline approaching, and the recent ratification of the CRPD, it is now the responsibility of the States with support of the international community and participation of women with disabilities to address the sexual and reproductive health (SRH) needs of women with disabilities.

In order to determine best practices for addressing the sexual and reproductive health needs of women with disabilities it is necessary to examine the existing research and available data. SRH services are inaccessible to women with disabilities for a plethora of physical and societal reasons. For the international community to move forward and recognize the rights of women with disabilities to SRH services it is important to attend to and understand not only the physical barriers women living with disabilities may face, but also the negative perceptions that stigmatize women with disabilities. To do so, this paper will examine various areas that directly and indirectly contribute to the barriers to SRH services which women with disabilities experience. The challenges to arriving at adequate standards of SRH will be addressed along with composite barriers including discrimination and gender based violence. Environment and geography also affect the availability of SRH services and women with disabilities' access to SRH. Accordingly, SRH needs within emergency situations will be analyzed. The challenges to the SRH of women with disabilities must be examined through a multi-faceted framework. While the situation will fluctuate on a conditional basis, it is important to understand and address the duality of the issue by identifying both actual and subjective root causes preventing women with disabilities from experiencing sufficient access to SRH services. In developing a framework to address this pressing issue, the goal is to bring women with disabilities to the attention of

Statistics on Women with Disabilities

Women with disabilities comprise 10% of all women worldwide.ⁱ

Women comprise 75% of persons living with disabilities in developing countries; between 65% and 70% of these women live in rural areas.ⁱⁱ

The World Bank estimates that out of approximately 1.3 billion people living below the poverty line worldwide 20% are persons with disabilities, or one in five people living on less than \$1 a day.ⁱⁱⁱ

Many causes of disability are preventable, and most often attributable to poverty: 20% of disabilities worldwide are caused by malnutrition; accidents, trauma and war account for 16% of disabilities; 11% are a result of infectious disease; 20% non-infectious disease; 13% of disabilities are a result of other causes, including ageing.^{iv}

the international community. By making them visible to agencies and communities responsible for ensuring the unrestricted access for women with disabilities to SRH services worldwide, it will help to advance the goal of a universal standard of health for all.

INVISIBILITY OF WOMEN WITH DISABILITIES

Invisibility is as an overarching issue for women with disabilities and their struggle to access SRH services. For the purposes of this paper we will define invisibility as remaining underrepresented as a focus of policies, programs, research and the media, as well as exclusion from social, political and economic participation. Women with disabilities have historically been invisible and this has led to poor reproductive health outcomes.

Misconceptions and lack of information and awareness concerning the SRH of women with disabilities have contributed to exclusionary practices by national governments, policymakers, and civil society. Studies show that women with disabilities remain invisible in policy discourse at both national and international levels.⁶ Policymakers often underestimate the number of persons with disabilities within a given population, and as a result persons living with disability are given low priority although there is a considerable need for procedural attention.⁷ In addition, there is a common consensus among studies conducted on issues concerning persons with disabilities that development practices today tend to exclude women with disabilities and their reproductive health needs due to the lack of data and information on women living with disabilities, especially from primary sources. Furthermore, significantly less information and fewer services are available for persons living with mental disabilities than persons with physical and sensory disabilities. Persons with mental disabilities tend to be more “invisible” and “hidden” from public view than persons with physical disabilities.⁸ Often there is greater discrimination and stigmatization of persons with mental disabilities, and family shame often leads to the persons with mental disabilities being hidden away, physically restrained and frequently neglected.⁹

As a result of invisibility and its contributing factors, it becomes very difficult not only to identify the key challenges faced by women with disabilities, but also to advocate for programs and initiatives that will respond to their needs. Additionally, a fundamental barrier to identifying, advocating for, and meeting the needs of women with disabilities is that persons with disabilities are still primarily viewed as *objects* of welfare or medical treatment rather than *holders* of rights. Despite being entitled to all human rights, persons with disabilities are still, in practice, denied the fundamental rights and freedoms that are outlined in the Universal Declaration of Human Rights and the CRPD. Many persons living with disabilities are denied basic human rights such as the right to education and vocational training, and the right to employment and basic health care. Many persons living with disabilities are also denied legal rights and do not have equal recognition before the law. In other situations persons living with disabilities have had their legal capacity completely, and unnecessarily, transferred to guardians who have abused the rights of the individual.¹⁰ Women with disabilities are underrepresented in social and medical research in order to address these crucial issues; partly because those who are disproportionately affected by disabilities are the poor; they may not have the capacity, time, and education to participate in research, policy and training.¹¹

INVISIBILITY: EDUCATION & EMPLOYMENT

Education gives a person the opportunity to develop their human capital and skills, making it possible to seek out skilled labor or participate in politics, organizations, legal matters and institutions. Current estimates suggest that the school enrollment rates of children living with disabilities in developing countries are as low as 1 to 3 percent; meaning that approximately 98 percent of children with disabilities do not go to school and are illiterate.¹² Physical barriers also exist, as transport to school may

not be accessible for children with disabilities. Because children with disabilities are largely absent from schools, the opportunity for awareness and understanding of disabilities by all children is lost.

In most societies, persons with disabilities have not been fully integrated into the labor market.¹³ The majority of persons with disabilities are either unemployed or have been discouraged from actively seeking work. Among those living with disabilities who are working, many are underemployed, paid below minimum wage, and work below their capabilities; this problem exists at a higher rate among women with disabilities in comparison to men with disabilities.¹⁴ In general, women also earn less than men when they are employed. The lack of economic participation has a significant impact on the lives of women with disabilities, leaving them unable to earn an adequate standard of living and to live independently. It should also be noted that in developing countries, most workers with disabilities are employed in the informal sector, where work is unstable.¹⁵ Labor regulations are also scant as many countries do not have legislation to promote and protect the rights of workers with disabilities.¹⁶

The invisibility of women with disabilities has led to exclusion on multiple levels, including social and political participation, education, employment and health services.

II. Challenges to Achieving Sexual and Reproductive Health

Persons living with disabilities, and women with disabilities in particular, are often viewed as asexual,¹⁷ incapable of engaging in a sexual relationship, and unable to bear and raise children, which severely limits the information and types of reproductive health services made available to them.¹⁸ Due to myths and assumptions, persons with disabilities, especially women and girls with disabilities, are not included in SRH information outreach efforts, as these individuals are perceived to have no risk for sexually transmitted infections (STIs), including HIV infection.¹⁹ However, persons with disabilities are as likely to be as sexually active as persons without disabilities²⁰ and sexual behavioral risk factors for HIV are the same among persons with disabilities and non-disabled persons.²¹

The CRPD stipulates that States parties need to provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of SRH and population based public health programs. Article 6 of the convention which specifically focuses on women with disabilities declares that “States Parties shall take all appropriate measures to ensure the full development, advancement and empowerment of women, for the purpose of guaranteeing them the exercise and enjoyment of the human rights and fundamental freedoms set out in the present Convention.”²² The fundamental freedoms mentioned maintain that States Parties must ensure that persons with disabilities can decide freely and responsibly on the number and spacing of their children while retaining their fertility on an equal basis with others.²³ In other words, the convention holds that women with disabilities not only have a need for information on SRH, including family planning, but also the right. Barriers to achieving sexual and reproductive health for women with disabilities can be categorized into three areas: challenges regarding the right to information, lack of access to health services, and lack of availability of health workers. These three areas combined augment the challenges preventing women with disabilities from achieving adequate SRH.

CHALLENGES REGARDING THE RIGHT TO INFORMATION

The six-hundred million people living with disabilities worldwide are far less likely than persons without disabilities to receive information on family planning, or access to counseling through community initiatives, education systems, or via traditional routes in the home or social arena.²⁴ The persistent lack

of communication from health institutions, organizations and agencies, and also from family members or women community leaders²⁵ results in women with disabilities being uninformed of safe sex practices. As a result women living with disabilities experience elevated risk for STIs, HIV/AIDS,²⁶ and unwanted pregnancies.²⁷ Despite incessant barriers to women with disabilities realizing vital and necessary information concerning SRH, international treaties such as the Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW) recognize the rights of women to information and education.²⁸ There is no distinction between the rights of women and the rights of women with disabilities; the universality of human rights principles applies to all people, devoid of any demarcation. CRPD calls for States Parties to ensure persons with disabilities access to information and communications, and furthermore to promote appropriate forms of assistance and support to persons with disabilities to ensure their access to information.²⁹

In circumstances where SRH information is conveyed in print on billboards or newspapers, women who are blind are unable to receive information. Deaf women cannot pick up information that is broadcast via radio campaigns.³⁰ Furthermore, public campaigns as such are often confusing to individuals with intellectual disabilities who cannot process a surplus of information at one time, let alone comprehend less complex topics, such as death.³¹ Low literacy levels of populations, especially women with disabilities, are an additional barrier to receiving SRH information. Worldwide, only 3 percent of persons with disabilities are literate. Only 1 percent of women with disabilities are literate.³² Dropout rates of children with disabilities are estimated to be double or triple those of their non-disabled peers.³³ A World Bank study in 57 countries found that children and adolescents with disabilities in school are likely to be excused from sex education classes, and are less likely than their non-disabled peers to receive general science and health education information.³⁴

The case of HIV/AIDS can be used to highlight how women with disabilities have been ignored by public health campaigns. The incidence of HIV/AIDS may be elevated among persons with disabilities because individuals with disabilities often face exclusion from HIV/AIDS awareness and outreach efforts.³⁵ HIV/AIDS remains a large problem among persons living with disabilities and has not received enough attention from AIDS and disability advocacy groups and organizations.³⁶ Individuals with physical, sensory, intellectual, or mental health disabilities were not given substantial attention before 2004 and subsequently a significant number were infected with HIV.³⁷

It is often widely believed that persons with disabilities are not at risk for contracting HIV/AIDS due to sexual inactivity, unlikeliness to use drugs and less risk of sexual violence or rape compared to non-disabled persons. However the veracity of the matter is that persons with disabilities are at an increased risk for each risk factor for HIV/AIDS.³⁸ Misconceptions that surround the sexual and reproductive lives of women with disabilities impede the dissemination of SRH information, protection against STIs, and HIV/AIDS prevention.

Persons with intellectual disabilities are often viewed as not capable of retaining information related to SRH, and thus no efforts are made to teach individuals with intellectual disabilities about sexuality.³⁹ In regards to HIV/AIDS sensitization programmes, individuals with mental disabilities have received more attention than persons with other types of disabilities,⁴⁰ yet still not enough compared to the general population. In Swaziland, a study was conducted in rural and urban areas that found adults with physical and communication disabilities less likely to understand the correct vehicles of HIV transmission and methods of HIV prevention, compared to a group of non-disabled adults of similar age.⁴¹

Women with disabilities may not always be capable of negotiating safer sex.⁴² In some societies a common belief is an HIV-positive man can become free of the virus if he engages in sexual intercourse with a virgin, thus women with disabilities are at an increased risk for HIV infection as they are often viewed as asexual.⁴³ High poverty levels often pre-dispose women with disabilities to HIV/AIDS when women engage in sexual activities with multiple partners to gain financial or other forms of support.⁴⁴

Adolescents with disabilities experience compounded risk factors for HIV/AIDS compared to their non-disabled peers.⁴⁵ Adolescents with disabilities often face exclusion from social activities and may not have the social skill set required to set boundaries with their peers or adults, leaving them powerless in the face of pressure to engage in sexual acts or drug use.⁴⁶ UNICEF estimates that one-third of all street children are disabled; many of these exceptionally vulnerable children frequently become involved in sex work and drugs.⁴⁷

The onset of HIV/AIDS may increase the risk of secondary disabilities, increase child mortality, and is a diminishing factor for maternal health. In utero exposure to HIV may cause developmental delays in infants.⁴⁸ Physical debilitating effects of AIDS are often experienced with persons living with HIV/AIDS.⁴⁹ Furthermore, mental health problems in persons living with AIDS may be directly attributable to the disease.⁵⁰ The lack of information about women with disabilities in the context of the HIV/AIDS epidemic is helping the disease to spread. Once contracted, accessing HIV treatment and other SRH services becomes another barrier that women with disabilities must navigate.

LACK OF ACCESS TO SEXUAL AND REPRODUCTIVE HEALTH SERVICES

Women with disabilities face multiple obstacles when trying to access sexual and reproductive health services. These challenges are similar for all women; however a disability can compound the situation. The challenges of access can be categorized into two areas: transportation and the services provided at health facilities. These broad areas will be addressed by highlighting the situation of women in Lusaka, Zambia. A qualitative study of women with disabilities and the barriers they face to reproductive health services in Lusaka was conducted in 2003. In-depth interviews of twenty purposefully sampled women with disabilities and in-depth interviews of twenty-five public sector reproductive health workers were conducted. The women with disabilities were purposefully sampled in order to speak to women with differing disabilities, socio-economic status, education level, and childbearing history.⁵¹

Zambia has a population of 9.8 million and approximately 40 percent live in urban areas. There are several statistics that highlight areas of concern surrounding the issue of reproductive health in Zambia. The maternal mortality is high at 870 deaths per 100,000 live births, and there is also a high HIV infection rate. Despite knowledge of contraceptive methods being high, close to 96 percent, the use of contraceptive methods remains low at around 26 percent. Zambia also has one of the highest fertility rates in sub-Saharan Africa at 6.1 children, although it has been decreasing.⁵²

Lusaka, where the study was conducted, is an urban area with an unusually high coverage of antenatal and delivery care. Approximately 88 percent of women give birth within the Lusaka health care facilities, and overall access to family planning has been facilitated by the public sector. Abortion care is also available at the University Teaching Hospital (UTH). Despite constrained resources, Lusaka has provided a good percentage of the surrounding population with reproductive health services.⁵³

The first barrier to be discussed is that of transportation. While many women in Africa face this same barrier in reaching health facilities, women with disabilities are faced with a double burden of affordability and suitability of transportation. This is not only an issue of poverty that many women with

disabilities face, but also one of access to public transportation, such as mini-buses or taxis. The first issue of transportation cost is important because the Zambia Association for Research and Development reports that women with disabilities are among the most affected by poverty. Pregnant women in the study reported that while they were able to get to their local clinic for antenatal care, they were not accepted for labor or delivery at the local level and were referred to hospital-level care due to possible complications. This referral not only increases the distance that women had to travel, but also the cost, making the journey beyond what they could afford. Interviewee 12 stated that, “What really caused me to deliver from home is because of not having money to book a car to go to the hospital for delivery.”⁵⁴

The other issue of transportation is that of suitability. In Zambia minibuses are a common and more affordable type of transportation, however they are not adapted to accommodate persons with disabilities. This causes many drivers to refuse transport to women with disabilities because any assistive devices would take up too much space in an already crowded bus, which could cost the driver another fare. In many cases the women were unable to enter into the minibus without help, further discouraging women from this more affordable form of transportation.⁵⁵

The second area of challenges is focused around the services offered at health facilities. As with transportation, part of the challenge is basic access to the facilities. The first barrier may be in entering the hospital or clinic if it is not wheelchair accessible. There is also an issue with the standard height of examination tables being too high, making it impossible for some women to transfer to the table without help. A policy paper written in the United States by the Berkeley Policy Associates on “Multiplying Choices: Improving Access to Reproductive Health Services for Women With Disabilities” notes that the exam can be one of the most challenging aspects of providing quality services to women with disabilities. If the exam does not go well, it is more unlikely that a woman will return for further services.⁵⁶

Health workers’ knowledge of disabilities plays an important role in the treatment of women with disabilities. In some cases, the simple act of making adjustments to the exam routine can make a woman with disability more comfortable. In other cases it is more complex as a woman with disability presents diagnostic and therapeutic challenges. This is particularly true in the case of many sexually transmitted infections (STIs), which may manifest differently in women with disabilities. Symptoms of Hepatitis C such as joint pain, fatigue, and elevated temperature resemble those of autoimmune diseases. HIV is another example with symptoms mimicking Multiple Sclerosis (MS), such as visual and cognitive impairment, imbalance, pain, and fatigue. The societal view that women with disabilities are asexual can also contribute to the misattribution of symptoms leading to many women with disabilities not being diagnosed properly or in a timely manner.⁵⁷ Women with disabilities might also respond differently to prescribed treatments or medication such as family planning methods.

In Lusaka, the beliefs and attitudes of both the women with disabilities and health workers created barriers to reproductive health services. Societal beliefs that women with disabilities are inferior existed in both populations, and led to reports of low self-esteem in women with disabilities. Many women also believed they would encounter negative attitudes from health providers when employing reproductive health services, although only some gave accounts of actual incidents. Many of the health workers interviewed admitted surprise when a woman with disability sought out reproductive health services; however they were also concerned about protecting the woman with disability from other clients staring at them. This led to women with disabilities being prioritized over other women, and while they were attended to quickly, such actions perpetuated the idea that a woman with a disability seeking out reproductive health services is an abnormality.⁵⁸

Issues of access to reproductive health services become particularly important in cases of pregnancy-related complications, which often result in maternal morbidity. It is estimated that more than 10 million women experience long-lasting illness or disabilities resulting from complications during pregnancy or childbirth as a result of the lack of access to SRH services.⁵⁹ Pregnancy-related disabilities include obstetric fistula, uterine prolapse, and complications from unsafe abortion.

Obstetric fistula is a childbearing injury caused by prolonged obstructed labor without timely medical intervention (usually a Caesarean section). During prolonged labor, the soft tissues of the pelvis are compressed between the descending baby's head and the mother's pelvic bone, causing a lack of blood flow that leads to tissue necrosis. This creates a hole between the mother's vagina and bladder (*vesicovaginal fistula*), or between the vagina and rectum (*rectovaginal fistula*), or both. The consequence is the leaking of urine, feces, or both, depending on the severity of the fistula

This condition is devastating for women, as they are usually ostracized and abandoned. Although it is almost entirely preventable, at least 2 million women in Africa, Asia and the Arab region are living with obstetric fistula, and approximately 50,000 to 100,000 new cases develop each year, occurring disproportionately among impoverished girls and women.⁶⁰ Several factors contribute to the development of an obstetric fistula, including poverty, malnutrition, early childbearing, gender discrimination and poor health services. Poverty, however, is understood to be the main social risk factor because in many locations, it is associated with early marriage and malnutrition. This greatly reduces a woman's chances of getting prompt obstetric care. In societies where women are held at a lower social status, they usually lack the power to decide when to start bearing children or where to give birth.

The experience of obstetric fistula often leaves women ashamed, traumatized, and isolated from their communities. Women are often stigmatized and ostracized by their own families and communities because of the smell from the constant leaking of urine and/or feces. There are social misperceptions regarding the exact cause of obstetric fistula; as a consequence some women are abandoned by their husbands and families. Women may become exiled from their social and family life in entirety, including not being able to participate in daily family life, attend social events, practice religion, or perform basic household tasks. As a result, some women fall further into poverty because they are unable to work in order to generate income. The condition of isolation may have mental health repercussions, such as depression, low self-esteem, and suicide.⁶¹

Obstetric fistula is a preventable disability, usually attributable to lack of or absence of trained health workers to provide emergency obstetrical care. In addition, women living with disabilities not only experience a lack of availability of trained health workers, but when services are available, health workers often see women with disabilities in a negative light, which leads to inadequate care and distrust on behalf of women with disabilities.⁶² Additionally, most health books and training manuals do not include information on women with disabilities. This lack of training and therefore understanding of the SRH of women with disabilities continues the cycle of stigmatization, which in turn leads to inadequate services for and a lack of self-confidence and feeling of self-worth by women with disabilities.⁶³ In many communities, health workers, social workers, and midwives provide SRH services in peoples' homes, but the homes of persons with disabilities are often skipped because it is assumed they are not sexually active and therefore do not need services. What many inadequately trained health workers do not know is existing services can usually be easily adapted to the needs of persons with disabilities.⁶⁴ Women with disabilities have the same SRH needs as other women, but they often are

neglected and do not receive or have access to adequate information and/or services.⁶⁵ Women with disabilities are vulnerable to SRH challenges and complications as a result of stigmatization, stereotypes, and myths concerning disability, gender, sexuality, and HIV/AIDS.⁶⁶

III. Discrimination

STIGMA AND STEREOTYPES

Discrimination against women is an issue that has been discussed at length over the years, but the dialogue about discrimination against women with disabilities has been inadequate.⁶⁷ The great majority of women with disabilities face prejudice and stigma in their daily lives⁶⁸ and are often seen as being victims to “double discrimination”, first from their status as women and second resulting from their disability. This widely held discrimination is common in both the home and in the community⁶⁹ and leads to women and young girls with disabilities being denied their basic human rights,⁷⁰ including freedom of movement and association, health (in extreme cases, the stigmatization can lead to withholding or delaying of critical care and in turn, lead to death), education, pursuit of livelihood, and more.⁷¹

Stigma makes it difficult for women with disabilities to exercise their rights, integrate into the community, and be self-sufficient.⁷² Additionally, they are more likely to be denied access to nutrition, vocational training, employment, and income generation opportunities. They are routinely excluded from social and community activities and are often denied access to the customary roles of women in their community. Lastly, adequate attention is not given to women with disabilities in self-help organizations, which further denies them the ability to be a part of an advocacy agenda.⁷³

Stigma can also lead to women with disabilities being “hidden” by their families in some societies.⁷⁴ Many families do not want to put in the time or energy necessary to properly care for women with disabilities because they are seen as being non-productive and unable to contribute. Further, women with disabilities are sometimes regarded as “bad” women and are kept hidden so as not to damage the marriage possibilities of their siblings.⁷⁵

There are 40 million women with disabilities in India alone. Women with disabilities in India face all of the above challenges, which are chiefly the result of societal stigmatization rather than the physical appearance of the disability.⁷⁶ Mobility India, a Bangalore-based NGO, believes that a greater understanding of women with disabilities can lead to a decrease of stigmatization at the community and family level as well as put pressure on governments to produce legislation. Mobility India conducted a sample survey of women with disabilities in Bangalore and its findings report that the majority of the women with disabilities live in poor and isolated conditions; the visibility of women with disabilities in the community is strikingly less than of their male counterparts; they are mostly deprived of their basic rights such as education, health care, skill training, employment, family life and other social services; very few women with disabilities partake in rehabilitation or use aids and appliances for their personal mobility; and only 1 percent of women take advantage of skills training workshops provided by government agencies and/or NGOs. In response to these findings, Mobility India created the “Rehabilitation Aids Workshop by Women with Disabilities.” The program aims to “train women with disabilities in the manufacture and repair of rehabilitation aids and appliances so that more women technicians would be available to address the needs of women with disabilities and promote equality for women with disabilities, to become economically independent, self-reliant and integrated into the mainstream.”⁷⁷

Although the program initially had some difficulties, it is seen as a success story and a model to follow in areas with similar issues faced by women with disabilities. According to the United Nations Economic and Social Commission for Asia and the Pacific, “through the training, the lives of the women trainees were expanded and enhanced. It gave the women their self-respect and confidence back, and demonstrated that they could be active members and contributors to their community and its development. Their newfound economic independence also brought social respect and acceptance. They earned this respect and acceptance in two important ways – through economic contributions to their families, and through their contributions to their community by providing much needed services and support for the rehabilitation of the physically impaired.”⁷⁸ This project demonstrates that a lack of knowledge about women with disabilities leads to harmful assumptions and in turn increases stigma. If a community can be better educated about women with disabilities, awareness can be heightened and stigma decreased.⁷⁹

MARGINALIZATION

Women with disabilities are often pushed to the fringes of society. With a strong gender bias present in many countries, there is an even higher chance that a woman living with disability will have all of her rights ignored, as she is seen as a burden, not a contributor. As a result, social support systems (where they exist) are not utilized for or by these women, nor do the same women have a voice in the improvement of these systems.⁸⁰ The UNDP International Poverty Center states:

“The concept of social exclusion (SE) describes the processes of marginalization and deprivation that can arise even in rich countries with comprehensive welfare provisions. It is a reminder of the multiple faces of deprivation. SE is perhaps the most difficult to interpret of the poverty concepts under review. Still, SE is the only approach that focuses intrinsically on the processes and dynamics that allow deprivation to arise and persist.”⁸¹

Common social practices such as marriage, social/community activities, access to education, participation in employment and the political sphere are much harder for women with disabilities compared to men with disabilities to access.

Marriage is an expected cultural tradition in Nepalese society⁸² as women are economically dependent on men.⁸³ Even so, a reported 80 percent of women with disabilities remain unmarried.⁸⁴

In Sweden, men with disabilities are given subsidies for the purchase of a personal adapted car, while women with disabilities receive subsidies only for public transportation.⁸⁵ This creates an obvious disadvantage for the woman in many areas that should be considered; for example, her ability to travel by public transportation (depending on type of disability), as well as a more limited location of possible employment opportunities, services and events that can be reached.

Employment is integral to participation in society and has a great effect on self-sufficiency as well as self-esteem. When denied this opportunity, women remain excluded - from the workplace, from society, from economic freedom - maintaining many women’s already dependent state. In Tunisia, 85 percent of persons with disabilities (15-64) are unemployed and women with disabilities are four times less likely than men with disabilities to secure employment.⁸⁶

In Nepal and India, the caste, class and gender of a person will determine the extent of marginalization faced by that individual; for the population with disabilities, this marginalization is critically intensified and therefore incrementally worse for women with disabilities. Although there is a strong presence of interest groups waging for the rights of women, indigenous groups, and the Dalit, or *untouchable* class,

the plight of persons with disabilities within these already marginalized groups is not a main focal point, and therefore intensifies their marginalization.⁸⁷

If developed nations with sufficient political and economic freedoms are still struggling to form viable consistent improvements for persons with disabilities (especially those in already marginalized groups), it can be assumed that the issue of suffering is increased in intensity in developing nations.

WOMEN WITH DISABILITIES IN INSTITUTIONS

Once a population is marginalized, it becomes easier to ignore any policies that are directly affecting that group, as they have been ensured no voice given their status. Even those in direct contact with persons with disabilities on a regular basis, who may be witness to the unjust policies imposed, may not have the power, inclination, or even education to advocate for change in this arena. This can be especially true in institutional settings.

During the industrial revolution of developed countries, the switch from agrarian or trade households to industrialized factory work in cities did much to weed out those unable to conform to a certain conveyor-belt style of work. Where previously those with a disability were still incorporated into the family business, the transition to factory work in urban areas made this almost impossible for many and created a much more visible population of people who were not seen as “average” or “normal”. This prompted the construction of more places to house groups of person living with disability– hospitals, asylums, and workhouses. In the same period, the ‘medicalization’ of persons living with disabilities by medical society also contributed to creating greater disparity in social, economic, and political status of persons with disabilities.⁸⁸

At this time, many countries have institutions in place to provide a place for those who have been labeled abnormal in any way – which could be any factor deviating from that society’s norm. A problem since the initial establishment of such institutions (usually remotely located, away from the general populace), is that very little has been done to ensure current policies have developed in alignment with the progression made in human rights standards.

In one example, the African Commission on Human and Peoples’ Rights ruled on a case in The Republic of Gambia in 2003, finding the state in violation of numerous articles in the African Charter on Human and Peoples’ Rights and International Standards and Norms. The only legislation in place to address mental health in The Gambia was the Lunatics Detention Act from 1917,⁸⁹ which had not been altered since its last amendment in 1964 and was therefore inadequate to address present health needs or patient rights. The government of The Gambia was urged to: repeal and replace the Lunatics Detention Act with mental health legislation congruent with the African Charter on Human and Peoples’ Rights and International Standards and Norms as soon as possible; allow for the review of all cases of persons currently held under the Detention Act by an expert group who will assess and provide suitable recommendations; and ensure proper care is provided for persons with mental health issues within The Gambia.⁹⁰

Many countries have shown an increase in the number of women with disabilities in prison in recent years.⁹¹ This may be due to the lack of social support services available or in existence elsewhere in the community but inaccessible to women with disabilities.⁹² This leads to the inappropriate redirection and housing of women with disabilities into the prison system⁹³ and subsequent inadequate and inefficient treatments of this population by programs aimed at incarcerated men.⁹⁴

Women and girls with disabilities who are dependent on others for care have a high risk of suffering abuse (mental, physical and sexual) at the hands of their caregivers – the family or an institutional setting.⁹⁵ Although it is difficult to estimate an accurate number as most cases go unreported, accounts from numerous studies suggest “...that more than 70 percent of women with a wide variety of disabilities have been victims of violent sexual encounters...”⁹⁶

For cases that have been documented, it was found that within institutions and psychiatric wards of prisons in North America, South America, Central and Eastern Europe, there have been extreme human rights violations, including abuse and violence, experienced by women with disabilities at the hands of the staff.⁹⁷ Documented cases include: complete isolation from outside world, sexual violence and abuse including rape, severe forms of restraint and seclusion (with no set time periods) including the use of unnecessary psychiatric medication, use of caged beds, medical experimentation that includes Electro Convulsion Therapy (ECT) (in modified and unmodified forms), as well as the use of greatly disputed medications, psychosurgery or other unalterable interventions (abortion, sterilization and lobotomy).⁹⁸ For women with disabilities and the experience of gender-based violence, including sexual violence, see section IV.

A survivor of a psychiatric hospital in the United States shares her “treatment” experience: “I’m a psychiatric survivor, and I don’t use that term loosely. I have been stored in warehouses labeled hospitals. I have endured weekly lectures termed therapy. I have been zapped until my brain burns white. I have been held down, tied down, put down. I have had pills forced down my throat and needles plunged into my flesh. All this to make me ‘normal’, a mold I will never fit.”⁹⁹

To clarify, not all institutions have been created to remove persons with disabilities from the public eye. In Addis Ababa, Ethiopia, a hospital, which began with an obstetrician-gynecologist couple providing service to underserved women in rural populations, eventually turned its focus to specifically serving women suffering from obstetric fistula, a disabling condition explained in section II in more detail. Most women needing these services experience hardships in saving enough money just for transportation to go to the hospital; but once checked in are provided services for free, for as long as needed. This is possible through donor based funding received by the hospital.¹⁰⁰ Despite the necessary services this hospital provides, there are thousands of more women living with obstetrical fistula that are unable to be treated due to lack of space and resources (estimates are at 25,000 – 30,000 in Ethiopia alone).¹⁰¹

Recent years have shown a switch toward community based rehabilitation (CBR) and Independent Living (IL); however this is somewhat limited to developed countries, or those with adequate resources. Developing countries and those with less resources still use up to 90 percent of health resources on hospital-dominated services.¹⁰²

“As long as rehabilitation services are largely provided by institutions and centres, they will remain out of reach of the vast majority of disabled persons, particularly women.”¹⁰³ The persistent approach of providing the majority of rehabilitation services within institutions and centers will continue to keep said services inaccessible to most persons with disabilities, and specifically women.

PERSONAL AUTONOMY

Personal autonomy is referred to as the capacity of every human being to exert autonomous self-directed action and behavior.¹⁰⁴ Article 3 of the CRPD contains the principle of “Respect for inherent dignity, individual autonomy including the freedom to make one’s own choices, and independence of

persons". This right applies to all decisions, including those concerning the sexual and reproductive life of a woman."¹⁰⁵

The reproductive autonomy and rights of women with disabilities are denied when sterilization practices are forced upon them. Forced sterilization is a dehumanizing violence, which denies women some of their basic rights, such as the integrity of the body and the right to bear children. These rights can be found in articles 16 of the Universal Declaration: "Men and women of full age, without any limitation due to race, nationality or religion, have the right to marry and to found a family"¹⁰⁶ and article 16 of CEDAW: "Women and men should enjoy the same rights to decide freely and responsibly on the number and spacing of their children and to have access to the information, education and means to enable them to exercise these rights"¹⁰⁷ In addition, article 17 of the CRPD states that: "every person with disabilities has a right to respect for his or her physical and mental integrity on an equal basis with others",¹⁰⁸ and article 3 of the CRPD says that one of the principles of the convention is the "respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons".¹⁰⁹

In the 21st century, sterilization is still promoted across countries, governments, medical and legal experts and even in some cases by families and caregivers. The 'best interest' of the woman with a disability is usually cited as the reason for sterilization. However, many justifications have to do with eugenic fears of women with disabilities producing disabled children and the best interest of the state, community and family.¹¹⁰ Women With Disabilities Australia (WWDA) states that the issue affects the lives of women and girls with all forms of impairments, including physical, sensory, and in particular, mental disabilities.¹¹¹ This is due to a common misconception that women with mental disabilities are not able to bear the responsibility of being a mother.

WWDA has listed reasons most commonly used to justify forced sterilization:

- 1. Genetic/Eugenic** –Based on the idea that women with disabilities will give birth to children with genetic defects. This view continues to exist in spite of evidence showing that the causes of disabilities are overwhelmingly social and environmental (including reasons of war, poverty and environmental degradation) and only a small percentage are due to genetic causes.
- 2. For the good of the state, community or family** – Arguments center around the 'burden' that mothers with disabilities and their potential children with disabilities will place on the resources and services for the state, as well as the 'burden' necessary for the informal care of these children. Other arguments relate to the added burden of care that menstrual and contraceptive management places on already overstretched families and caregivers. Evidence, however, suggests that for women with disabilities, menstrual and contraceptive concerns can be met with the same approaches used with non-disabled women.¹¹² The failure of governments to adequately develop satisfactory resources and support structures and services for women with disabilities and their families must not be accepted as a legitimate reason for forced sterilization. Under Article 4 of the CRPD (general obligations), states are obliged to take the necessary measures to improve the living situation of women with disabilities. In addition, evidence suggests that when parents of children living with disabilities are given the appropriate support and resources, the issue of sterilization loses importance.¹¹³

3. **Incapacity for parenthood** –A common belief that women with disabilities cannot be effective parents creates attitudes of discrimination against mothers with disabilities and socially accepted practices of preventing pregnancies. These judgments are based on subjective ideas about what constitutes ‘good’ and ‘bad’ parenting. There is ample evidence to assert that women with disabilities are as capable for parenthood in the same extent as non-disabled mothers.¹¹⁴

Despite the apparent contemporary acceptance of a human rights approach to disabilities, issues such as those aforementioned continue to hold legitimacy for legislators, medical, legal and other disability professionals to justify the continuance of sterilization procedures.

DISCRIMINATION AGAINST CAREGIVERS

Families, especially female family members, constitute the primary source of care of women with disabilities. The help families provide to persons with disabilities greatly affects their own lives on all levels. Informal caregivers often go unnoticed except by those who depend on their care. Informal caregivers are understood to be and defined as those individuals who provide extraordinary, uncompensated care predominantly at home; this role is carried out primarily by family members and involves sacrificing significant amounts of time and energy over long periods, providing physical, emotional, social and financial support to help a person or persons with a disability.¹¹⁵

There are enormous psychological, physiological and financial costs associated with informal caregiving. Research has shown an increase in stress and depression,¹¹⁶ a worsened social and family life,¹¹⁷ increase in mortality and risks of physical illness,¹¹⁸ and a decrease in quality of life¹¹⁹ of informal caregivers. In addition, they are usually less likely to be employed and more likely to miss days of work and to retire or quit early.¹²⁰ Because of the high percentage of women engaged in providing care to persons with disabilities, the issues mentioned above affect the female population disproportionately. According to a study on the impact of ‘parent care’ on the supply of female labor, about three-quarters of all informal caregivers in the United States are females.¹²¹

In a study performed on the quality of life of family caregivers of stroke survivors, different variables were identified to determine the quality of life of the caregivers. These variables fall under three areas and include the status of the patient, such as the patient’s functional status: physical, emotional, behavioral, cognitive and communication disabilities; the characteristics of the caregiver (including age, gender and personal attributes such as experience and mastery of her/his role) and variables that are part of the overall environment (including the relationship with the patient, support from family and friends, support from the health-care system and financial resources). It is believed that all of these factors together influence the degree of quality of life of caregivers.¹²² In regards to the first factor of the status of the patient, studies provide evidence of the existing relationship between the functional situation of the person with disability and the caregiver. Behavioral and mood disturbances of an individual with disabilities are consistently negatively associated with the caregiver’s quality of life, while the association between physical disabilities and the quality of life of the caregiver is less evident.¹²³ Regarding the characteristic of the caregiver, results also showed that there was a decrease of enjoyment of life related to increased domestic responsibilities and interference with leisure and social life.¹²⁴

Efforts to help those providing care to persons living with disabilities are very difficult to evaluate because many factors regarding the situation of caregivers are not easily isolated, therefore it is difficult to generalize the specific results of interventions. For example, in households where a family member is

living with a disability, caregivers often find themselves socially isolated, faced with the experience of stigma and a lack of a support system. Also, in a number of societies, if a child is born with a disability, it is assumed that the mother has been unfaithful or has otherwise sinned. In addition, the stress associated with being a caregiver of a woman with disabilities can sometimes lead to divorce with the caregiver's spouse, which in many countries continues the cycle of poverty.¹²⁵

IV. Gender Based Violence, Including Sexual Violence

*"The degree of risk of sexual abuse of persons with disabilities appears to be at least 150 percent of that for individuals of the same sex and similar age without disabilities."*¹²⁶

Persons with disabilities are up to three times more likely to be victims of violence, including sexual violence, and have less access to physical, psychological and judicial interventions.¹²⁷ Poverty and a lack of awareness on acts of violence and appropriate responses are risk factors for women with disabilities experiencing forms of violence.¹²⁸ Furthermore, abuse and violence can result in permanent physical disability¹²⁹ and/or psychological trauma.¹³⁰ Violence against women with disabilities is an urgent global problem; however the topic of gender-based violence (GBV) remains ignored in many societies in both developed and developing countries. Persons with disabilities and their families often lack awareness and information about taking precautions against sexual abuse or other forms of violence.

Consequences of acts of violence, including sexual violence, against women may affect their reproductive and sexual health, and include: unwanted pregnancies, unsafe abortion, complications from frequent/high-risk pregnancies, STIs, HIV/AIDS, continuous gynecological problems, and psychological trauma.¹³¹ Rape in conflict settings is extremely common¹³², and acts of violence may be more severe in time of war, natural disaster, and in settings of displacement, as explained further in section V. According to the CRPD, the right to physical integrity is a central tenet of the right to life and liberty of person. The right to physical integrity encompasses two important reproductive freedoms: guarantee of freedom from torture and from cruel, inhuman or degrading treatment or punishment, and the prohibition of medical or scientific experiments without the consent of the person concerned.¹³³

The underreporting of acts of violence is common among non-disabled women; women with disabilities may experience additional compounding factors that further diminish the likelihood that an act of violence will be reported, such as a high level of dependency on caregivers who are often perpetrators of violence, high levels of social isolation and discrimination, and a lack of information and insufficient support services.¹³⁴ Women with disabilities face more barriers to accessing the criminal justice system and GBV support services, compared to women without disabilities.¹³⁵

Women living with disabilities encounter unique obstacles and different vulnerabilities depending on individual conditions such as physical injuries, chronic disease, mental illness, or cognitive impairment. The risk levels and forms of abuse and violence women with disabilities may be exposed to will vary,¹³⁶ as these individuals do not form a homogeneous group.¹³⁷ Violence against women with disabilities may manifest in different ways when compared to non-disabled women, due to the nature of their particular disability. For example, physical violence against women with disabilities may include unjustified administration of drugs, or withdrawal of drugs, neglect to continue basic care required to maintain the health and safety of the individual, mobility restrictions such as the removal of a device for social interaction or communication, or refusal to aid in leaving the home.¹³⁸ Research has shown that compared to non-disabled women, women with disabilities experience violence at higher rates and more frequently, has fewer options to reach safety, are often subjected to violence for longer periods of

time and are vulnerable to a greater number of perpetrators.¹³⁹ Perpetrators of violence often choose their victims based on perceived powerlessness, vulnerability and limitations.¹⁴⁰ Women with disabilities are rendered physically, socially, economically and psychologically vulnerable to perpetrators of violence.¹⁴¹ Furthermore, perpetrators of violence against women with disabilities are often among the people closest to the victim.¹⁴² Mental illness has been identified as a possible consequence of exposure to family violence.¹⁴³ The abuse of women with disabilities by personal assistance providers (PAS) has been identified as a significant problem worldwide. A study conducted in North America reported that in 44 percent of cases of sexual abuse affecting adults and children with developmental disabilities, the abuser had a particular relationship with the victim related to the individual's disability.¹⁴⁴ The majority of women with disabilities are dependant on others for basic care, leaving them more vulnerable to different forms of violence than non-disabled women.¹⁴⁵ However, the issue of violence and abuse by medical professionals in medical settings is difficult to ascertain and suggests the need for the establishment of concrete guidelines and standards for medical practice involving persons with disabilities.¹⁴⁶

Some unique factors that increase the vulnerability of women with disabilities to violence and abuse include: women with disabilities are generally not believed when reporting or disclosing sexual abuse (especially women with cognitive disabilities); social isolation and increased risk of manipulation; lack of support from caregivers; lack of or limited education concerning appropriate vs. inappropriate sexuality; physical helplessness and vulnerability in public areas; lack of safe, affordable and reliable alternatives for services and care; lack of access to information about protections, legislation, and redress; perceptions of powerlessness and internalized oppressive beliefs; high dependency on others for care and survival.¹⁴⁷

Women with disabilities who are victims of violence face barriers to accessing assistance, service, and care. Women with developmental disabilities often cannot independently access reproductive health services, or report cases of GBV without the assistance of a caregiver, family member, or friend.¹⁴⁸ Physical barriers to reaching police and the court system may exist, and authorities may stigmatize women with disabilities who claim to be victims of sexual abuse due to myths of asexuality or sexual undesirability.¹⁴⁹ Programs to assist women who are victims of violence are often designed without taking into account the capabilities of women with disabilities; these facilities are often architecturally inaccessible, lack interpreter services for deaf women and cannot accommodate women who need daily self-care assistance or medications.¹⁵⁰ Women with disabilities aiming to escape violence need accessible and affordable alternative housing arrangements; this is often a barrier to leaving or escaping the violent situation.¹⁵¹ In addition, persons with disabilities have a higher probability of living in low-income and high crimes areas, therefore increasing their exposure to victimization.¹⁵²

One of the leading problems identified for women with disabilities regarding the experience of GBV including sexual violence, is the lack of resources to create various response pathways for victim survivors. Service pathways are complex and dependent on a variety of factors such as the location of the woman, the nature of her disability, the information and knowledge to seek help, an understanding of the situation and accessibility of services.¹⁵³ With all risk factors and barriers in place, the sexual abuse of women with disabilities becomes relatively invisible.

When I went [to the police] again because he hit me, I asked them to lock him up. They didn't lock him again. They said you are disabled, we don't want to discuss disabled matters." -29-year old physically disabled woman, abused by her husband¹⁵⁴

Women with disabilities are often viewed by states as lacking legal capacity.¹⁵⁵ Women with cognitive disabilities may face greater barriers to legal support, as they may require in-depth explanations of legal procedures and processes.¹⁵⁶ Often, legislation alone is not sufficient to bring justice to women with disabilities who are victims of violence and abuse. Women with disabilities seeking justice should not face barriers, such as in the case of a 10-year old girl with a hearing impairment in Kenya, who was sexually abused by a neighbor. The police officer handling the case declared that “such a case cannot be properly supported in court as the girl is deaf and disabled...she cannot be able to give evidence in court.”¹⁵⁷ Although legislation grants certain rights to women with disabilities in Kenya such as the People with Disabilities Act of 2003, a structure in which these rights can be realized is evidently not in place.

In South Africa, the law on sexual abuse and protections for victims of abuse with mental disabilities has been strengthened; however the sexual abuse of persons with disabilities remains underreported. If a case involving an individual with a disability is even carried out to trial, there is a good likelihood that it would be difficult for an individual with a disability to take the stand and independently testify. The intervention program, Cape Mental Health, in the Western Cape provides assistance for persons with intellectual disabilities in legal matters involving cases of sexual assault.¹⁵⁸

Existing human rights provisions entitle women with disabilities to freedom from all forms of abuse and exploitation.¹⁵⁹ Article 16 of CRPD calls for States Parties to: 1. Take all appropriate legislative, administrative, social, educational and all other measures to protect persons with disabilities, both within and outside the home, from all forms of exploitation, violence and abuse; 2. Ensure appropriate forms of assistance and support for persons with disabilities and their families and caregivers, including through the provision of information and education on how to avoid, recognize and report instances of exploitation, violence and abuse; 3. Ensure that protection services are age-, gender-, and disability-specific. States Parties are bound to enact policy and legislation on the issue of exploitation, violence and abuse against persons with disabilities, to ensure investigation and prosecuting when applicable.¹⁶⁰

If society does not value people, and especially women, with disabilities as worthy citizens, then violence will continue to be perpetrated and cases of abuse in which the victim is a person with disability might seem “less worthy of criminal prosecution.”¹⁶¹

Research indicates that violence against children living with disabilities occurs at annual rates of at least 1.7 times greater than children living without disabilities.¹⁶² Children and adolescents with disabilities become targets of sexual violence and abuse because of their lack of knowledge, protection and power at increased rates compared to many adults with disabilities.¹⁶³ Young people, especially girls, with intellectual disabilities thus become easier victims of sexual abuse and exploitation.¹⁶⁴ It has been noted that young girls with intellectual disabilities may interpret sexual interest for affection and love, and may be unclear on the distinction between the terms ‘love’ and ‘sex’, as complex terminology is confusing for some persons with intellectual disabilities.¹⁶⁵

The consequences of sexual violence towards persons with disabilities are strikingly grave; the case of reproductive health and HIV/AIDS among persons with disabilities in Ugandan districts illustrates the magnitude and complexity of these interwoven challenges to SRH. A study was conducted in 2003 by the Disabled Women’s Network and Resource Organization (DWNRO) and Action Aid Uganda on reproductive health and HIV/AIDS among persons with disabilities in Kampala, Katakwi and Rakai districts of Uganda. Eighty-four percent of male study participants had ever been to school, while only 64 percent of female participants had any schooling. More men in the sample were married, 51 percent

compared to 37 percent of the women. Thirty percent of women had not planned their last pregnancy. Both men and women with disabilities claimed to be excluded from local RH sensitization programs. In Kampala district, 42 percent of women with disabilities have never heard of reproductive health services. Almost 60 percent of both males and females felt that reproductive health services are not accessible to persons with disabilities.¹⁶⁶

In the Ugandan district study, women with disabilities identified sexual exploitation by men as one of the most significant problems they face, citing the reason of such exploitation to be men simply using women with disabilities for sex. Adolescents with disabilities disclosed engaging in risky sexual behavior with men to fulfill sexual lives similar to those of their non-disabled peers; adolescents with disabilities assumed they are unable to engage in conventional relationships.¹⁶⁷ In Kampala district, 42 percent of women with disabilities reported to have ever been forced to have sex, compared to 15 percent of males with disabilities (Approximately 83 percent of both men and women study participants with disabilities have engaged in sex).¹⁶⁸

Rape was identified by 37 percent of study participants as the most harmful practice in the community in relation to RH and HIV/AIDS among persons with disabilities. Study results indicated that individuals with vision impairments, hearing impairments, and mental disabilities are extremely vulnerable to forced sex and rape. Blind individuals cannot identify perpetrators of violence, including strangers, and deaf individuals and persons with mental disabilities are unable to communicate and find safety in situations of forced sex. Individuals with physical disabilities felt themselves too weak to engage in self-defense from perpetrators of rape and forced sex. Factors predisposing women with disabilities who participated in the study to HIV/AIDS include rape, non-use of condoms, traditional and cultural practices such as forced marriage, widow inheritance and sharing of wives among brothers, polygamy, and lack of awareness and general information on RH due to exclusion by government and development partners.¹⁶⁹

FORCED STERILIZATION AND FORCED ABORTION

Forced sterilization, as discussed prior in section IV is a form of violence against women¹⁷⁰, and a critical issue concerning women with disabilities. According to the Centre for the Study of Violence and Reconciliation the practices of forced abortion and forced sterilization are often carried out on women with disabilities because they are often considered incapable of experiencing the sensation of physical or emotional pain or pleasure.¹⁷¹ Sterilization is a procedure that is notorious for having been performed on young women with disabilities for various reasons, including menstrual management and personal care, and prevention of pregnancy, including pregnancy as a result of sexual abuse.¹⁷²

Globally, many women with disabilities undergo sterilization with coerced consent or without their consent at all. According to the International Community of Women living with HIV (ICW) this practice can have detrimental health consequences to women. For instance, sterilizing a woman or a girl when she is not fully aware of the consequences of the procedure or in control of her decision may cause severe physical and emotional distress. In many cases, adverse outcomes of forced sterilization do not become evident until later. However, in other cases, there are immediate, potentially life-threatening complications. In the case of forced abortion, some of the risks include: life-threatening hemorrhage, future miscarriages and birth defects or permanent infertility.¹⁷³

Women with disabilities have also reported exposure to forced abortions, because it is assumed that women with disabilities cannot be adequate parents or are incapable of independently making reproductive choices.¹⁷⁴ A study performed by Berkeley Planning Associates shows that women with

disabilities in the United States were undergoing abortions before 1973, when the Supreme Court protected women's rights to have legal and safe abortions.¹⁷⁵ However, forced abortion has been continuously performed without taking women's personal integrity, autonomy and emotional values into consideration.¹⁷⁶

INFANTICIDE

According to the National Commission for Women in India, girls with disabilities are often abandoned, and adolescent girls with disabilities are exploited within their own homes.¹⁷⁷ Discrimination towards females with disabilities can start as early as birth through the practice of infanticide. Infanticide is not uncommon in certain communities if a significant physical 'deformity' is noticeable in a newborn. In some Eritrean ethnic groups the midwife is often the perpetrator of infanticide on the grounds that an infant born with a visible disability is evil. It may be communicated to the public that the birth was stillborn to cover acts of infanticide.¹⁷⁸

Infanticide may be practiced for reasons of preserving a family's social status, avoidance of social or economic burdens and preventing a child from having to live a life of hardship.¹⁷⁹ Anita Ho argues in the review of *The New Disability History*, "Practices such as infanticide are tolerated and even socially approved because of the idea that a life with disability is not worth living and family members of people with disabilities are burdened victims."¹⁸⁰ It may be said that in regions within South Asia where female foeticide and infanticide are highest,¹⁸¹ foetal or infant disability is a compounding factor for intersectional discrimination on basis of gender and disability.

TRAFFICKING

Women and girls with disabilities may be at greater risk of trafficking and forced prostitution.¹⁸² According to UNICEF, in Thailand deaf female children and adolescents have been sought out to be trafficked, as these children would experience difficulties communicating distress, or be incapable of locating their homes if they are unable to communicate to other sex workers, employers, or customers.¹⁸³ In China in 2007 the government rescued a total of approximately 1,340 people from forced labor in brick kilns. Many of those rescued were children that had been kidnapped from railway stations, and about one-third had intellectual disabilities.¹⁸⁴

In *Asian News*, "TRAFFICKED: How Asian countries are fighting human trafficking", disability is highlighted as "attractive" to traffickers. Generally communities do not hold worth to persons with disabilities, however traffickers may view girls and women with disabilities as more valuable in brothels or begging rings.¹⁸⁵ A recent study in Taiwan found that the ratio of child sex workers who had mild developmental disabilities was six times that of the ratio of children in the general population with the same genre of disabilities.¹⁸⁶ Once trafficked into a brothel or begging ring, it is extremely difficult for children with disabilities to escape, as traffickers gain control over vulnerable young girls and boys.¹⁸⁷

In the begging industry, persons with disabilities are in increased demand because of their ability to evoke sympathy. A study in Bangkok showed that over 80 percent of people giving money to beggars claimed beggars with disabilities were influential in their decision to give money.¹⁸⁸ World Vision reports that individuals with disabilities often have diminished value to their families, often inviting shame and stigma by the community. Families may seek out traffickers as a means of gaining relief from the perceived burden of an individual living with disability.¹⁸⁹

V. Emergency Situations

Emergency situations such as armed conflict and natural disasters exacerbate disability. Women with disabilities suffer the consequences of disasters and conflicts with much more intensity than other segments of the population, and at the same time disasters and conflict also increase the number of people living with disabilities.¹⁹⁰ These new disabilities are often not sufficiently taken into account by emergency responses, and due to the lack of a long-term rehabilitation, in most cases temporal disabilities become permanent. In addition, during emergency situations, people with disabilities suffer from the loss of assistive devices, the loss of family members or caregivers, and the scarcity or disruption of medication and healthcare services.¹⁹¹

Article 11 of the CRPD maintains: “States Parties shall take, in accordance with their obligations under international law, including international humanitarian law and international human rights law, all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk, including situations of armed conflict, humanitarian emergencies and the occurrence of natural disasters.”¹⁹²

NATURAL DISASTERS

Natural disasters create an extremely difficult environment for women with disabilities. They suffer from the lack of response by humanitarian actors since emergency preparedness usually fails to recognize their specific needs when programming and implementing relief responses. In addition, the disaster not only compounds the problems of persons with disabilities but also creates an insecure environment resulting in new disabilities. Following the earthquake in Haiti in January 2010, more than 2,000 Haitians underwent amputations and more than 200,000 suffered serious injuries.¹⁹³ Many of these injuries will become permanent disabilities.¹⁹⁴

In the aftermath of a disaster, both those who were disabled before the disaster and those who have become disabled as a result of the disaster face enormous difficulties in terms of access to humanitarian aid. Humanitarian relief provided in times of natural disaster rarely addresses the needs of persons with disabilities although they represent a significant part of the population. In the case of Haiti, eight percent of Haitians were already living with disability before the earthquake.¹⁹⁵ Persons with disabilities tend to be excluded from disaster responses and they face inadequate physical accessibility to the services provided. They also suffer from the lack of specialists and long term rehabilitation programmes, sometimes in a very alarming way, for instance almost four months later after the earthquake in Haiti there were only twelve physiotherapists to help 4,000 to 6,000 people who have lost their limbs.¹⁹⁶ In addition, persons living with disability may suffer more from emotional distress due to their crisis situation.¹⁹⁷

The incurrence of disability upon an individual or population is not limited to the effect of natural causes in time of natural disaster, it is also often a result of human actions. Amidst the chaos in the aftermath of disasters, the disruption of security measures leads to increased vulnerability and the number of attacks suffered by the population rises. Such attacks can bring both temporal and permanent disabilities. Women living with disability before a disaster, or those women who may incur disability at the time of disaster, are more vulnerable to suffer attacks since they often have more difficulties to defend themselves. The attacks, for instance rape, may increase or worsen their previous disabilities.¹⁹⁸

A significant initiative to ensure the inclusion of women and persons with disabilities in humanitarian preparedness and response is the Bonn Declaration, which is the result of the international conference

“Disasters are always inclusive! Persons with disabilities in Humanitarian Emergency Situation”¹⁹⁹ held November 7-8, 2007. Disability-sensitive humanitarian efforts are currently being taken, however more action at all levels is still a pressing concern. An example of such efforts can be found in the Working Group established by the Global Partnership for Disability and Development (GPDD) in Haiti. GPDD is working in alliance with UN agencies, NGOs, Disabled Peoples’ Organizations (DPOs) and other agents to ensure that rehabilitation projects involve people with disabilities in all stages of emergency responses and that the services provided are barrier-free to persons with disabilities.²⁰⁰ However, the lack of information about specific SRH programmes for women with disabilities in Haiti or other emergency scenarios illustrates the neglect of this issue.

ARMED CONFLICT

*For every child killed in warfare, three are injured and permanently disabled.*²⁰¹

In recent years, as conflict around the world has transitioned from a prevalence of inter-state to intra-state civil conflicts, violence against the general population of civilians has become more pervasive, leading to a more widespread occurrence of disabilities resulting from war. While persons with disabilities constitute 10 percent of the population globally, in situations of civil conflict this figure often reaches 20 percent.²⁰² During the civil war in Sierra Leone, which began in 1991, a characteristic tactic of the RUF and other rebel forces was to chop off the hands or legs of civilians as a way of sowing terror amongst the population; it is estimated that at least 10,000 people were victims of such assaults.²⁰³

Attacks against civilians also often have a gender-based violence component, as rape is frequently used as a weapon of war. Not only is rape committed during conflict because the assailant is in a situation where he is unlikely to fear impunity and where he may feel his actions constitute taking the “spoils of war” to which he is entitled, but also as a tool to destroy the integrity of the society. Rape is used as a deliberate method to humiliate communities seen as adversaries. In many societies a woman who has been a victim of rape is considered ruined, is a source of shame for her family, and often is stigmatized and outcast. Therefore, rape committed on a large scale destroys the fabric of society. In the Democratic Republic of Congo the victims of sexual violence committed during the course of the conflict are estimated to number close to one hundred thousand, although establishing exact figures is extremely difficult.²⁰⁴ The brutality of rape and violence may cause serious injuries such as traumatic fistula, and often leads to permanent physical disabilities, as well as psychological disturbance. Women suffering in this manner in areas of armed conflict are perhaps the most disadvantaged, as they are completely unaccustomed to living with disabilities, and must face the associated difficulties and trauma in a dangerous and unstable environment.

As with natural disasters, health care and social support systems are likely to be disrupted during civil conflicts. This disruption deprives the local population, in particular, those who are especially vulnerable, including persons with disabilities, of the basic essential preventive or curative medical care and health programs on which they depend. This is likely to mean that persons with existing disabilities do not receive the treatment they require and their conditions may worsen, while people with wounds and injuries resulting from the conflict or disaster may not receive essential treatment, leading to permanent disabilities. Lack of preventive health care, poor nutrition and disruptions to health programs can lead to persons incurring disabilities during times of crisis that could otherwise have been prevented.

For persons with disabilities, especially for those with disabilities pertaining to mobility, escaping the region suffering from conflict is also problematic, more dangerous and difficult than for non-disabled

individuals. In some cases, families have to make agonizing decisions to leave behind less able family members who may not survive the flight. In Sierra Leone, for example, many children with disabilities were abandoned by their families when they fled the conflict.²⁰⁵ In situations which communities are forced to escape immediately from danger, persons living with physical, mental or sensory disabilities may be less able to flee, especially children and older people. Furthermore, people with disabilities may be more likely to face physical or sexual abuse and violence during the escape because they are the least able to flee or defend themselves.

DISPLACEMENT AND REFUGEE SETTINGS

As mentioned previously, WHO estimates that there are 650 million persons with disabilities worldwide (approximately between 7 and 10 percent of the world's population). Therefore, according to the most recent report by the Women's Commission for Refugee Women and Children²⁰⁶ it can be assumed that from approximately 35 million displaced people in the world, between 2.5 and 3.5 million are living with disabilities. This estimated data of the global population living with disabilities is in fact higher in the cases of displaced people, both refugees and internally displaced persons (IDPs) due to the compounded circumstances of their situation.

Unfortunately, the situation for persons with disabilities seldom significantly improves once they have crossed a border or reached a place of "safety." As Sadako Ogata, the former UN High Commissioner for Refugees explains: "disabled refugees face a double vulnerability—often the last to receive food, water and care...and, in many situations, viewed as a burden to be left behind."²⁰⁷

Refugees with disabilities have traditionally been neglected in terms of official care and assistance. The invisibility and discrimination of women with disabilities has already been noted, and the situation of disabled refugee women represents one of the most aggravated cases. Their existence is marginal among the refugee community, there is almost no data and research concerning their situation and thus, their needs are not taken into account when designing and conducting assistance programmes. Typically, they are not identified or counted during refugee registration and data collection measures. Therefore, those that are even able to physically reach services remain excluded from or unable to access mainstream assistance programs. There are often serious problems with the physical layout and infrastructure of refugee camps—few services such as toilets, shelters, and health facilities are accessible to persons with disabilities. Persons with disabilities are forgotten in the organization of targeted and specialized services. In general, no special accommodations are made for acquiring food and other supplies that refugees with disabilities need on a daily basis. Many refugees living with disabilities are housebound, rarely leaving their shelters. Predictably, they are ignored in the selection of camp leadership and community management structures. The potential of refugees living with disabilities to contribute to and benefit from the services in the camps is typically not recognized. Overall, the presence of persons with disabilities in refugee and IDP camps is largely ignored. Furthermore, current measures to address health issues in refugee and IDP settings rarely address SRH and if so, little information is provided to guide camp staff. Even fewer efforts have been made to provide specific guidance and support for refugee women with disabilities concerning SRH. Displaced women with disabilities face triple invisibility on the basis of their gender, their displacement, and their disability. This situation can trigger feelings of despondency and apathy in women with disabilities in refugee settings, and they are often so demoralized that they fail to ask for their needs, which include sexual and reproductive health.²⁰⁸

It is crucial to stress the vulnerability represented by the case of refugee and displaced women with disabilities. The status of being displaced implies that a woman with disability might have lost her family,

neighbors, caregivers or any person who before the catastrophe provided support for them. Therefore, many of these women find themselves completely alone to face the daily challenges of being displaced. This vulnerability can exacerbate their condition and can also increase their risk of suffering from sexual and physical abuse, which can increase and perpetuate disability. Furthermore, sexual abuse contributes to the spread of HIV/AIDS among women with disabilities in refugee settings and in certain locations the prevalence rate is becoming disproportionate, for an example see country case of Kenya below.

The results from different field studies prove²⁰⁹ that in IDP and refugee camps (cases of Ecuador, Yemen, Jordan, Thailand and Nepal as well as significant field input from Darfur and Kenya) there are neither specialized doctors for refugees and displaced persons with disabilities, nor specific medicines or treatments for them. In addition, a language barrier is also created for the entire IDP community, because in many cases they are relocated to countries in which another language is spoken. Because the entire refugee community would share this impediment, the humanitarian personnel would most likely address it as soon as possible, but the communication challenges of refugees with disabilities are far more complex. For instance, most medical staff cannot understand sign language and this is the only way of communication for some refugees with disabilities. Additionally, informational materials are rarely provided in Braille in permanent settings, much less refugee and IDP camps.²¹⁰

Despite the extended lack of special health services for refugee women with disabilities, the Women's Commission report has underlined a positive finding, that women with disabilities have been able to access the general reproductive health services available in the Kharaz camp of Yemen. Although there was no health program designed specifically for women with disabilities, they were able to benefit from the reproductive health services in the camp.²¹¹ This situation proves that even if there are not resources to create and develop specific SRH programs for women with disabilities, most can easily benefit by those designed to reach the general community.

Kenya, one of the African countries most affected by HIV/AIDS, where the virus kills 400 people daily, has a population of more than 319,400 refugees and asylum seekers.²¹² Since 1992, the Kakuma refugee camp in the Northwest region of the country has provided assistance to refugees mainly from Somalia, Ethiopia, and Sudan. Several initiatives related to SRH, including women with disabilities, have been conducted in the camp. The past efforts by the International Rescue Committee (IRC) and the Community Based Rehabilitation (CBR) have been mostly replaced recently by the NCCK (National Council of Churches of Kenya).²¹³ The NCCK, an NGO which deals with SRH issues, has also been working on developing income-generating activities since 2005 to empower vulnerable women in the camp and help them to ameliorate their lifestyles, with a focus on commercial sexual workers. Mr. Rafael, the NCCK Project Coordinator explained, "We first do reproductive health advocacy to help have safe motherhood and prevention of HIV, safer sex through condom use and change of livelihood. Secondly, the program protects them from violence, arrest by law enforcement officers, risk of acquiring HIV/AIDS and STIs, and SGBV [sexual and gender based violence]."²¹⁴

Handicap International, an NGO focused on improving the lives of persons with disabilities, has also launched different projects in Kenya concerning the reproductive and sexual health of the refugee population. Handicap International has conducted campaigns in the Garissa District to raise awareness about AIDS prevention and improving the care management of people living with HIV/AIDS. Between 2002 and 2004, disabilities programs were conducted in Nairobi focusing on coordinating stakeholders and on promoting HIV/AIDS work amongst people with disabilities.²¹⁵ This work included carrying out studies on the accessibility of screening, counseling and HIV/AIDS prevention services for refugee

persons with disabilities. In their fight against HIV/AIDS in Nairobi, Handicap International has provided HIV/AIDS information and education sessions for people with hearing difficulties.²¹⁶

VI. Role of Stakeholders

THE INTERNATIONAL COMMUNITY

As the awareness of human rights increases across countries, so does the strength of the international community and its importance to act on matters regarding women with disabilities. The international community can have an effective role in promoting and protecting the rights of women with disabilities.

While the international community recognizes the importance and increasing role of international law in promoting the rights of persons with disabilities, domestic legislation remains one of the most effective means of facilitating social change and improving the status of persons with disabilities. International norms concerning disability are useful for setting common standards for legislation, however standards set by international organizations (IOs) also need to be appropriately reflected in policies and programs that reach persons with disabilities and can result in positive changes in their lives.²¹⁷

To recognize the importance of the needs of persons with disabilities, the United Nations had declared 1981 as the International Year of Persons with Disabilities and the years 1983-1992, as the International Decade of Persons with Disabilities. The initiatives were very effective in raising awareness. In fact it inspired the proclamation of many other declarations across regions of the world, such as the African Decade of Disabled Persons (1999-2009), the Asian and Pacific Decade of Disabled Persons (2003-2012), the Arab Decade of Disabled Persons (2004-2013), and the Council of Europe Disability Action Plan (2006-2015). However, despite these accomplishments, further efforts to increase the cooperation among decades and regions are needed.²¹⁸

The UN General Assembly adopted the World Programme of Action in 1982. The program calls for the promotion of equal opportunities for persons with disabilities, rehabilitation measures intended to compensate for the loss of function or functional limitations and the facilitation of social adjustment (or readjustment) in society. These measures refer to the following: social and psychological counseling, training in self-care (including technical aid devices), specialized educational and vocational services, and guidance and training for placement in employment.²¹⁹

The World Programme of Action represents a long-term plan based on extensive engagement with governments, UN agencies, intergovernmental and non-governmental organizations. The progress in reaching the goals of the Programme could be achieved more quickly and could be more effective if a close cooperation is maintained at every level and with each stakeholder. In addition, the trust fund which was established by the General Assembly during the International Year of Disabled Persons should be used to mobilize resources, increase funds from donor countries and encourage voluntary contributions. In general, there is a need to increase funding to developing countries in order to provide assistance, and to further the activities of the World Programme of Action.²²⁰

Furthermore, the Administrative Committee on Coordination needs to consider the implications of the World Programme of Action for the organizations within the United Nations, strengthening the existing mechanisms for continuing liaison and coordination of policy and activities. To this end, an inter-agency support group for the CRDP was established in 2007 to ensure that the programmes and policies of the United Nations system are inclusive of persons with disabilities and that the principles of the CRPD and its Optional Protocol are recognized and respected accordingly.²²¹ The relationship between international non-governmental organizations and the United Nations should also be strengthened to

increase the cooperative efforts needed to accomplish the objectives of the World Programme of Action. In addition, all national and international organizations should be urged to assist the organizations composed and representing women with disabilities in order to include them approach in subjects related to the World Programme of Action.²²²

In 1987, a review was conducted to establish the achievements accomplished by the program. The Economic and Social Council of the Asia-Pacific (ESCAP) of the UN and the Asia-Pacific Council of Disabled People's International did this in the form of a regional expert seminar. The results identified negative societal attitudes as a major impediment to the World Programme of Action in the Asia-Pacific region.²²³ These results prove that dealing with disability is not only a matter of health, but in many countries, disability might be perceived differently and misconceptions can lead to the non-acceptance and exclusions of persons with disabilities from society. Therefore the international community plays an important role in demystifying what disability represents in many of these countries.

UNICEF and WHO have taken active roles in trying to include persons with disabilities by enabling children with disabilities to go to school and learn livelihood skills, and by removing landmines from fields in order to prevent further disabilities.²²⁴ In addition, the World Bank has established the Global Partnership for Disability and Development (GPDD), a global initiative to strengthen international cooperation and to achieve integration for persons with disabilities in social and economic developmental efforts. The GPDD is an alliance of Disabled People's Organizations (DPOs), government ministries, United Nations agencies, non-governmental organizations and bilateral and multilateral donors.²²⁵ The GPDD's work is focused on four primary activities: capacity building, knowledge sharing, knowledge creation and research and networking.²²⁶

The international community can have an effective role in promoting and protecting the rights of persons with disabilities, giving the proper attention to these matters will certainly bring improvements of the status of women with disabilities around the world.

GOVERNMENTS

Article 6 of the CRPD asserts that States parties recognize that women and girls with disabilities are subject to multiple discrimination, and in this regard shall take measures to ensure the full and equal enjoyment by them of all their human rights and fundamental freedoms, and States parties shall take all appropriate measures to ensure the full development, advancement, and empowerment of women for the purpose of guaranteeing them the exercise and enjoyment of the human rights and fundamental freedoms set out in the present convention.²²⁷

As of 29 of April 2010, the CRPD had received 144 signatories to the Convention, 88 signatories to the Optional Protocol, 85 ratifications of the Convention, and 52 ratifications of the Optional Protocol. Signing the Convention or Optional Protocol only indicates a state's intention to take steps to be bound by the treaty at a later date, while ratification "is a concrete action taken by states which signals the intention to undertake legal rights and obligations contained in the Convention of the Optional Protocol."²²⁸ Considering there are over 192 countries in the world, only 88 ratifications of the Convention and only 52 ratifications of the Optional Protocol (which allows civil society to bring petitions to the Committee claiming a breach of their rights after having exhausted national remedies and gives the Committee authority to investigate violations and is perhaps the most important monitoring tool available to civil society)²²⁹ is not sufficient. Among the many countries that did not ratify the Optional Protocol are India, Australia, The United States, Cambodia, Sri Lanka, and Japan. In regards to the Convention, states in general must:²³⁰

- 1) Adopt legislation and administrative measures to promote the human rights of persons with disabilities
- 2) Adopt legislative and other measures to abolish discrimination
- 3) Protect and promote the rights of persons with disabilities in all policies and programmes
- 4) Stop any practice that breaches the rights of persons with disabilities
- 5) Ensure that the public sector respects the rights of persons with disabilities
- 6) Ensure that the private sector and individuals respect the rights of persons with disabilities
- 7) Undertake research and development of accessible goods, services and technology for persons with disabilities and encourage others to undertake such research
- 8) Provide accessible information about assistive technology to persons with disabilities
- 9) Promote training on the rights of the Convention to professionals and staff who work with persons with disabilities
- 10) Consult with and involve persons with disabilities in developing and implementing legislation and policies and in decision-making processes that concern them

Although there are 85 ratifications to the Convention, requiring the above from states and 52 ratifications of the Optional Protocol, allowing for monitoring of states by civil society, there still exists many challenges to complete the implementation of the Convention worldwide to protect the rights of women with disabilities as promised when they ratified the Convention. Some of the many challenges include how new the Convention is - budget allocations must be ensured and time must be given to implement national policies and protocols, including those in the health sector. The inclusion of women with disabilities in all sectors requires a complete reform, which will hopefully take place over time.

There exists no realistic data about women with disabilities in most countries; therefore it does not appear to authorities to be a problem worth addressing.²³¹ Women with disabilities are largely underreported and are rarely included in policy-making surrounding disability.²³² Governments are expected to collect data about women with disabilities, but the reality is more often than not they fail to do so. Additionally, “comparative studies on disability legislation show that only 45 countries have anti-discrimination and other disability specific laws”, let alone legislation about women with disabilities.²³³ In many existing human rights treaties, the rights of women with disabilities are largely unaddressed, including in CEDAW. According to Caroline Frohmader of WWDA, “CEDAW does not acknowledge or respond to the rights violations suffered by women with disabilities.”²³⁴ Having realized this, the Committee on the Elimination of All Forms of Discrimination Against Women has recommended that States include in their reports the progress of women with disabilities, however, most States’ reports fail to do so.²³⁵

Despite the United States’ vast non-discrimination laws, the country’s reason for not needing to sign the Convention,²³⁶ a 2003, Rutgers Study “found that people with physical and mental disabilities continue to be vastly underrepresented in the United States workplace. One-third of the employers surveyed said that persons with disabilities cannot effectively perform the required job tasks. The second most common reason given for not hiring persons was the fear of costly special facilities.”²³⁷ Furthermore, United States disability law does not specifically address women with disabilities. In fact, The National Council on Disability administered a comparative study in regards to the disability laws in the United States and the United Nations Convention on the Rights of Persons with Disabilities. The study found that “there is no legal impediment to U.S. signature and ratification on the basis that, in large measure, the legal standards articulated in the CRPD align with U.S. disability law.”²³⁸

Positive action concerning women with disabilities from a limited number of governments has taken place, however. Currently, the report of the Secretary-General regarding the Fifth quinquennial review and appraisal of the World Programme of Action concerning Disabled Persons, states that Australia, Austria, China, Costa Rica, Mexico, Morocco, New Zealand, Portugal, Senegal, Thailand, and Tunisia are among some of the countries that have collected data on national prevalence rates of persons with disabilities. Further, the Philippines, Slovenia, and Qatar plan to collect more data. It is the hope that these countries will specifically collect data on women with disabilities and that more countries will follow.²³⁹ One of Austria's development priorities is to support women with disabilities. For women with disabilities who are victims of violence, Portugal has instituted accessibility provisions in regulations on shelter homes. Switzerland has included the gender perspective as its guiding principle in their Landmine Action Strategy. Thailand has promoted women with disabilities participating in education, employment, and other social doings. In their policymaking and programs, Qatar and the former Yugoslav Republic of Macedonia have stressed the needs of women and girls with disabilities. Lastly, in the Philippines, the National Commission on the Role of Filipino Women has established the women with disabilities network.²⁴⁰

CIVIL SOCIETY

Civil society organizations of women with disabilities have been increasingly more prominent in recent years. This has come about because of the invisibility and marginalization of women with disabilities discussed above and because they are rarely included in policymaking surrounding disability.²⁴¹ The promotion of the rights of women with disabilities in policy and lawmaking is largely a result of the work of civil society organizations. It is important that disability be mainstreamed in policies and that women with disabilities are involved in every step of the process. As many documents and organizations say, "nothing about us without us." Many countries, including Canada, the Czech Republic, Fiji, and Norway have stressed the need for governments and international organizations to collaborate with civil society.²⁴²

A number of civil society organizations involving women with disabilities exist today. For example, Women with Disabilities Australia (WWDA) began in 1995 and is run by women with disabilities for women with disabilities and is the only one of its kind in the country. WWDA's policies and programs targets issues of violence against women with disabilities, sterilization and reproductive health of women and girls with disabilities, leadership and mentoring, information and communication technology, housing, health and well-being, ageing, education and employment, income support, and human rights. Additionally, they advocate for and partake in research about women with disabilities. They have received a number of awards for their work including the 2001 National Winner of the Australian Human Rights Award.²⁴³

Disabled Women's Network Ontario (DaWN) is a Canadian based NGO whose mission is to "generate knowledge, information, and skills to advance the inclusion, citizenship, and equality rights of women and girls with disabilities." DaWN facilitates debates and helps to building the organizational and individual capacities of those involved with women with disabilities. It is an all female, completely volunteer grassroots level organization but collaborates with many national and international organizations.²⁴⁴

In Sri Lanka, despite much legislation on persons with disabilities, many persons with disabilities are unaware of their rights. An organization of women with disabilities across Sri Lanka called AKASA, aims to raise awareness about the rights of women with disabilities and believes in empowering people with disabilities through education and economic development. What began as a grassroots organization,

founded by one woman without funding, is now a large group of rural women aged 18-40 with financial support from the Swedish Handicapped International Aid Foundation (SHIA).²⁴⁵ The group has been pivotal in enacting change in Sri Lanka concerning women with disabilities and it is the groups' belief that the reason for success is attributable to people with disabilities advocating for themselves.²⁴⁶

Another civil society organization worth highlighting is Mobility International. Mobility International's mission statement is, "Empowering people with disabilities around the world to achieve their human rights through international exchange and international development."²⁴⁷ The organization conducts international exchange programs, which emphasize leadership training and education about disability rights. Mobility International recognizes that few women with disabilities are in leadership positions, and so want to provide women with disabilities the skills needed to start their own organization, especially because many NGOs do not have accurate information about the issues. The impact of Mobility International's work has been life changing to many women with disabilities. Alumni of the program include a government Minister and an elected representative to National Parliament, founders, directors, and officers of national and international organizations, and Fulbright scholars and Fellowship recipients.²⁴⁸

Lastly, Handicap International supports 240 programs in about 60 countries involving persons with disabilities. A co-recipient of the Nobel Peace Prize, Handicap International provides persons with disabilities the skills in order to achieve self-development. Their work includes fitting artificial limbs, providing psychological support, mine-clearance work and especially prevention, and advocacy. Additionally, the organization executes critical work during emergency situations as many persons with disabilities are routinely forgotten. In all of Handicap International's programs, they work to address the vulnerable populations, including women with disabilities.²⁴⁹

MEDIA

The negative impact of the media on women with disabilities is twofold – one, there exists an inaccessibility of information, and two, the media plays an important role in shaping the public opinion in matters concerning women with disabilities and their sexual and reproductive rights.

In a study conducted by Lex Frieden on the dangers associated with inaccessibility to the media, persons with disabilities were more likely to be victims of danger and death because they were unaware of the preventive measures needed during natural disasters.²⁵⁰ The absence of general representation of women with disabilities in the media has an impact on the marginalization of women with disabilities from society.

Additionally, accessibility of media by women with disabilities is an important factor. If, for example, there is no one using sign language in the news, or if no one describes the images presented, people with hearing or visual disabilities will be excluded from accessing the news and therefore, information. State signatories to the CRPD have agreed in Article 4 to take measures to "undertake or promote research and development of, and to promote the availability and use of new technologies, including information and communications technologies, mobility aids, devices and assistive technologies, suitable for persons with disabilities, giving priority to technologies at an affordable cost."²⁵¹ Additionally, in Article 9 regarding accessibility, States are committed to adopt measures, which shall include the identification and elimination of obstacles and barriers to accessibility, and these apply to: "Information, communications and other services, including electronic services and emergency service."²⁵²

The Convention mentions in Article 9, regarding the role of stakeholders that states parties are committed to: “provide training for stakeholders on accessibility issues facing persons with disabilities.” Standards regarding these measures exist within the electronic and information world in some countries, but most often, they are not applied.²⁵³

The media can play a crucial role in spreading information and awareness of the situation of women with disabilities. In fact, one of the main obstacles faced by women with disabilities is the issue of invisibility in the eyes of others. Too often, the media addresses issues of disability by only highlighting problems that touch on the physical support they need, representing them as ‘burdens’ in need of extra help from families and societies, and constantly neglecting their rights as equal human beings.

Ann Pointon and Chris Daviesbook, the authors of the book, “Framed: Interrogating Disability in the Media”, talk about the under-representation and misleading portrayal of persons with disabilities in the media, commonly represented as either “Superheroes” or “tragic villains.”²⁵⁴ This consistent representation, they say is “one of the most persistent stereotypes and a major obstacle to disabled peoples’ successful integration into the community.”²⁵⁵

The erroneous depiction of persons with disabilities in the media has far reaching consequences such as:

- Lack of role models for people with disabilities
- Continued reinforcement of negative/ misguided stereotypes of persons with disabilities
- The distance placed between disabled people and the intended audience underpins the gap between disabled and non-disabled people

Furthermore, the SRH of persons with disabilities is particularly absent in the media. Society does not recognize the need for women with disabilities to have access to sexual education.²⁵⁶

Lessons Learned

The results from a review conducted in 1987 showed that the major obstacle to the effective implementation of the UN World Programme to help persons with disabilities was the negative social attitude towards disability existing in various countries. Disability in many countries is perceived differently, and false notions can lead to the marginalization of persons with disabilities and to their inability to access the programmes put in place by the international community.

Challenges and barriers faced by women with disabilities span farther than accessibility and health services, it is also important to inform and educate the society about what disability is in order to eradicate misconceptions. Therefore, it is important that the international community plays a role in demystifying what disability represents in many countries so that the help associated with the UN World Programme can be more effective.

Disability-awareness integration training in government agencies and civil society organizations that play a role in issues concerning women with disabilities would have considerable impact on respective policies and programmes; as people within institutions and organizations are behind these decisions. To date, low priority has been given to the reproductive health and rights of women and girls with disabilities.

For this reason, networking and collaboration on initiatives concerning women with disabilities must be consistent across sectors from NGOs at the ground level, to government agencies, on a vertical and horizontal scale (top-down, bottom-up, and across sectors). Inconsistent and uncooperative efforts and

lack of partnership on part of any sector or sectors depletes the result of efforts and curtails the capacity of organizations and institutions.

Women with disabilities are essential in decision-making processes for the creation of policies and programmes, implementation, and monitoring and evaluation. Their involvement is necessary and important at all levels, as they and their families are directly affected.

International standards on the issue of violence against persons with disabilities, specifically women, must be utilized by national governments to inform legislation. Ownership and accountability must be enforced to ensure national and local governments are engaging in appropriate legislative provisions to promote and protect the rights of women and girls with disabilities.

Although there are groups within marginalized populations fighting for rights, the plight of persons with disabilities does not factor in, and therefore their situation continues to be ignored and worsen. Women with disabilities living in poor rural areas are also at a higher risk of not receiving appropriate care, even when there are existing services located in cities in the same country.

This marginalization exists in every country; even developed nations with the economic and social means have not successfully eradicated antiquated procedures, methods, or perceptions of persons with disabilities, so it is not merely an issue of resources, but the importance placed on the rights and wellbeing of this previously ignored population.

An increase in the number of women with disabilities in prisons in many countries is evidence of the lack of other appropriate social support systems available. Criminalizing and imprisoning those with disabilities not only perpetuates the constant negative perception of this population, but is also an outright refusal to address their right to dignity, decency, and inclusion in society. The fact that many institutions still have outdated policies in direct violation of at least three UN Conventions suggests that not enough progress has been made in this area.

Moving to community based rehabilitation and independent living models offers opportunities and services based on inclusion within the community and independent decision making, allowing for the participation of women with disabilities in the betterment of their own lives and in turn, society.

The contributions of informal caregivers are irreplaceable. Individuals or society could not afford to pay the costs of replacing all informal caregivers with paid personnel, particularly in those countries where financial means are very limited. The work of caregiving cannot be underestimated. Providing informal care, particularly to individuals who require a lot of assistance on a daily basis, involves dedication, perseverance, patience and a substantial amount of time. In order to support the well-being of caregivers, the latter should not be expected or required to work to the point that their own psychological and physical health is placed in jeopardy.

The positive outcome of past experiences in emergency situations reveals that in most cases, the needs of women with disabilities can be covered when they have access to mainstream health services. Although sometimes more specialized care may be required, enormous progress is made when women with disabilities are recognized as part of the community and are given access to the same resources as other victims in the situation.

The media plays a pivotal role in abandoning the negative representations of persons with disabilities. In addition to bringing awareness of the reality concerning this invisible group within society, the media can be very influential in positively affecting social policies and societal attitudes towards persons with disabilities.

Recommendations

Women with disabilities represent a significant part of the global population, and are present in almost every community. If the Millennium Development Goals are to be achieved, the sexual and reproductive health of this population can no longer be ignored. Based upon the limited research on the SRH of women with disabilities and resulting lessons transpired from available data, information and case studies, the following recommendations for each area of analysis are being put forward:

Invisibility:

- Ensure that women with disabilities, both physical and mental, are recognized as a group with the right to, and in need of, sexual and reproductive health services.
- Educate policymakers and train healthcare workers to create programs and policies to address the SRH needs of women with disabilities.
- Include the perspectives and opinions of women with disabilities in the decision-making process of programs and policies addressing sexual and reproductive health. Women with disabilities should also be employed as project facilitators and survey investigators in projects with disability components.
- Ensure to the fullest extent possible that children with disabilities are included in, and able to, access traditional schools. Children with disabilities must be educated in order to have optimal opportunities for political and economic participation. Furthermore, integration of children with disabilities and children without disabilities from a young age promotes awareness and understanding, and therefore social inclusion.
- Address the discrimination that persons with disabilities suffer in the labor market. Provide vocational training programs that fit the needs of persons with disabilities.
- Increase the amount of research on the barriers to accessing sexual and reproductive health services for women with disabilities.

Challenges to Achieving Sexual and Reproductive Health:

- Decrease physical barriers to SRH services by addressing transportation needs and infrastructure of health facilities.
- Appropriate information campaign strategies should be implemented respective of disability-specific challenges women may face, such as the inability to read signs, or hear broadcasts on the radio. For example, specific outreach efforts must be tailored to women who are deaf, and those that have intellectual impairments that require particular attention. SRH outreach efforts targeting women with disabilities should utilize *accessible* media. Tools to transfer information must be available in alternative formats developed to cater to specific disabilities in a clear, easily comprehensible manner. (i.e. illustrated direction boards, large-lettered signs)
- Training and awareness-raising programs for organizations to understand the unique needs of women with disabilities, and provide effective services and care programs. Accordingly, guidelines and protocols of organizations require development in order to manage cases involving women with disabilities.
- Address the quality of service provided to women with disabilities through the education of health workers. This should address not only misinformation and reduce stigma and stereotypes

of women with disabilities as asexual, but also biology and symptomology of diseases that can present differently in some women with disabilities.

- Women with disabilities should be involved in assessing service level and quality of care provided. Women with disabilities should be included in the process of designing SRH programs and services, and also be given active roles in carrying out various services.
- Programs to foster empowerment among women with disabilities should be developed, for example, peer education programs designed to transfer and share information on SRH of women with disabilities.
- All existing SRH programs must be evaluated and expanded accordingly to reach, and meet the respective needs of persons with disabilities. Outreach and services to women with disabilities should be integrated into regular programming, rather than special programs of limited duration or isolated efforts. Services require flexibility and customizability to meet the unique needs of women with disabilities.

Discrimination:

Women with disabilities in institutions

- Increase spending allotment for social services to create and expand on programs such as community based rehabilitation, including in-home services. If correctly implemented, community based rehabilitation can reach a much larger percentage of persons with disabilities, not just those who live near a city or can afford transportation. Care must be taken to form these services *with* persons with disabilities within the community, not *for* them. Persons with disabilities must have the direct voice in decision-making and implementation during this process, as all resolutions will directly affect type of services and care made available. The focus on independent living and social inclusion, combined with adherence to all human rights, can create safe, affordable, accessible services in a dignified atmosphere.
- Include preventive health measures when developing sexual and reproductive health programs for women to avert potential (avoidable) disabilities. For example, the identification of women within a community who are at a higher risk for complicated pregnancy and the availability/accessibility of hospital services when they give birth can greatly reduce the risk of obstetric fistula, and therefore avoid subsequent disability.

Personal autonomy

- The guardians of women with minor mental disabilities should consider the importance of informed consent and assent when dealing with issues regarding sterilization or abortion. Various studies have shown that the majority of women with mental disabilities are able to function in society, being able to hold jobs and develop and maintain relationships, as well as live independently if they have access to education and to the community,²⁵⁷ and should therefore have the right to be mothers.
- Only in extreme cases of mental disability is substituted judgment appropriate, especially when severe emotional disturbances or cognitive impairment prohibits the woman from giving informed consent. However, these remain controversial issues as there is a continuing debate over what constitutes mental incapacity.²⁵⁸ Any restriction or denial of decision-making authority of a woman with disability should result in objective procedures, with relevant medical tests. Proper legal safeguards should also be ensured to avoid any form of abuse.²⁵⁹

Caregivers

- Community leaders, including policymakers, educators, the clergy, and the media should acknowledge and celebrate informal caregiving as one of the most notable strengths of families and communities.
- Enact policies that support and sustain caregivers of women with disabilities. Most caregivers and communities lack the resources to fully meet the needs of their patient with disabilities. Policies should focus on changing the expectations of caregivers and families, allowing for concessions in different areas such as the workplace.

Gender Based Violence, including Sexual Violence:

- Social services must be made physically accessible to women with disabilities, including shelters, police stations, courts, counseling centers, local health care facilities, and other social services.
- Awareness among women with disabilities must be raised concerning identifying acts of violence, and responding to violence.
- More research is needed on the issue of disability and vulnerability, especially in developing countries. This research will prove vital in gaining an understanding of the issue of violence onto women with disabilities, and further inform policy and programs.
- Public information campaigns on the issue of GBV should also include disability-specific campaigns on GBV and abuse. Community awareness-raising on women with disabilities and violence, including sexual violence, should be a priority to inform the general population as well as those individuals living with disabilities themselves.

Emergency Situations

- Increase the collection of data on displaced women with disabilities. Further research of refugees and IDPs with disabilities needs to be conducted in order to identify their needs and provide appropriate forms of support.
- The SRH needs of women with disabilities should be taken into account when designing emergency relief programs. These services should not have an individual approach but a social one to aid the integration of women with disabilities into their communities and societies.
- Revise general SRH programs to ensure that those programs for the community also reach women with disabilities. There must be full and equal participation, involvement, and assistance for women with disabilities when implementing SRH services provided by humanitarian relief. Even if the programs have not been designed for women with disabilities, they still can obtain benefits from the programs as long as they have access to them. Sometimes minor adaptations are enough for general SRH programs to fully serve most women with disabilities.
- Promote awareness-raising campaigns to facilitate the integration of women with disabilities in humanitarian management. The participation of women with disabilities when planning and conducting programs will help to ensure equal access.
- Partnerships between humanitarian organizations in the camps and disabled persons' organizations (DPOs) / local disability providers should be made to integrate displaced women with disabilities into local disability services. In addition, women with disabilities should be included in the training of SRH providers to ensure that their SRH needs will be attended. It is relevant as well to train women with disabilities as peer educators so they can assist other women with disabilities in their communities.
- Consult existing guides and tools regarding people with disabilities that focus specifically on emergency situations.²⁶⁰

Role of Stakeholders

Civil Society

- Civil society organizations must conduct their own statistics and help to inform governments themselves.²⁶¹ Self-help organizations (SHOs) and women with disabilities are the best informed to speak about their needs and status. Women with disabilities can contribute to solutions that concern their wellbeing and governments and NGOs should support and help to develop SHOs. Additionally, women with disabilities should participate in all national and international organizations surrounding disabilities.²⁶²
- It is imperative women with disabilities work with government sectors in order to achieve sustainable development and integration into mainstream society. In 2007, the United Nations Department of Economic and Social Affairs, in collaboration with the Office of the High Commission for Human Rights, the Government of Spain and Fundación ONCE, organized an Expert Group Meeting called “Making It Work: Civil Society Participation in the Implementation of the Convention on the Rights of Persons with Disabilities.” The result of the Expert Group Meeting, which consisted of Disabled People Organization (DPO) leaders and allied NGOs, was a list of recommendations for Member States and Civil Society. Some of the highlights of the recommendations to civil society include, encouraging DPOs and allies to work together and coordinate their activities at national, regional, and international levels, advocating for deep involvement of civil society in policy-making, advocating for an increase of human and financial resources for the work and coordination of the UN different agencies among themselves regarding their work on disability, and advocating for close consultation and active involvement of DPOs in design, development, and implementation by UN agencies of policies and programs related to the CRPD and other matters concerning persons with disabilities.²⁶³ The document further makes recommendations to undertake activities such as, establishing thematic working groups to produce training material on the CRPD, developing resources on how to advocate for the implementation of the CRPD, advocating for and contributing to the translation of the CRPD into local languages, and realizing awareness raising and education campaigns around the CRPD.²⁶⁴

Governments

- States should increase their financial and technical assistance and help developing countries in capacity building. This is imperative in order for developing countries to achieve effective implementation of the Convention.

The Media

- The media should take an active role in spreading information and awareness of the situation of women with disabilities. This information transfer must also be accessible to persons with disabilities.
- The CRPD asserts in Article 9 that States parties are committed to: “provide training for stakeholders on accessibility issues facing persons with disabilities.” Signatories should take the responsibility to inform the media of its obligations to uphold Article 9 of the CRPD.

The International Community

- The international community should put pressure on the government of countries who are signatories to the CRPD to properly incorporate its provisions into national law.
- It is important for the international community to monitor the subsequent actions of governments that have signed the CRPD. The United Nations human rights treaties are already associated with the task of monitoring implementation of treaties. In particular, the UN Economic and Social Council (ECOSOC) created a committee of experts who perform their function of monitoring in an independent capacity, meeting periodically throughout the year.

The treaty bodies consider state parties' reports as well as individual complaints to establish the progress of the implementation of various human rights treaties (including the rights of persons with disabilities as set in the CRPD). However, this method can mean slow progress on the ground, and the international community should consider additional monitoring measures to speed up the implementation process.²⁶⁵

- The international community should be active on different fronts: by establishing partnership with local organizations, raising awareness within each organization (UNFPA should strengthen its work and raise awareness of the issue of women with disabilities through the UN system and in cooperation with different departments); It should reach out and serve the disabled population through the existing programmes; it should make improvements in policy, laws and budgets and lastly it should encourage research as stronger evidences will improve the programmes involving SRH of persons with disabilities.

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