Women Enabled International Submission to OHCHR:  
Maternal Mortality of Women and Girls with Disabilities  

February 15, 2018

Women Enabled International (WEI) welcomes the opportunity to provide information to the Office of the High Commissioner for Human Rights (OHCHR) for its forthcoming report on good practices and challenges in the application of a human rights-based approach to the elimination of preventable maternal mortality and morbidity.¹ WEI works at the intersection of women’s rights and disability rights to advance the rights of women and girls with disabilities around the world. Through advocacy and education, WEI increases international attention to—and strengthens international human rights standards on—issues such as violence against women, sexual and reproductive health and rights, access to justice, education, legal capacity, and humanitarian emergencies. Working in collaboration with women with disabilities rights organizations and women’s rights organizations worldwide, WEI fosters cooperation across movements to improve understanding and develop cross-cutting advocacy strategies to realize the rights of all women and girls.
Access to maternal and newborn health services is fundamental for ensuring safe pregnancy and delivery, as well as for preventing maternal and newborn deaths and related long-term health issues. Women and girls with disabilities, however, experience disproportionate barriers to accessing maternal health services due to discrimination and stereotypes that are based on both their gender and disability, including inaccessible facilities, legal barriers, communication barriers, and lack of provider training. This lack of access to maternal health services is itself a violation of the rights of women with disabilities, including the rights to health and to found a family, among many others. It also increases their vulnerability to violations of the right to life in the context of maternal mortality.

OHCHR’s Technical Guidance on the Application of a Human Rights-Based Approach to the Implementation of Policies and Programmes to Reduce Preventable Maternal Mortality and Morbidity (Technical Guidance) notes that the key elements of a national plan on this topic must be assessed for their likely impact on the maternal health of different population groups and income quintiles, considering in particular the impact on excluded populations, such as women with disabilities. However, the Technical Guidance does not provide specific guidance to states about how to ensure the right to be free from maternal mortality for women with disabilities.

This submission will briefly identify challenges for preventing maternal mortality specifically for women with disabilities and provide examples of good practices. It will then provide some recommendations for OHCHR to consider including as part of its report on the elimination of preventable maternal mortality and morbidity.

II. Challenges for implementing a human rights based approach in policies to eliminate preventable maternal mortality and morbidity of women and girls with disabilities

The World Health Organization (WHO) estimates that between 88% and 98% of maternal deaths are preventable. Although maternal mortality has fallen by almost 50% since 1990, developing regions face significant challenges in meeting their commitment under the Sustainable Development Goals (SDGs) to reduce the global maternal mortality ratio to less than 70 per 100,000 live births, by 2030. In this context, women with disabilities are at even higher risk of maternal mortality because they face increased barriers to accessing maternal health services, and there is a higher likelihood that they will lack many of the social determinants of a healthy pregnancy.

States have an obligation to respect, protect, and fulfil the sexual and reproductive health (SRH) and rights of women with disabilities. In order to prevent maternal mortality, states must ensure that SRH information, goods, and services—particularly maternal health services—are available, accessible, acceptable, and of good quality (AAAQs) for women with disabilities. This not only requires that women with disabilities have access to the same types of SRH services as other women, but also that those services meet their particular needs and are provided free from discrimination. To fulfil these obligations, states must undertake the following:

States must ensure that health facilities—and the infrastructure needed to access those facilities—are physically accessible to women with disabilities. Ensuring physical accessibility of health facilities not only requires making buildings physically accessible, but also requires ensuring that there are enough health facilities, particularly in rural areas, so that women with disabilities do not have to travel far to access them and that exam rooms have beds and equipment that are accessible and meet the needs of persons with disabilities. Furthermore, states must ensure accessible and affordable transportation is available to allow women with disabilities to access these health facilities. Finally, because many women with disabilities are segregated into long-term residential care institutions or family and group homes, often in violation of Article 19 of the Convention on the Rights of Persons
with Disabilities (CRPD), states must also ensure that SRH services are available in these contexts on the basis of free and informed consent.\textsuperscript{17}

Additionally, women with disabilities often lack access to information about SRH, which increases their vulnerability to unintended pregnancy and ultimately to maternal mortality.\textsuperscript{18} To ensure the accessibility of this information, states must distribute materials about maternal health in alternative formats; and women with disabilities must have access to free and confidential family planning services, counselling, pre-conception care, and maternal health services.\textsuperscript{19} Both women and girls with disabilities should also have access to comprehensive sexuality education, offered both inside and outside of schools.\textsuperscript{20}

Furthermore, states must ensure that maternal health information, goods and services are scientifically, medically, and culturally appropriate for women with disabilities, and delivered by trained personnel in a respectful and human rights based manner. Women with disabilities often face substandard care, including discrimination and abusive treatment. For example, women with disabilities may be pushed to undergo unnecessary caesarean sections\textsuperscript{21} or face other mistreatment during childbirth related to the perception that they cannot make decisions for themselves, or related to the lack of adequate decision-making support available to them.\textsuperscript{22} This attitudinal barrier may be further compounded for girls with disabilities. For instance, a 2005 academic study found that 40–50\% of gynaecologists felt unprepared to treat adolescents with disabilities.\textsuperscript{23}

Women with disabilities also face abuses in health care settings, based on stereotypes about their sexuality and capabilities, including the assumption that persons with disabilities are asexual or hypersexual, that they cannot make decisions for themselves, and they cannot be good parents, as well as laws and policies such as being deprived of legal capacity.\textsuperscript{24} These stereotypes and abuses make many health care services, including maternal health services, unacceptable to women with disabilities. For instance, a 2015 study on motherhood and maternal health services for women with disabilities in Poland found that several women with disabilities experienced degrading treatment in maternity wards, including frequent and intrusive observation, lack of communication, misunderstandings about their disabilities, and lack of respect for their decisions about how to give birth.\textsuperscript{25} This treatment increased their sense of isolation, vulnerability, and lack of self-determination.\textsuperscript{26} Women with disabilities are further often subject to coercive health care practices and medical procedures, such as forced sterilization, forced abortion, and forced contraception as well as disrespectful and abusive treatment in health care settings.\textsuperscript{27} These harmful and discriminatory practices persist, particularly but not only, in institutional settings.\textsuperscript{28} States must address how the stereotypes and violence that women with disabilities experience in health care settings can diminish women’s trust of health care workers and prevent them from seeking services, including maternal health services, which then increases the risk that pregnancy complications will turn into life-threatening conditions.\textsuperscript{29}

Specific risks in humanitarian settings

Despite the obligation to ensure protection for women with disabilities in situations of risk, including humanitarian emergencies,\textsuperscript{30} they are at higher risk of violence during these situations, which puts them at higher risk of unwanted pregnancy.\textsuperscript{31} This higher risk and the lack of accessible sanitation facilities,\textsuperscript{32} combined with the frequently-resulting inadequate and inaccessible medical infrastructure means they may be more at risk of having pregnancy complications go undiagnosed and untreated, leading to higher risk of maternal mortality. In addition, in these settings, there is often a shortage of medical providers in general,\textsuperscript{33} let alone ones trained on the rights of women with disabilities and how to provide them adequate care, further increasing the risk of maternal mortality.

In situations of risk states must make camps and temporary shelters accessible and provide information in accessible formats. Also, states must proactively identify women with disabilities in
these settings and ensure that they know about available and accessible services, including contraceptive, maternal health and safe abortion services, and that women with disabilities know about the services and how to access them.

III. Good practices based on a human rights approach for designing, implementing, and evaluating policies to prevent maternal mortality for women and girls with disabilities

Many states and non-governmental organizations (NGOs) have undertaken good practices to ensure that SRH information and services, particularly maternal health services, are available, accessible, acceptable, and of good quality for women with disabilities. This section identifies good practices in two specific areas: the strengthening of maternal health systems and training of health providers, and the empowerment and participation of women with disabilities to make the maternal health policy reflect the needs and concerns of women with disabilities.

A. Strengthening maternal health systems, raising awareness and training of health care providers

States must guarantee rights-based access to maternal health information and services for women with disabilities, as a means of preventing maternal mortality and morbidity. As noted above, this requires that services be available, acceptable, accessible, and of good quality. There are several good practice examples from states, NGOs, and other bodies to draw from in this context:

- In Costa Rica, the National Human Rights Institution (NHRI) identified lack of accessibility and non-accessible equipment as barriers in health service facilities. After this monitoring work, accessible gynaecological beds were purchased, and the National Rehabilitation Center provided specially-trained sexual and reproductive health professionals for persons with disabilities.
- The Disabled Women’s Network and Resource Organization in Uganda (DWNRO) identified barriers pregnant women with disabilities faced in accessing healthcare, and through workshops with doctors and midwives provided feedback that made hospitals more accessible. For instance, a deaf women’s group trained midwives in sign language.
- In Uruguay, a guide to sexual and reproductive rights of persons with disabilities is used to raise awareness among women and men with disabilities, medical practitioners, educators, social workers, and others. Involvement from the head of the health services administration was key in making this practice a success, contributing to raise interest in eliminating barriers in health services. The guide is a mandatory part of education for students pursuing careers in medicine, nursing, and gynecology.

To ensure the rights of women with disabilities, other good practices identified by UN agencies, research studies, and treaty monitoring bodies include:

- Guarantee confidentiality and privacy, give direct answers, provide comprehensive information, and practice good listening skills.
- Ensure access to safe abortion, without the consent of a parent, guardian or spouse, and quality post-abortion care.
- Ensure that health providers are competent, able to identify danger signs of pregnancies, and able to provide emergency care specifically needed by women with disabilities.
- Develop antenatal classes in the framework of the gender, disability and intercultural approach, and a birth plan.
- Implement community or peer support groups to foster emotional support during pregnancy for women with disabilities.
- Adapt services, such as exams, procedures and equipment, to accommodate women with disabilities. The manual “Table Manners and Beyond: The Gynecological Exam for Women with Developmental Disabilities and Other Functional Limitations,” offers guidance for providers, including alternative positions and accommodations.
- Offer alternative birthing positions and supports. Hesperian’s “A Health Handbook for Women with Disabilities” offers suggestions for making the birth process easier. Also, it is important to adapt guidelines on skin-to-skin promotion and breastfeeding.
- Ensure that women with disabilities can be accompanied by a person of their choice to provide support during and after labor.
- Strengthen partnerships between traditional birth attendants and formal health providers, which can facilitate access to information, care, and social support in the community. Training should be provided to traditional birth attendants about working with women with disabilities, and any woman with a disability who delivers with a traditional birth attendant should also have access to a health facility in case of complications, in a timely and safe manner.
- Guarantee essential physical resources, audit mechanisms, and functional referral systems. For example, “Quality of Care for Pregnant Women and Newborns—the WHO Vision”, “Promoting Sexual and Reproductive Health for Persons with Disabilities,” by WHO & UNFPA, and “Disability-Inclusive Sexual and Reproductive Health Component: Training of Trainers Manual on Disability- Inclusive HIV and Sexual and Reproductive Health for Health Workers,” are good references for how to train providers about disability-inclusive services in this area.
- Ensure feedback and accountability mechanisms on the quality of maternity health services.
- Improve communication between maternal, newborn service, and mental health practitioners where multidisciplinary teams exist.
- Provide assistance to register the birth of the child and to access any support mechanisms to which new mothers may be entitled and implement parenting programs for persons with disabilities.

B. Empowerment and participation of women and girls with disabilities in accountability of the maternal health system

An important part of ensuring the empowerment and participation of women with disabilities in the context of maternal health is ensuring their access to information, including comprehensive sexuality education, thereby limiting their risk of maternal mortality. Indeed, women with disabilities, particularly those with intellectual and psychosocial disabilities, must be educated as active agents to make informed decisions around pregnancy and motherhood, as well as how to access maternal health services. As such, comprehensive sexuality education should be part of the mandatory school curriculum and reach out-of-school adolescents and others, highlighting the prevention of early pregnancy and where to access services. For example:

- In Uruguay, the Inter-American Institute for Disability and Inclusive Development, the National Public Education Administration, UNFPA and UNICEF developed “It is Part of Life: Support materials on sexuality education and disability to share with family.”
- In Pakistan, the National Forum for Women with Disabilities (NFWWD) provides information and counseling about sexual and reproductive health and family planning services. NFWWD also advocates for SRHR in policy negotiations with the Women Parliament Caucus.
- Social media and digital media are excellent ways of providing comprehensive sexuality education materials. For instance, the Sexuality and Disability Blog, created by Point of View and CREA, promotes easy access, and is offered in an accessible format, for free. Another example is The “Decimelo a mi!” phone application in Uruguay.

Furthermore, states should ensure that women with disabilities are included and participate in the identification of problems in the provision of maternal health care, in design and budget allocation, in evaluation and in implementation of maternal health policy. Community engagement and local advocacy involving women with disabilities is essential to raise awareness about their rights to become mothers, as well as men’s role in facilitating access to maternal and newborn health services. For instance, in the Philippines, the W-DARE project is a great example of research to
increase access to SRH services and information for women with disabilities. It increases awareness among women with disabilities, their families, and carers, as well as health providers, and academic researchers, and provides training to a group of women with disabilities to facilitate peer support groups. 62

In addition, it is important for states to establish and support spaces where women with disabilities can discuss their SRH in a safe, supportive, and educational way. For example, In Vietnam, the Project “Raising awareness about sexual and reproductive health for people with disabilities” provides an experiential exchange program for discussion on SRH for women and men with disabilities, who share their experiences to bring SRHR issues to the table, as well as training on the use of contraceptive methods for both, men and women. 63 Also, in Nepal, YUWA, Nepal’s youth-led organization working to promote youth participation through empowerment and advocacy, works in collaboration with several disability rights organizations to organize focus group discussions with young people with disabilities on SRH. 64

C. Conclusion and Recommendations

Women with disabilities have a right to available, accessible, acceptable, and quality maternal and newborn health services to ensure their rights, including their rights to life and to be free from maternal mortality and morbidity. 65 Existing SRH services, goods, and information must be made accessible to women with disabilities, while services, goods, and information to meet their specific needs must also be established.

As an addition to the OHCHR’s Technical Guidance, we encourage OHCHR to include the following recommendations to states in its report on preventable maternal mortality and morbidity:66

• Repeal laws, policies and practices that restrict access to maternal health facilities, services, goods, and information for women with disabilities. For instance, repeal laws imposing third-party authorization requirements that restrict the autonomy of women with disabilities. Train providers and implement safeguards to ensure that informed consent of women with disabilities is requested before any medical service or procedure.
• Implement a national maternal health strategy and action plan that addresses the specific barriers women with disabilities face, with adequate budget allocation, periodically monitored through a participatory and transparent process, with measurable indicators and concrete results. Implement guidelines on maternal health of women with disabilities specifically for health care providers.
• Collect disaggregated data on maternal health specific to women with disabilities in the health information system, including data in crisis settings. This information should include maternal mortality ratio, disaggregated by disability, 67 proportion of women with disabilities who receive skilled care at birth, and those who receive at least one postpartum care visit.
• Ensure access to legal, safe abortion in a wide variety of circumstances to prevent unsafe abortions, and provide post-abortion care and counselling that is accessible for women with disabilities.
• Guarantee transparent mechanisms for accountability, and significant participation by women with disabilities. National Human Rights Institutions should also promote accountability with regard to maternal health of women with disabilities, including the mechanisms charged with monitoring the CRPD under Article 33.
• Ensure accessible information, education, and counselling on maternal health that are non-discriminatory and non-biased, including as part of comprehensive sexuality education, as well as develop awareness-raising campaigns on this topic.
• Guarantee access to effective remedies and redress, including administrative and judicial remedies, for violations of the right to maternal health, considering that women with disabilities face multiple barriers to access to justice. 68
Thank you for your time and attention to this submission. Should you have any questions or require further information, please feel free to contact WEI at the email addresses provided below.

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3 For purposes of this submission, the term “women” refers to women and girls of all ages, unless otherwise specified.
5 CRPD Committee, General Comment No. 3: Article 6: Women and Girls with Disabilities, ¶ 42-48, U.N. Doc. CRPD/C/GC/3 (Nov. 25, 2016) [hereinafter CRPD Committee, General Comment No. 3].
6 These also include the rights to privacy, liberty and security of the person, and to decide the number and spacing of children; to information and education on sexual and reproductive health; to equality and non-discrimination; to enjoy the benefit of scientific progress; to freedom from torture or cruel, inhuman or degrading treatment or punishment, and to accessibility and reasonable accommodation. Women Enabled International, Sexual and Reproductive Health and Rights of Women and Girls with Disabilities Fact Sheet, at 2 (2018), available at https://www.womenenabled.org/atk/WEI%20SRHR%20Fact%20Sheet%20Jan%20%2018.pdf
8 WHO, Maternal mortality: helping women off the road to death, 40 WHO CHRONICLE, at 175–183 (1986).
16 Id.
17 CRPD Committee, General Comment on Article 19: Living Independently and being included in the Community, ¶ 1, U.N. Doc. CRPD/C/18/1 (2017).


30 CRPD, at art. 11.


34 Id., ¶ 52(e).


38 Id.


41 ICPD Programme of Action, ¶ 7.6, 8.25, 13.14(b).


43 Table Manners and Beyond: The Gynecological Exam for Women with Developmental Disabilities and Other Functional Limitations 25 (Katherine M. Simpson ed. May 2001)


45 Id., at 251.

46 Id.
49 USAID & HI, REPRODUCTIVE HEALTH TRAINING MANUAL, at 38 (2011)
55 CRC Committee, General Comment No. 20 on the implementation of the rights of the child during adolescence, ¶ 61, U.N. Doc. CRC/C/GC/20 (2017)
58 Various Authors, SEXUALITY AND DISABILITY, available at http://blog.sexualityanddisability.org/
59 "DECIMELO A MI!," available at http://decimeloami.com/web/
61 Id., at 15-18.
64 Id., at 24-25.