Women Enabled international

Submission to OHCHR for the follow-up report on good practices and challenges in the application of a human rights-based approach to the elimination of preventable maternal mortality and morbidity

I. Introduction

Women Enabled International (WEI) appreciates the opportunity to contribute to OHCHR's forthcoming "*Follow-up report on good practices and challenges in the application of a human rights-based approach to the elimination of preventable maternal mortality and morbidity.*"

Access to sexual and reproductive health (SRH) information, goods, and services, including maternal health services, is fundamental to preventing maternal death[1]. Women, girls, and gender diverse persons with disabilities, however, experience disproportionate barriers to accessing sexual and reproductive healthcare in general and maternal health services[2], including due to discrimination and stereotypes about their sexuality and ability to parent that are based on both their gender and disability, inaccessible facilities, communication barriers, and lack of provider training.[3] During times of crisis, such as the COVID-19 pandemic, these barriers are deepened, further jeopardizing the realization of their sexual and reproductive health and rights (SRHR) and increasing their vulnerability to violations of the right to life in the context of maternal mortality.

In 2020, WEI alongside the U.N. Population Fund (UNFPA), UN Women, and 7 women-led organizations of persons with disabilities around the world conducted a global human rights study with women, girls, and gender diverse persons with disabilities to better understand how the pandemic impacted their lives. The study included virtual consultations and written survey results from over 300 women and gender diverse persons with disabilities in all the major world regions. Furthermore, partnering with the Pacific Disability Forum, WEI and UNFPA also worked together to conduct needs assessments related to access to services for SRHR and gender-based violence (GBV) in the Pacific, including Fiji, Vanuatu, and Samoa. This submission includes findings of both these initiatives and examples of good practices implemented in some States, as well as recommendations that we hope will help inform the forthcoming report.

This submission presents an overview of how the pandemic is disproportionately and negatively impacted the SRHR of women and gender diverse persons with disabilities[1], including their right to maternal health. Then, it details good practices that have been implemented around the world to ensure SRHR, including maternal health, from a gender and disability-inclusive perspective. Finally, it provides a set of recommendations for OHCHR to consider including as part of its follow-up report.

[1] Many of these barriers noted in the submission are common to all women, while others are particular to women and gender diverse persons with disabilities, based on both gender and disability.

II. Preexisting Barriers to Maternal Healthcare and Broader Sexual and Reproductive Healthcare

Before the COVID-19 pandemic, women with disabilities worldwide were already facing specific barriers to accessing and exercising their SRHR, including maternal healthcare, due to both their gender and disability. These barriers included lack of accessibility and provider training, and stereotypes and discrimination.

Research in Samoa identified that lack of accessible SRH information, education and communication materials at healthcare clinics was preventing people with disabilities from being able to independently access information from healthcare providers and impeding the care received. One deaf woman described how when she was pregnant, she would attend "trainings" with her sister but was unable to understand any of the information being conveyed.[4]

Lack of provider training has also been a long-term barrier for women and gender diverse people with disabilities seeking SRH services, particularly for those in remote areas. For instance, a support person of a participant in a focus group from Vanuatu stated that "a woman with a physical disability was sexually abused and got pregnant. In her area, a remote village in Santo, there is a clinic, but the health worker is not properly trained to provide certain services. The women arrived at the clinic to deliver her baby, but the healthcare worker was not able to provide the service. So, they had to travel by boat and through bumpy roads to get to the hospital. It was a very difficult birth. Only the baby survived."[5]

Before the pandemic, women with disabilities often experienced substandard maternal care, including discrimination and abusive treatment 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 that they cannot be good parents.[6] Participants in consultations conducted in Vanuatu identified that derogatory treatment was particularly prevalent against women with disabilities during labor and delivery, with a deaf woman adding, "when I was in labor, I was crying, but no one wanted to help me in the hospital."[7]

III. Barriers to Maternal Healthcare and Broader Sexual and Reproductive Healthcare Exacerbated or Caused by the COVID-19 Pandemic and Response

The barriers described above were exacerbated by the onset of the pandemic and were compounded by new obstacles arising with it, such as COVID-19-related restrictions and protocols that often failed to incorporate a disability perspective.[8]

These barriers have largely impacted women and gender diverse persons with disabilities, particularly those seeking and receiving maternal healthcare, at times putting them under extreme health risks. For instance:

- A 20-year-old deaf woman from Gau Island in Fiji recounted her attempt to secure police authorization to travel to the hospital to deliver a baby. Despite being in labor with her water broken, her mother spent hours calling the police to secure the necessary pass to go to the hospital. As a result of this delay, she delivered her baby in the car on the way to the hospital—almost 18 hours after her mother

had first contacted the police to try to secure a pass—and fainted during the delivery.[9]

- A woman with a visual impairment in Bangladesh reported that she was not receiving adequate maternal healthcare during her pregnancy, due to the pandemic. She had to change doctors several times because they did not pay enough attention to her.[10]

A. Accessibility Barriers to SRH Exacerbated or Caused by COVID-19 Restrictions

The lockdowns and social distancing measures imposed in many countries during the pandemic resulted in a number of gender and disability-related accessibility barriers to accessing SRH services, including maternal healthcare. Those barriers, coupled with the closing of clinics in local communities and the reallocation of resources towards COVID-19, have had a disproportionate impact on women with disabilities, including those seeking maternal healthcare, who often lack sufficient accessible transportation options to access services or goods in other communities or cannot afford such transportation.[11]

These measures also created barriers towards ensuring accessible information and communications for women with disabilities related to SRHR during the pandemic. These barriers particularly impacted the Deaf community. In some contexts, they were not allowed to bring interpreters and other support people to their appointments. As Sekarani, a deaf person and advocate for deaf women from Malawi stated: "If you don't have a sign language interpreter, the doctors often say that they can't help you because you don't have a sign language interpreter. Also, sometimes when you go with an interpreter, they won't let the person to get in."[12] The lack of accessible transportation mentioned above also impacted support persons, including interpreters, which further limited access to maternal and other SRH services for women and gender diverse persons with disabilities, particularly those from the Deaf community.

Lack of accessible and quality information about COVID-19 restrictions themselves—particularly when translated into sign language—created issues in ensuring access to maternal healthcare and other SRH services. For instance, a 35-year-old deaf woman from Fiji reported that the information available to the Deaf community underscored that you could not leave your home during the COVID-19 pandemic, and despite being pregnant, she was too scared to leave her home even to go to the hospital for maternity care.[13]

The lack of accessible information about COVID-19 and the confusion about shifting social distancing measures and lockdowns created confusion and stress for pregnant women with disabilities. For instance, Ruth, a woman with a partial visual impairment in Malawi who was pregnant at the beginning of the crisis, shared her experience with changes to maternal healthcare, even before the first case of COVID-19 in Malawi:

> "At the time that this issue of COVID-19 was coming out, it was the time that I was heavily pregnant. I already had scheduled appointments with my doctor, however, on getting to the hospital, arrangements at the hospital had changed (…) I think that was something disrupting and even when you meet the doctor, you would not want to stay long, the doctors fear you and you fear the doctor as we don't know who is carrying the virus (…) I received the news of the first cases discovered in Malawi while my baby was at the Nursery special care at the hospital, I had stayed there for two weeks. It was

> tough moment as nurses and everyone was afraid and the hospital was the most feared place of spread of the virus."[14]

These changes to healthcare protocols and services had a negative impact on SRHR for all women and girls, but women with disabilities were particularly impacted. Several consultation participants reported that they feared going to health clinics or hospitals, because they did not want to catch COVID-19 or be suspected of having it, a particular concern for persons with disabilities who have been disproportionately impacted by the virus. As Nidhi, a woman with a visual impairment and advocate for women with disabilities in India stated: "There are very few hospitals that are non-COVID and many women with disabilities because of many co-morbidities, they need safer environments."[15]

Access to family planning services and goods, such as contraceptives, was also affected during the pandemic. For instance, Jembell, a young woman with a physical disability in Panama, shared: "I tried accessing the morning after pill, and four out of five pharmacies asked me for a prescription … and I was wondering why they did that … None of the pharmacies [we] went to were accessible. As a woman with a disability, it is impossible to get a safe emergency contraception method."[16]

B. Stigma, Stereotypes, and Discrimination Exacerbated by the COVID-19 Pandemic

During the pandemic, negative stereotypes about women with disabilities—including about their sexuality and capabilities, that they are asexual or hypersexual, that they cannot make decisions for themselves, and that they cannot be good parents—were compounded by misconceptions around COVID-19 and assumptions that women with disabilities may be infected with COVID-19.[17] These assumptions led to hostile treatment of those seeking SRH services. For instance, a woman with a disability in Asia reported that, when she went to the gynecologist, the hospital staff was scared about her bringing the virus because she uses a wheelchair, which cannot be easily sanitized.[18]

C. Impact of Related Rights Issues on SRHR During the COVID-19 Pandemic

The COVID-19 pandemic also had a significant impact on many of the social determinants of health for women, girls, and gender diverse persons with disabilities. During the COVID-19 pandemic, women with disabilities reported significant issues with meeting their basic needs—like accessing affordable and accessible food, water, housing, and sanitation. These barriers stemmed from COVID-19 restrictions that limited their ability to access needed systems of support.[19] Many women with disabilities also reported barriers to continuing their education and to receiving reasonable accommodations for employment during the pandemic. Some advocates expressed fears that the barriers to education and employment at the intersection of gender and disability during the pandemic would mean a loss of opportunity and a setback in rights for a whole generation of women and girls with disabilities.[20] Several others reported that there was a lack of accessible social protection and assistance programs during the pandemic, and highlighted the inadequacy of such programs for persons with disabilities, a situation that particularly impacted women and girls with disabilities who were less likely to have savings and adequate income before the pandemic.[21]

Furthermore, women and gender diverse persons with disabilities experienced a heightened risk of violence, including GBV, during the COVID-19 pandemic, impacting bodily autonomy for these individuals at the same time that needed SRH services to address the impacts of violence became harder to access. With COVID-19 restrictions confining women with disabilities at home with their families, they lost their usual systems of support. Family and friends were often new to caretaking responsibilities, and tensions rose, leading to physical, sexual, emotional, and psychological violence against them. Consultation participants and survey respondents reported that family sometimes withheld needed assistance or weaponized disability to denigrate or undermine women and girls with disabilities. At the same time, GBV support services became even harder to access due to lockdown measures, and police were re-allocated resources away from investigating GBV and towards enforcing COVID-19 restrictions. Justice mechanisms also moved even more slowly in some contexts, leading to virtual impunity for perpetrators.[22]

IV. Good practices related to SRHR and maternal health for women and gender diverse persons with disabilities in the context of the COVID-19 pandemic

Around the world, good practices to address the maternal health and other SRH needs of women and gender diverse persons with disabilities[23] have been implemented, including:

- In **Malawi**, the *National COVID-19 Preparedness and Response Plan* identified persons with disabilities and pregnant and lactating women as people needing special protection during the COVID-19 period, including related to preventing violence, accessing education, meeting basic needs, and COVID-19 detection and treatment. To ensure disability inclusion, the plan called for the review of screening and other protocols and provided material for quarantine facilities to make sure they were addressing the needs of marginalized populations, including people with disabilities.[24]
- In March 2020, the state of **New York** in the **United States of America,** issued a set of resources on pregnancy and COVID-19 and a subsequent executive order for healthcare providers requiring that pregnant persons be allowed to bring one support person with them to the hospital at the time of labor and birth. This measure was of critical importance to pregnant persons with disabilities, who often require the assistance of professional support persons, such as sign language interpreters, even just to effectively communicate with medical providers during labor, deliver, and the immediate postpartum period. [25]
- In **Tajikistan**, the Ministry of Health and the UNFPA country office and local organizations of persons with disabilities launched a project to provide access to information, free SRH services, sanitation and hygiene products, and psychosocial support for persons with disabilities, including pregnant persons, to ensure their SRHR during the pandemic. The project also included the training of healthcare professionals on the rights of persons with disabilities and how to provide them with quality care, which proves essential to dismantling myths and stereotypes about persons with disabilities and their SRHR, both during the pandemic and in the long-term.
- In **Spain**, CERMI Mujeres Foundation developed an online peer support group to respond to and prevent GBV and discuss SRHR, including issues related to

motherhood and maternal health. In the **United Kingdom**, a similar initiative was adopted by My Life, My Choice (MLMC), a self-advocacy organization led by persons with learning disabilities. MLMC convened a group of women with learning disabilities to talk about issues that were important to them, including their right to access SRHR during the pandemic.

- **Globally**, WEI, UNFPA, and UN Women developed a series of tools on SRHR and gender-based violence during the COVID-19 crisis—including two checklists, a Know-Your-Rights guide, and a compendium of good practices—intended to guide States, UN agencies, service providers, and gender and disability advocates. These resources were based both on human rights standards and the lived experiences of women and gender diverse persons with disabilities during the crisis. Although these resources were developed in response to the COVID-19 crisis, they may be broadly useful for future public health and humanitarian emergencies.[26]

V. Recommendations

Women and gender diverse persons with disabilities have the right to available, accessible, acceptable, and quality maternal health services and SRH more broadly at all times, particularly during times of crisis such as the COVID-19 pandemic. As such, States must incorporate intersectional gender and disability perspectives and human rights in their crises response and take proactive steps to ensure that women and gender diverse persons with disabilities are engaged in policy conversations about SRHR, including maternal health and crisis response and recovery, with a view to protecting their right to life in the context of maternal mortality during crises.

With this in mind, we hope OHCHR will consider including the following recommendations to States and healthcare providers in its upcoming report:

General recommendations

- Collect disaggregated data on maternal health specific to women and gender diverse persons with disabilities, including data in crisis settings. Further collect data specific to the experiences of pregnant persons with disabilities, including how many were able to obtain accessible and respectful SRH and maternal health services.
- Ensure accessible, non-discriminatory and non-biased information and counselling on maternal health. Also ensure that maternal health and SRH facilities are accessible.
- Train healthcare workers to work with women and gender diverse persons with disabilities and provide services that are based on dignity and that respect the autonomy of persons with disabilities.[27]

Specific recommendations for gender and disability-inclusive crisis response

- Implement international guidance on crisis response and guidelines on rights-based and disability-inclusive service provision to ensure an effective response to future crises, referencing, for instance, the *Inter-Agency Standing Committee Guidelines on the Inclusion of Persons with Disabilities in Humanitarian Action.*[28]

- Include women and gender diverse persons with disabilities and their representative organizations in the response and recovery process for COVID-19, as well as in preparation, response, and recovery for future crises.
- Ensure rights related to SRHR, including maternal health, at all times, including before and during crises. Define and promote SRH goods and services—including maternal and newborn care, abortion, contraception, family planning, and menstrual hygiene products—as essential goods and services, including during future crises. Also classify disability support providers, including sign language interpreters, as essential workers.

Thank you for your consideration of this submission. If you have any questions, please contact Amanda McRae, a.mcrae@womenenabled.org and Virginia Ossana, v.ossana@womenenabled.org.

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[1] Ö Tunçalp, et al., *Quality of Care for Pregnant Women and Newborns—The WHO Vision*, 122 BJOG 1045, 1046 (May 2015).

[2] *See* CRPD Committee, *General Comment No. 1: Article 12: Equal recognition before the law*, ¶ 41, U.N. Doc. CRPD/C/GC/1 (2014); *General Comment No. 2: Article 9: Accessibility*, ¶ 40, U.N. Doc. CRPD/C/GC/2 (2014); *General Comment No. 4: Article 24: Right to inclusive education*, ¶ 52, U.N. Doc. CRPD/C/GC/4 (2016); *Concluding Observations: United Arab Emirates*, ¶ 45, U.N. Doc. CRPD/C/ARE/CO/1 (2016); *Colombia*, ¶ 56, U.N. Doc. CRPD/C/COL/CO/1 (2016); *Uganda*, ¶¶ 46 & 50, U.N. Doc. CRPD/C/UGA/CO/1 (2016); *Serbia*, ¶ 51, U.N. Doc. CRPD/C/SRB/CO/1 (2016); *Qatar*, ¶ 45, U.N. Doc. CRPD/C/QAT/CO/1 (2015); *Ukraine*, ¶ 46, U.N. Doc. CRPD/C/UKR/CO/1 (2015); *New Zealand*, ¶ 51, U.N. Doc. CRPD/C/NZL/CO/1 (2014); *Mexico*, ¶ 49, U.N. Doc. CRPD/C/MEX/CO/1 (2014); *Italy*, ¶ 61, U.N. Doc. CRPD/C/ITA/CO/1 (2016); *Slovakia*, ¶ 69, U.N. Doc. CRPD/C/SVK/CO/1 (2016); *Chile*, ¶ 47, U.N. Doc. CRPD/C/CHL/CO/1 (2016); *Paraguay*, ¶ 59, U.N. Doc. CRPD/C/PRY/CO/1 (2013); *El Salvador*, ¶ 51, U.N. Doc. CRPD/C/SLV/CO/1 (2013).

[3] 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, *Gen. Comment 3*].

[4] WOMEN AND YOUNG PEOPLE WITH DISABILITIES: A NEEDS ASSESSMENT OF SEXUAL AND REPRODUCTIVE HEALTH AND RIGHTS, GENDER-BASED VIOLENCE, AND ACCESS TO ESSENTIAL SERVICES, SAMOA at 25 (2021), https://womenenabled.org/reports/needs-assessment-pwd-samoa/ [hereinafter SAMOA NEEDS ASSESSMENT REPORT].

[5] WOMEN AND YOUNG PEOPLE WITH DISABILITIES: A NEEDS ASSESSMENT OF SEXUAL AND REPRODUCTIVE HEALTH AND RIGHTS, GENDER-BASED VIOLENCE, AND ACCESS TO ESSENTIAL SERVICES, VANUATU at 24 (2021), https://womenenabled.org/reports/needs-assessment-pwd-vanuatu/ [hereinafter VANUATU NEEDS ASSESSMENT REPORT].

[6] CRPD Committee, *Gen. Comment 3*, *supra* note 3, ¶¶ 38-39.

[7] VANUATU NEEDS ASSESSMENT REPORT, *supra* note 5 at 22.

[8] Many pre-existing barriers imposed to women with disabilities when exercising their SRHR were deepened during the pandemic. For more information, *see* UNFPA, UN WOMEN & WEI, THE IMPACT OF COVID-19 ON WOMEN AND GIRLS WITH DISABILITIES: A GLOBAL ASSESSMENT AND CASE STUDIES ON SEXUAL AND REPRODUCTIVE HEALTH AND RIGHTS, GENDER-BASED VIOLENCE, AND RELATED RIGHTS (2021), https://womenenabled.org/wp-content/uploads/2021/11/UNPRPD-UNFPA-WEI-The-Impact-of-COVID-19-on-Women-and-Girls-with-Disabilities.pdf [hereinafter UNFPA, UN WOMEN & WEI, COVID-19 IMPACT ASSESSMENT].

[9] WOMEN AND YOUNG PEOPLE WITH DISABILITIES: A NEEDS ASSESSMENT OF SEXUAL AND REPRODUCTIVE HEALTH AND RIGHTS, GENDER-BASED VIOLENCE, AND ACCESS TO ESSENTIAL SERVICES, FIJI at 12 (2021), https://womenenabled.org/reports/needs-assessment-pwd-fiji/ [hereinafter FIJI NEEDS ASSESSMENT REPORT].

[10] UNFPA, UN WOMEN & WEI, COVID-19 IMPACT ASSESSMENT, *supra* note 8 at 12.

[11] A girl with an intellectual disability, Morocco, age 12 (written survey response); Janine, a woman with a visual impairment, the Philippines, age 43 (December 2020); Lyness, a woman with a physical disability and advocate for children with disabilities, Malawi (September 2020) ("Most women with disabilities live below poverty line and can't afford private transportation."); Laxmi, a woman with a disability, Nepal (October 2020) ("[A]fter the lockdown and even sometimes in between the lockdown period, public transportation, like some transportation were allowed, but public transportation and all were closed for so many months. So women with disabilities like everyone they don't have their own private vehicles. So for other health-related needs, they could not have transportation to go for checkups."); Patience, a woman with a physical disability, Nigeria, age 47 (October 2020) ("It [COVID-19] has made access to healthcare very difficult. A woman with disability told me that she has resorted to self-medication even more harmful because there's no way the woman can reach the hospital.").

[12] UNFPA, UN WOMEN & WEI, COVID-19 IMPACT ASSESSMENT, *supra* note 8 at 14.

[13] FIJI NEEDS ASSESSMENT REPORT, *supra* note 9 at 12.

[14] UNFPA, UN WOMEN & WEI, COVID-19 IMPACT ASSESSMENT, *supra* note 8 at 35.
[15] *Id.,* at 12. *See, e.g.*, a virtual consultation participant, Malawi (October 2020) ("Women with disabilities are scared to access these services because if their temperature is found to be high at the hospital, they might be forced to be quarantined and may not be allowed to go home."); Sofía, a woman with a disability, Argentina, age 21 (October 2020) ("There are cases where you can't go to the hospital because you run the risk of getting infected [with COVID-19] and medical practices are closed.").
[16] Jembell, a young woman with a physical disability, Panama, age 29 (October 2020).
[17] *See, e.g.*, Rama, a woman with a physical disability, Nepal (October 2020) ("[D]octors have prejudices about disability and COVID-19. They think all disabilities might bring the corona, so they have a negative attitude toward women with disabilities.").
[18] UNFPA, UN WOMEN, & WEI, COVID-19 IMPACT ASSESSMENT, *supra* note 8 at 15.
[19] *Id*. at 27-28.
[20] *Id.* at 28.
[21] *Id.* at 28-30.
[22] *Id.* at 2-3.
[23] For more good practice examples related to SRHR for women and girls with disabilities, see the UNFPA, UN WOMEN & WEI, COMPENDIUM OF GOOD PRACTICES DURING THE COVID-19 PANDEMIC: ENSURING SEXUAL AND REPRODUCTIVE HEALTH AND RIGHTS FOR WOMEN AND GIRLS WITH DISABILITIES (2021), https://womenenabled.org/wp-content/uploads/2021/11/UNPRPD-UNFPA-WEI-Compendium-of-Good-Practices-during-the-COVID-19-Pandemic.pdf.
[24] The full text of Malawi's "National COVID-19 Preparedness and Response Plan" is available at https://covidlawlab.org/wp-content/uploads/2020/06/Malawi_National-COVID-19-Preparedness-and-Response-Plan_Final_08-04-2020_.pdf
[25] State of New York, *Executive Order No. 2012.12: Continuing Temporary Suspension and Modification of Laws Relating to the Disaster Emergency* (Mar. 28, 2020), https://www.governor.ny.gov/news/no-20212-continuing-temporary-suspension-and-modification-laws-relating-disaster-emergency.
[26] To access these resources, please visit: https://womenenabled.org/wei-responds-to-the-covid-19-pandemic/.
[27] See Women Enabled International, *Factsheet: Sexual and Reproductive Rights of Women and Girls with Disabilities* (2017), https://womenenabled.org/fact-sheets.html.
[28] Inter=Agency Standing Committee, *Guidelines: Inclusion of Persons with Disabilities in Humanitarian Action* (2019), https://interagencystandingcommittee.org/iasc-guidelines-on-inclusion-of-persons-with-disabilities-in-humanitarian-action-2019.