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**Women Enabled International**

**Submission to the Office of the High Commissioner for Human Rights (OHCHR):**

**Maternal Morbidity and the Rights of Women and Girls with Disabilities**

**January 17, 2020**

Women Enabled International (WEI) appreciates the opportunity to contribute to OHCHR’s “Follow-up report on the application of the 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.” WEI advances human rights at the intersection of gender and disability to respond to the lived experiences of women and girls with disabilities; promote inclusion and participation; and achieve transformative equality.

Pregnant persons with disabilities can have particularly negative experiences during pregnancy and childbirth that have an impact on their physical and mental health, resulting in maternal morbidities. These abuses are often the result of poor treatment by health care workers or others, stemming from discrimination, stigma, and stereotypes about the ability of pregnant persons with disabilities, particularly women with disabilities, to make decisions for themselves, to have children, and to parent. The abuses that lead to maternal morbidities are also a result of lack of provider training to treat and accommodate pregnant persons with disabilities.

This submission will address the main areas of concern related to maternal morbidity for pregnant persons with disabilities, particularly women and girls with disabilities, including the causes of those morbidities. In doing so, it will elaborate on why pregnant persons with disabilities may face unique or disproportionate risks of maternal morbidity, though note that this issue as such is not widely studied. Finally, this submission will outline a disability-inclusive approach to discussions on maternal morbidity, including addressing the use of language surrounding maternal morbidity, taking a twin-track approach to programs and service provision for persons with disabilities and those who experience maternal morbidities and those who acquire disabilities as a result of maternal morbidities, and ensuring that persons with disabilities, particularly women and girls with disabilities, are part of discussions surrounding programs and policies on this issue.

1. **Maternal Morbidity and Pregnant Persons with Disabilities**

* 1. *Underlying Causes of Abuse Leading to Maternal Morbidities*

Women with disabilities worldwide face specific barriers to accessing needed health information, goods, and services, including reproductive health care, due to both their gender and disability. Stereotypes and discrimination, accessibility barriers, and lack of provider knowledge and training all play a role in perpetuating mistreatment of women with disabilities in reproductive health care settings.

Discrimination at the intersection of gender and disability, as well as specific stereotypes about women with disabilities such as that they are asexual, cannot make decisions for themselves, cannot become pregnant, or cannot be good parents, may lead health care workers to discount their needs or subject them to abuse, violating their rights.[[1]](#endnote-1) Indeed, while all women may face discrimination in that they may be perceived as primarily mothers and caregivers, women with disabilities are further stigmatized in that they are perceived as not being able to fulfill this otherwise discriminatory gender role. For instance, a 2015 study involving interviews with women with physical and sensory disabilities in Polandfound that Polish society consistently lacked acceptance of women with disabilities as mothers and also questioned the quality of parenthood these women could provide, undermining their confidence.[[2]](#endnote-2) Indeed, although Polish women with disabilities have the legal right to biological and adoptive parenthood, their reproductive rights are considered a taboo subject, as is their sexuality.[[3]](#endnote-3)

Sexual and reproductive health care personnel, like others in society, often hold particular stereotypes about women with disabilities that affect their attitudes towards these women, and thus the care they provide. One place where this discrimination comes into play is in access to assistive reproductive technologies (ARTs). For instance, in the United States of America (U.S.), access to ARTs is at the discretion of the reproductive health providers. Women with disabilities are more likely to be denied access to ARTs because of discrimination and biases about disability that lead providers to believe that the welfare of a future child would be at risk.[[4]](#endnote-4) Many providers may also deny persons with disabilities access to ARTs due to “gestational concerns”—that the person’s disability presents a threat to a future child during gestation—even when there is no evidence to support these concerns.[[5]](#endnote-5)

Furthermore, women with disabilities may face significant physical, financial, communications, or information barriers to accessing quality reproductive health care, including maternal health care. As Committee on the Elimination of Discrimination against Women (CEDAW Committee) noted in its General Recommendation No. 24 on the right to health, “women with disabilities, of all ages, often have difficulty with physical access to health services.”[[6]](#endnote-6) Formal and informal user fees in health facilities, as well as indirect costs for transportation and accommodation, can make accessing quality sexual and reproductive health services prohibitively expensive for women with disabilities.[[7]](#endnote-7) Finally, communications and cultural barriers between providers and persons with disabilities may inhibit access to respectful reproductive health care. For instance, Deaf women in Nigeria reported that communications barriers and lack of knowledge of sign language in sexual and reproductive health settings prevented them from receiving quality information and services.[[8]](#endnote-8)

Lack of provider knowledge and training about the rights and lived experiences of women with disabilities can lead to misunderstandings and miscommunications, which themselves can also lead to mistreatment and violence resulting in maternal morbidities. For instance, some providers may consider women with disabilities a “high risk” group for pregnancy and delivery, when in reality, pregnancy for women with disabilities is not necessarily more “high risk” than it is for other women.[[9]](#endnote-9) Many women with physical disabilities are told that they must give birth via Caesarean section (C-section), even though in practice this is not always necessary, exposing these women to greater risks from this surgery.[[10]](#endnote-10) Women with disabilities may also be denied needed confidentiality and privacy, because providers do not feel comfortable communicating directly with them, and as a result, they may not receive needed information about maternal health or newborn care.[[11]](#endnote-11)

* In **Poland**, the 2015 study cited above found that the Polish health care system was not prepared “to take care of and support pregnant women with disabilities.”[[12]](#endnote-12) Interviewees identified that the health care system was not equipped to offer them specialized services in the context of pregnancy.[[13]](#endnote-13) Women with disabilities interacting with the maternal health system further reported that, because they were considered a “high risk group,” they had trouble finding a doctor or midwife willing to provide them with care.[[14]](#endnote-14)
* Furthermore, in **Kenya**, women with disabilities have often not been granted the privacy they require or that is usually accorded to other women in the context of sexual and reproductive health care, as health care personnel often do not know how to relate to persons with disabilities, especially in the presence of their assistants, and instead communicate with the assistants rather than with the women with disabilities themselves.[[15]](#endnote-15) This limits the extent to which women with disabilities are willing to share private information, due to concerns about confidentiality. This also serves as a deterrent among these women to visiting health centers because they feel that their privacy will be violated.[[16]](#endnote-16)
	1. *Abuses Leading to Maternal Morbidities for Pregnant Persons with Disabilities*

Pregnant persons with disabilities experience a range of abuses during pregnancy, childbirth, and the postpartum period. These abuses—including forced abortion, mistreatment in maternal health and childbirth facilities, and being stripped of newborns shortly after birth—are uniquely or disproportionately experienced by pregnant persons with disabilities because of their gender and disability status. These abuses can result in severe mental or physical health consequences for persons with disabilities, particularly women and girls with disabilities, as described below.

* + - 1. *Forced Abortion of Women with Disabilities*

Forced abortion is sometimes perpetrated against pregnant persons with disabilities, with potentially severe physical or mental health impacts. While State laws and policies frequently fail to prohibit forced reproductive health interventions on women with disabilities, forced abortion in particular is sometimes specifically permitted under law, with no repercussions for perpetrators.

* In **India**, under the Medical Termination of Pregnancy Act, 1971 (as amended in 2002), guardians can consent to abortions for women with psychosocial disabilities.[[17]](#endnote-17) Although the Supreme Court of India in 2009 found that guardians of women with “mild to moderate” intellectual disabilities cannot similarly provide consent to abortion on behalf of their wards, the Court did not strike down the provisions of the Medical Termination of Pregnancy Act, 1971, that allows for forced abortion of women with psychosocial disabilities.[[18]](#endnote-18) Furthermore, the Criminal Law (Amendment) Act 2013 fails to criminalize forced or coerced sterilization or abortion for women with disabilities, meaning that it is unclear whether there are any sanctions or punishments for those who participate in these human rights violations.
* In **Kenya**, the Reproductive Health Bill of 2014[[19]](#endnote-19) still allows guardians or parents to make the decision for a “mentally unstable person”—which includes women with intellectual or psychosocial disabilities—to undergo what amounts to a forced abortion.[[20]](#endnote-20)
* In **South Africa**, the Choice on Termination of Pregnancy Act allows for substitute decision makers to consent to the termination of a woman’s pregnancy if she has been classified as “severely mentally disabled,” without a requirement to even consult with or consider the views of the woman herself, let alone obtain her informed consent.[[21]](#endnote-21)
	+ - 1. *Mistreatment of Women with Disabilities in Prenatal Care and Childbirth Facilities*

Due to provider biases and stereotypes, lack of provider training, and the inaccessibility of information and services, women and girls with disabilities may also be subjected to specific mistreatment and violence in maternal health settings, including childbirth facilities. In some instances, this mistreatment is physical in nature, and even more frequently, it is verbal or psychological.

* In **Nepal,** the Nepal Disabled Women Association documented a case in which a woman with a disability who underwent a C-section to deliver her baby was then put in an inaccessible room in the hospital for several days and was ignored by nursing staff when she asked for assistance for visiting the toilet. In another case, when a woman with a physical disability went to the hospital for a delivery and was not able to push, an attending nurse started beating her abdomen and insulting her about her sexuality. The woman ultimately underwent a C-section.
* Furthermore, in **Poland**, health care providers’ attitudes towards pregnant women with disabilities ranged from indifference, to patronizing treatment, to explicitly expressing negative opinions about their plans to have children or about their disabilities.[[22]](#endnote-22) Several women experienced degrading treatment in maternity wards, including aggressive observation, lack of communication, misunderstandings about their disabilities, and lack of respect for their decisions about how to give birth.[[23]](#endnote-23) This treatment increased their sense of isolation, vulnerability, and lack of self-determination.[[24]](#endnote-24)
* In **Kenya**, pregnant women with disabilities cited that they were often insulted by female nurses when they visited hospitals and presented for treatment.[[25]](#endnote-25) Similarly, in **India**, women with physical disabilities are frequently criticized and taunted for getting pregnant. Providers and communities often highlight their supposed inability to look after themselves to perpetuate mistreatment.[[26]](#endnote-26)
	+ - 1. *Separating Newborns from Women with Disabilities*

The removal of newborns from women with disabilities is not yet comprehensively documented. However, recent studies and cases in North America highlight that this removal does occur, including while women with disabilities are in the hospital shortly after delivery, and particularly impacts new mothers with intellectual disabilities, with significant negative consequences for these women:

* A 2018 study in Ontario, **Canada**, found that women with intellectual disabilities were more than 25 times more likely than other women to have their newborns taken into protective custody shortly after birth. The study found that 5.7% of newborns of women with intellectual disabilities (about 1 in 20) were discharged from the hospital directly into child protective services, as compared to 0.2% of newborns of other women (about 1 in 500).[[27]](#endnote-27) The study found that women with intellectual disabilities who also lived in poverty, had mental health concerns, or who had received poor prenatal care were at even higher risk of being separated from their newborns.[[28]](#endnote-28) The study noted that these separations have negative consequences for both women and babies, because “they disrupt maternal-fetal bonding and breastfeeding” and may also lead to trauma and long-term mental health issues for these women.[[29]](#endnote-29) In a news story outlining the results of this study, a social worker also noted that there is a common misconception that women with intellectual disabilities cannot parent, but that in reality they can do so successfully if they receive “appropriate and effective support.”[[30]](#endnote-30)
* Recently in the **U.S. state of New York,** a young woman with an intellectual disability had her newborn child removed from her custody by the Administration for Children’s Services (ACS) before she was discharged from the hospital. The child was removed on the basis that the woman had neglected the newborn by failing to attend parenting and treatment programs she had previously been assigned. However, ACS had failed to provide the woman with the reasonable accommodations she needed to attend these classes and further failed to accommodate her during the conference to determine the removal of her newborn, despite knowing the mother had an intellectual disability and required documented reasonable accommodations. This case was recently decided by the New York Court of Appeals, which noted that ACS has an obligation to ensure reasonable accommodations under U.S. law in cases like these.[[31]](#endnote-31)

This removal is likely due to pernicious stereotypes specifically about women with intellectual disabilities and their ability to parent. According to a 2012 report by the National Council on Disability in the U.S., parents with intellectual disabilities, who face a child removal rate of 40 to 80 percent in the U.S., encounter negative expectations about their parenting, including “that children will eventually be maltreated and that parenting deficiencies are irremediable.”[[32]](#endnote-32) This leads to removal even when there is not any evidence of neglect or abuse.[[33]](#endnote-33) Parents with intellectual disabilities are also more likely to have frequent contact with service providers or government officials, who are also more likely to report them to the child welfare system and whose allegations may be taken more seriously within that system than reports from others, such as neighbors, teachers, or other family members.[[34]](#endnote-34)

1. **Ensuring a Disability-Inclusive Approach to Maternal Morbidity**

Although the prevention of maternal morbidity should be an important policy priority, policymakers and others should avoid stigmatizing language about disability when speaking about maternal morbidity, particularly when these morbidities result in long-term physical, sensory, intellectual, or psychosocial impairments. For instance, a 2013 study published in the *Bulletin of the World Health Organization* described maternal morbidity as “a potential cause of lifetime disability and poor quality of life,”[[35]](#endnote-35) Language like this or other language implies that having an impairment or being a person with a disability is a tragedy or devastating or that persons with disabilities are a burden on their families and communities. This attitude in turn sends the message that the lives of persons with disabilities have less value, leading to further exclusion and discrimination against this group.

Instead, we hope that policymakers and others who wish to address maternal morbidity will first treat persons with disabilities as rights holders and acknowledge the significant barriers that women with disabilities in particular face, focusing on addressing societally established barriers to full inclusion and rights rather than on “fixing” persons with disabilities. As part of addressing these barriers, States must ensure that supports, services, education, employment, and general participation in the community is accessible to all persons with disabilities, particularly women and girls with disabilities. States must also ensure that women with disabilities themselves are included in the design, implementation, and monitoring of programs to provide maternal health services more broadly and to address maternal morbidities.

When considering services for women with disabilities and others affected by maternal morbidity, States should adopt a twin-track approach, in line with disability rights standards and standards outlined for women more broadly. This includes ensuring that services, including those related to sexual and reproductive health, are all available, accessible, acceptable, and of good quality for those who have experienced maternal morbidities, including women with disabilities. It also requires that States ensure that there are services established to specifically meet the health and other needs of those who have experienced maternal morbidities, including women with disabilities.

For examples:

* Women and girls with disabilities must be able to make decisions for themselves about their sexuality and reproduction, with support to ensure their voluntary and informed consent when needed.
* Information, goods, and services must be accessible to persons with disabilities, sensitive to their needs, and provided on the basis of non-discrimination, with reasonable accommodations as needed.
* Comprehensive sexuality education courses and materials, as well as information on sexual and reproductive health and rights generally, must be available in alternative formats.
* Physical spaces where health care services are provided, medical equipment, and transportation to and from these facilities must be available and accessible to women and girls with disabilities.
* Health care workers must be trained to work with women and girls with disabilities and provide services that are based on dignity and that respect the autonomy of persons with disabilities.[[36]](#endnote-36)

Thank you for consideration of this contribution. Please do not hesitate to reach out to Women Enabled International (Amanda McRae, Director of U.N. Advocacy, a.mcrae@womenenabled.org, or Stephanie Ortoleva, President and Executive Director, president@womenenabled.org) if you have any further questions.

1. CRPD Committee, *General Comment No. 3: Article 6: Women and girls with disabilities*, ¶ 38, U.N. Doc. CRPD/C/GC/3 (2016). [↑](#endnote-ref-1)
2. Agnieszka Wołowicz-Ruszkowska, *How Polish Women With Disabilities Challenge the Meaning of Motherhood*, in 40(1) Psych. of Women Quarterly 80, 86 (2015), http://journals.sagepub.com/doi/pdf/10.1177/0361684315600390 [hereinafter Wołowicz-Ruszkowska, *Motherhood of Polish Women With Disabilities*]. [↑](#endnote-ref-2)
3. *Id.* [↑](#endnote-ref-3)
4. Nat’l Council on Disability, *Rocking the Cradle: Ensuring the Rights of Parents with Disabilities and Their Children* 209-222 (Sept. 27, 2012), https://www.ncd.gov/publications/2012/Sep272012. [↑](#endnote-ref-4)
5. *Id.* [↑](#endnote-ref-5)
6. CEDAW Committee, *General Recommendation No. 24: Article 12 of the Convention (women and health)*, ¶ 25, U.N. Doc. CEDAW/C/GC/24 (1999). [↑](#endnote-ref-6)
7. Women Enabled International & UNFPA, Women and Young Persons with Disabilities:
Guidelines for Providing Rights-Based and Gender-Responsive Services to Address Gender-Based Violence and Sexual and Reproductive Health and Rights 108 (2018), https://womenenabled.org/wei-unfpa-guidelines.html.. [↑](#endnote-ref-7)
8. *See* *Women with Disabilities Submission to the Special Rapporteur on the Rights of Persons with Disabilities on the Right to Health: Annex A (Kenya)* 4 (Mar. 30, 2018), https://womenenabled.org/pdfs/Annex%20A%20-%20Kenya.docx. [↑](#endnote-ref-8)
9. Wołowicz-Ruszkowska, *Motherhood of Polish Women With Disabilities*, *supra* note 2 at 84. [↑](#endnote-ref-9)
10. Jane Maxwell, Julia Watts Belser, & Darlena David, Hesperian Health Guides, *A Health Handbook for Women with Disabilities* 244 (2007), http://hesperian.org/books-andresources/#. [↑](#endnote-ref-10)
11. WEI & UNFPA, Guidelines on GBV and SRHR Services, *supra* note 7, at 108. [↑](#endnote-ref-11)
12. Wołowicz-Ruszkowska, *Motherhood of Polish Women With Disabilities*, *supra* note 2, at 84. [↑](#endnote-ref-12)
13. *Id.* [↑](#endnote-ref-13)
14. *Id.* [↑](#endnote-ref-14)
15. *See* *Women with Disabilities Submission to the Special Rapporteur on the Rights of Persons with Disabilities on the Right to Health: Annex A (Kenya)* 4 (Mar. 30, 2018), https://womenenabled.org/pdfs/Annex%20A%20-%20Kenya.docx. [↑](#endnote-ref-15)
16. *Id.* [↑](#endnote-ref-16)
17. Medical Termination of Pregnancy Act, § 3(4)(a) (1971) (India), http://tcw.nic.in/Acts/MTP-Act-1971.pdf. [↑](#endnote-ref-17)
18. Supreme Court of India, *Suchita Srivastava & Anr vs. Chandigarh Administration* (28 August 2009), https://indiankanoon.org/doc/1500783/. [↑](#endnote-ref-18)
19. The Reproductive Health Care Bill 2014 (Kenya), http://kenyalaw.org/kl/fileadmin/pdfdownloads/bills/2014/ReproductiveHealthCareBill2014\_\_1\_.pdf. [↑](#endnote-ref-19)
20. *Id.* at § 20. [↑](#endnote-ref-20)
21. Choice on Termination of Pregnancy Act, 92 of 1996, § 5(5) (S. Afr.); Ashwanee Budoo, Rajendra P. Gunuth, *Termination of Pregnancy of Persons with Mental Disabilities on Medical Advice: A Case Study of South Africa*, 2 African Disability Rights Yearbook 101, 103-104 (2014). [↑](#endnote-ref-21)
22. Wołowicz-Ruszkowska, *Motherhood of Polish Women With Disabilities*, *supra* note 2, at 85. [↑](#endnote-ref-22)
23. *Id.* [↑](#endnote-ref-23)
24. *Id.* [↑](#endnote-ref-24)
25. *See* *Women with Disabilities Submission to the Special Rapporteur on the Rights of Persons with Disabilities on the Right to Health: Annex A (Kenya)* 3 (Mar. 30, 2018), https://womenenabled.org/pdfs/Annex%20A%20-%20Kenya.docx. [↑](#endnote-ref-25)
26. Women with Disabilities India Network, *Submission of Alternative Report (Article 6) to the Committee on the Rights of Persons with Disabilities: India 2019* *(Annexure 1: Inputs from respondents from consultation with women with disabilities in Kolkata, Patna, Bhubaneswar, and Koppal)* (2018), https://tbinternet.ohchr.org/\_layouts/15/treatybodyexternal/Download.aspx?symbolno=INT%2fCRPD%2fICO%2fInd%2f33879&Lang=en. [↑](#endnote-ref-26)
27. Wency Leung, “Study finds newborns of Ontario women with developmental disabilities are more likely to be taken into protective custody,” The Globe and Mail (Canada) (Nov. 6, 2018),

https://www.theglobeandmail.com/canada/article-study-finds-newborns-of-ontario-women-with-developmental-disabilities/. [↑](#endnote-ref-27)
28. *Id.* [↑](#endnote-ref-28)
29. *Id.* [↑](#endnote-ref-29)
30. *Id.* [↑](#endnote-ref-30)
31. *Lacee L*., 2018 N.Y. 06966 (slip op.) [↑](#endnote-ref-31)
32. Nat’l Council on Disability, *Rocking the Cradle: Ensuring the Rights of Parents with Disabilities and Their Children* 80 (Sept. 27, 2012), https://www.ncd.gov/publications/2012/Sep272012.. [↑](#endnote-ref-32)
33. *Id.* [↑](#endnote-ref-33)
34. *Id.* [↑](#endnote-ref-34)
35. Tabassum Firoz, et al, Measuring maternal health: focus on maternal morbidity, 91 Bulletin of the World Health Organization 794 (2013), <https://www.who.int/bulletin/volumes/91/10/13-117564/en/>. [↑](#endnote-ref-35)
36. See Women Enabled International, *Factsheet: Sexual and Reproductive Rights of Women and Girls with Disabilities* (2017), <https://womenenabled.org/fact-sheets.html>.

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