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Women Enabled International
Submission to the Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health
Report on Medical Education and Health Workforce Strengthening
May 20, 2019

Women Enabled International (WEI) welcomes the opportunity to provide information to the Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical and Mental Health for his forthcoming report on medical education and health workforce strengthening. 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.

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Women and girls[1] with disabilities make up a substantial portion of the world population.[2] Yet, globally, health workers do not receive adequate pre-service education or in-service training on health care provision for women with disabilities, particularly in the context of sexual and reproductive health care.[3] This systemic failure in health workforce education means that health workers are often not trained on the lives and rights of women with disabilities and on how to provide them with adequate care. As a result, disabled women are more likely than others to face violations of their right to health, including sexual and reproductive health (SRH), in the context of the patient-provider relationship.

A. Impact of Inadequate Health Worker Training on the Sexual and Reproductive Rights of Women with Disabilities

The lack of adequate health care provider training significantly impacts the information, goods and services women with disabilities receive in SRH care settings, as well as the degree to which they can exercise their rights. In interactions with providers, disabled women frequently encounter substandard care,[4] a lack of specialized care,[5] significant communication barriers,[6] negative provider attitudes, verbal abuse, degrading treatment,[7] and violations of their rights to confidentiality,[8] informed consent and autonomy[9] in health decision-making.

For example, due in part to providers' misconceptions and discriminatory stereotypes about their sexuality, ability to make decisions for themselves, and ability to be good parents,[10] women with disabilities may not be offered needed SRH information, goods, and services—such as contraception, STI prevention or screening for reproductive cancers[11]—and are frequently subjected to medical interventions without their consent, including forced sterilization, abortion, and contraception.[12] In addition, reproductive health care providers often demonstrate a lack of sensitivity, courtesy, and support for women and girls with disabilities,[13] largely due to the lack of appropriate, evidence-based training for health care providers.[14]

Disabled women may also be denied needed confidentiality and privacy by health care providers because providers do not feel comfortable communicating directly with them and, as a result, these women may also not receive needed health information.[15] Furthermore, because SRH providers do not have a full understanding of the health needs of women with disabilities, some may consider them 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,[16] or may insist that they must give birth via Caesarean section, even though in practice this is not always necessary.[17]

B. *States Have an Obligation to Ensure Health Care Workers are Adequately Trained, Skilled, and Culturally Competent to Provide Sexual and Reproductive Health Care to Women with Disabilities*

States have a human rights obligation to ensure that the health care workforce provides acceptable and good quality services to disabled women, which further requires that health workers are adequately trained to provide those services.[18] The Committee on the Rights of Persons with Disabilities (CRPD Committee) has affirmed that women with disabilities have the right "to have control over and decide freely and responsibly on matters related to their sexuality, including sexual and reproductive health, free of coercion, discrimination and violence"[19] and has found that "[t]he lack of awareness, training and policies to prevent harmful stereotyping of women with disabilities by public officials, . . . [including] health service providers, . . . can often lead to . . . violations of rights."[20]

To this end, the Committee on Economic, Social, and Cultural Rights has found that "reasonable accommodation must be made to enable persons with disabilities to fully access sexual and reproductive health services on an equal basis, such as physically accessible facilities, information in accessible formats and decision-making support, and States should ensure that care is provided in a respectful and dignified manner that does not exacerbate marginalization."[21] The CEDAW Committee has further called on States to "take appropriate measures to ensure that health services are sensitive to the needs of women with disabilities and are respectful of their human rights and dignity"[22] and has also recommended that States provide training to medical professionals to "raise awareness toward their own prejudices" about women with disabilities.[23] The CRPD Committee has also specifically recommended that at least one State "[c]onduct training to ensure that health-care practitioners are aware of the rights of persons with disabilities under the Convention and have the tools to provide appropriate advice for persons with disabilities, including on sexual and reproductive rights."[24]

C. *Good Practices: Health Workforce Training on the Provision of Care to Women with Disabilities*

Studies have repeatedly shown the benefits of integrating disability education into pre-service training for health care providers.[25] More comprehensive training curricula have addressed "discriminatory attitudes and practices, communication skills, physical accessibility, the need for preventative care, and the consequences of poor care coordination" and have been led by people with disabilities.[26] These types of educational interventions—particularly when led by people with disabilities[27]—have been successful in changing provider attitudes and stereotypes concerning people with disabilities.[28]

In-service training on the provision of health care to disabled women can also have a significant impact on service delivery and health outcomes. For example, the Disabled Women's Network and Resource Organization (DWNRO) in Uganda developed a program to target discrimination and barriers pregnant women with disabilities faced in accessing healthcare. Through workshops with doctors and midwives, DWNRO succeeded in making hospital wards more accessible through physical modifications, attitudinal changes, and training midwives in sign language.[29]

D. *Indicators To Assess and Monitor Progress on Rights-Based Approaches To Health Worker Education*

The following indicators may be useful in assessing States' progress towards addressing shortcomings in health workforce training related to the SRH needs and rights of disabled women:

- Sexual and reproductive health services for women and adolescent girls with disabilities are included in the mandatory pre-service training curriculum for healthcare providers.[30]
- Pre-service health worker education includes training to provide appropriate attention, support and assistance to women with disabilities, on applicable human rights standards, and on identifying and combating discriminatory norms and values in relation to disabled women.[31]
- Health care facilities and equipment are physically accessible, services and goods are financially accessible, information is available in accessible formats,[32] and health care providers consistently offer communications and decision-making support to disabled women.
- Public and private health care providers offer SRH services to, and receive continuing, in-service education on working with, women and adolescent girls with disabilities.

E. Conclusions and Recommendations

As part of his report on medical education and health workforce strengthening, we hope that the Special Rapporteur recognizes the following key points, in order to improve the quality of care provided to disabled women:

- Lack of provider training contributes to violations of the right to health for women and girls with disabilities. States must ensure that health care personnel are trained to work with women and girls with disabilities and about their rights and lived experiences, as a means of changing attitudes and practices and encouraging the accessibility of health information, goods, and services, particularly in the context of SRH .
- In particular, States must ensure that health care workers are trained to provide services that are based on dignity and that respect the autonomy of persons with disabilities. 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.
- States must support health care workers to provide quality, acceptable, and accessible care to disabled women through the provision of evidence-based clinical practice guidelines, in-service continuing education, and medical equipment and informational resources that are sensitive to the needs of disabled women, as well as communications assistance to women with disabilities when needed.

Thank you for your time and attention to this submission. Should you have any questions or require further information, please do not hesitate to contact WEI at the email addresses provided below.

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[1] Throughout this submission, the term "women" will be used to refer to women and girls of all ages, unless otherwise noted.
[2] According to the World Health Organization and World Bank's World Report on Disability, the female disability prevalence rate worldwide is 19.2 per cent. World Health Organization (WHO) and World Bank, World Report on Disability 28 (2011).
[3] According to the WHO, "[u]ndergraduate training programmes for health-care workers rarely address the health needs of people with disabilities," affecting providers' ability to provide and coordinate care. World Health Organization (WHO) and World Bank, World Report on Disability 78 (2011). For example, one study in the United States found that 40–50 per cent of gynecologists felt somewhat to completely unprepared to treat adolescents with disabilities. UNFPA and Women Enabled International, 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 92 (2018).
[4] UNFPA and Women Enabled International, 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).
[5] *See, for e.g.,* Agnieszka Wołowicz-Ruszkowska, *How Polish Women With Disabilities Challenge the Meaning of Motherhood*, in 40(1) PSYCH. OF WOMEN QUARTERLY 80, 84-85 (2015), *available at* http://journals.sagepub.com/doi/pdf/10.1177/0361684315600390; INCLUSIVE FRIENDS & NIGERIA STABILITY AND RECONCILIATION PROGRAMME, WHAT VIOLENCE MEANS TO US: WOMEN WITH DISABILITIES SPEAK 13-14 (2015).
[6] UNFPA and Women Enabled International, 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).
[7] *See, for e.g.,* Agnieszka Wołowicz-Ruszkowska, *How Polish Women With Disabilities Challenge the Meaning of Motherhood*, in 40(1) PSYCH. OF WOMEN QUARTERLY 80, 85 (2015), *available at* http://journals.sagepub.com/doi/pdf/10.1177/0361684315600390; *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 (noting that, in Kenya, pregnant women with disabilities cited that they were often insulted by female nurses when they visit hospitals and present for treatment).
[8] For example, in Kenya, women with disabilities have reported that health care personnel prefer to communicate with a third party instead of directly with them. This limits the extent to which women with disabilities are willing to share private information, due to concerns about confidentiality. Deaf women also 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. *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; Arulogun O. S. Titiloye M. A. Afolabi N. B. Oyewole O. E. , & Nwaorgu O. G. B . (2013). Experiences of girls with hearing impairment in accessing reproductive health care services in Ibadan, Nigeria. African Journal of Reproductive Health, 17, 85 – 93. doi: 10.4314/ajrh.v17i1.
[9] CRPD Committee, *General Comment No. 3: Article 6: Women and girls with disabilities*, ¶¶ 44, 51 U.N. Doc. CRPD/C/GC/3 (2016).
[10] 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. These attitudinal barriers include stereotypes about whether women with disabilities have sex and can make decisions for themselves, and discriminatory attitudes about whether women with disabilities should become parents. CRPD Committee, *General Comment No. 3: Article 6: Women and girls with disabilities*, ¶ 38, U.N. Doc. CRPD/C/GC/3 (2016).
[11] *See, e.g.*, Women Enabled International, *Facts: Sexual and Reproductive Health and Rights of Women and Girls with Disabilities* 1 (2016), https://womenenabled.org/pdfs/Women%20Enabled%20International%20Facts%20-%20Sexual%20and%20Reproductive%20Health%20and%20Rights%20of%20Women%20and%20Girls%20with%20Disabilities%20-%20ENGLISH%20-%20FINAL.pdf?pdf=SRHREasyRead; UNFPA and Women Enabled International, 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 131 (2018), https://womenenabled.org/wei-unfpa-guidelines.html.
[12] Rashida Manjoo, Report of the Special Rapporteur on Violence against Women, Its Causes and Consequences, ¶¶ 28, 36, U.N. Doc. A/67/227 (2012).
[13] For example, a study on maternal healthcare provision in Poland found that 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. 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. This treatment increased their sense of isolation, vulnerability, and lack of self-determination. Agnieszka Wołowicz-Ruszkowska, *How Polish Women With Disabilities Challenge the Meaning of Motherhood*, in 40(1) PSYCH. OF WOMEN QUARTERLY 80, 85 (2015), *available at* http://journals.sagepub.com/doi/pdf/10.1177/0361684315600390.

[14] Women Enabled International, *Facts: Sexual and Reproductive Health and Rights of Women and Girls with Disabilities* 1 (2016) (citing to: T. Kroll, et al., *Barriers and Strategies Affecting the Utilisation of Primary Preventative Services for People with Physical Disabilities: A Qualitative Inquiry*, 14 Health & Social Care in the Community 284 (2006)), https://womenenabled.org/pdfs/Women%20Enabled%20International%20Facts%20-%20Sexual%20and%20Reproductive%20Health%20and%20Rights%20of%20Women%20and%20Girls%20with%20Disabilities%20-%20ENGLISH%20-%20FINAL.pdf?pdf=SRHREasyRead/.

[15] UNFPA and Women Enabled International, 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.

[16] Agnieszka Wołowicz-Ruszkowska, *How Polish Women With Disabilities Challenge the Meaning of Motherhood*, in 40(1) PSYCH. OF WOMEN QUARTERLY 80, 84 (2015), *available at* http://journals.sagepub.com/doi/pdf/10.1177/0361684315600390.

[17] Jane Maxwell, Julia Watts Belser, & Darlena David, Hesperian Health Guides, *A Health Handbook for Women with Disabilities* 244 (2007), http:// hesperian.org/books-andresources/#.

[18] Under international human rights law, the right to health requires that States ensure health care goods, information, and services are available, accessible, acceptable, and of good quality. To be acceptable and of good quality, health service provision must be "respectful of medical ethics and culturally appropriate," as well as "scientifically and medically appropriate." This requires adequately trained, culturally competent and "skilled medical personnel." ESCR Committee, *General Comment No. 14 (2000): The right to the highest attainable standard of health*, ¶ 12, U.N. Doc. E/C.12/2000/4 (2000). In particular, health workers must be "trained to recognize and respond to the specific needs of vulnerable or marginalized groups." *Id.*, ¶ 37. And, specifically on how to provide sensitive and human rights-based care to persons with disabilities, including women with disabilities. *See, e.g.*, CRPD Committee, *Concluding Observations: South Africa*, ¶ 42, U.N. Doc. CRPD/C/ZAF/CO/1 (2018); CEDAW Committee, *General Recommendation No. 24: Article 12 of the Convention (women and health)*, ¶ 25, U.N. Doc. CEDAW/C/GC/24 (1999).

[19] CRPD Committee, *General Comment No. 3: Article 6: Women and girls with disabilities*, ¶ 38, U.N. Doc. CRPD/C/GC/3 (2016).

[20] *Id.,* ¶ 17.

[21] ESCR Committee, *General Comment No. 22 (2016) on the right to sexual and reproductive health (article 12 of the International Covenant on Economic, Social and Cultural Rights),* ¶ 24, U.N. Doc. E/C.12/GC/22 (2016).

[22] CEDAW Committee, *General Recommendation No. 24: Article 12 of the Convention (women and health)*, ¶ 25, U.N. Doc. CEDAW/C/GC/24 (1999).

[23] CEDAW Committee, *Concluding Observations: Hungary*, ¶ 33, U.N. Doc. CEDAW/C/HUN/CO/7-8 (2013).

[24] CRPD Committee, *Concluding Observations: South Africa*, ¶ 42, U.N. Doc. CRPD/C/ZAF/CO/1 (2018).

[25] World Health Organization (WHO) and World Bank, World Report on Disability 79 (2011) (citing to multiple studies).

[26] World Health Organization (WHO) and World Bank, World Report on Disability 79 (2011) (citing to Shakespeare T, Iezzoni LI, Groce NE. Disability and the training of health professionals. *Lancet*, 2009,374:1815-1816. doi:10.1016/S0140-6736(09)62050-X PMID:19957403; Kroll T, Neri MT. Experiences with care co-ordination among people with cerebral palsy, multiple sclerosis, or spinal cord injury. *Disability and Rehabilitation*, 2003,25:1106-1114. doi:10.1080/0963828031000152002 PMID:12944150).

[27] Ideally, pre-service and in-service training for providers on the provision of care to persons with disabilities should:

- Be informed by, and preferably led by, persons with disabilities;
- Contain information about the rights and lived experiences of persons with disabilities;
- Address specific stereotypes held by health care providers about persons with disabilities, including that they are asexual, cannot make decisions for themselves and would not make good parents;
- Provide concrete information about how to ensure that facilities and services are physically and financially accessible, information is available in accessible formats and health care providers can effectively communicate with persons with disabilities.

[28] World Health Organization (WHO) and World Bank, World Report on Disability 79 (2011).

[29] UNFPA and Women Enabled International, 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 112 (2018), https://womenenabled.org/wei-unfpa-guidelines.html.

[30] UNFPA and Women Enabled International, 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 138 (2018), https://womenenabled.org/wei-unfpa-guidelines.html.
[31] CRPD Committee, *General Comment No. 3: Article 6: Women and girls with disabilities*, ¶ 62, U.N. Doc. CRPD/C/GC/3 (2016).
[32] Accessible formats include: Braille; large print; audio; digital formats, compatible with screen readers; sign language with an interpreter of a preferred gender; captioning; simplified formats (e.g. plain language or easy read); pictorial guides; and local language interpretation. UNFPA and Women Enabled International, 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 43 (2018), https://womenenabled.org/wei-unfpa-guidelines.html.