Women Enabled International Submission for

OHCHR Report on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health in the implementation of the 2030 Agenda for Sustainable Development

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Drafted by: Women Enabled International

Endorsed by: Colectiva Polimorfas (Colombia), Shanta Memorial Rehabilitation Centre (India), Women with Disabilities India Network (India), Advocacy for Women with Disability Initiative (Nigeria), Legal Defence and Assistance Project (Nigeria)

I. Introduction

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 the Sustainable Development Goals (SDGs) and the right to health. 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.

According to the World Health Organization (WHO) and the World Bank, approximately 15% of people worldwide are persons with disabilities, and women and girls with disabilities account for 19.2% of the total population of women around the world. Women with disabilities in particular are discriminated against based on both their gender and disability in many aspects of their lives. In particular, women with disabilities face specific forms of discrimination in health care settings, including when accessing sexual and reproductive health information, goods, and services, frequently finding that these services are unavailable, unaffordable, and/or inaccessible or that health care workers have particular prejudices against them. Furthermore, women and girls with disabilities are frequently denied the opportunity to make their own decisions about their health, including sexual and reproductive health, leading to forced medical interventions that violate not only their right to health but also their rights to be free from violence, exploitation and abuse and to be free from torture or ill-treatment. In order to ensure that the right to health is realized for all in the implementation of the SDGs, States must address the specific barriers women with disabilities face in accessing sexual and reproductive health services, as well as the abuses they experience in those settings.

This submission outlines two common areas where women with disabilities experience violations of their sexual and reproductive rights and suggests measures States can take to address these violations through the implementation of the SDGs. This submission first outlines violations of the right to health and other related rights when women and girls with disabilities are denied informed consent for medical treatments, including current human rights and medical ethics standards requiring free and informed consent for reproductive health procedures. Secondly, the submission outlines violations women with disabilities experience concerning the accessibility of sexual and reproductive health information, goods, and services, as well as discrimination experienced in health care contexts that limits their access. Each section concludes with suggested recommendations that OHCHR should make to States and other UN
agencies to ensure that they implement and monitor the SDGs with the right to health for women and girls with disabilities in mind.

II. Informed Consent, Guardianship, and Forced Reproductive Health Procedures

Target 5.6 of the SDGs calls on states to “[e]nsure universal access to sexual and reproductive health and reproductive rights as agreed in accordance with the Programme of Action of the International Conference on Population and Development [ICPD Programme of Action] and the Beijing Platform for Action and the outcome documents of their review conferences.”³ Under the ICPD Programme of Action, States committed to a definition of the right to health for women and girls that “includes their right to make decisions concerning reproduction free of discrimination, coercion and violence, as expressed in human rights documents.”⁴ As part of monitoring the indicators for Target 5.6, UN agencies will measure the percentage of women aged 15-49 who make informed decisions about their sexual and reproductive health and the number of countries with laws and policies that guarantee sexual and reproductive health care, information, and education.⁵ Too often, however, women and girls with disabilities are left behind in monitoring and implementing these types of policies, are then subjected to discrimination that leads them to be denied the opportunity to make decisions about their health, including their reproductive health. As a result, they can be subjected to forced or coerced sterilization, contraception, and abortion—all of which human rights bodies have recognized as forms of gender-based violence and torture or ill-treatment.⁶

Background

Around the world, persons with disabilities are formally and informally deprived of the right to make decisions for themselves, including by being deprived of legal capacity and being placed under guardianship.⁷ According to the Committee on the Rights of Persons with Disabilities (CRPD Committee), Article 12 of the Convention on the Rights of Persons with Disabilities (CRPD) “does not permit discriminatory denial of legal capacity” on the basis of disability.⁸ As such, the CRPD Committee has consistently recommended that states abolish their systems of guardianship—which fully or partially remove legal capacity on the basis of disability and delegate the power of decision-making in key areas of an individual’s life to a third party—and instead ensure that persons with disabilities can access support to make decisions for themselves.⁹

Women with disabilities face more severe consequences than do men with disabilities when they are deprived of legal capacity and placed under guardianship. Women with disabilities are more often subjected to forced reproductive health procedures or medication, such as forced sterilization, forced abortion, and forced contraception, frequently only with the consent of a parent, guardian, or doctor, but not with the woman’s consent.¹⁰ Forced sterilization is a major interference with a woman’s reproductive health, bearing on many aspects of her personal integrity, including her physical and mental wellbeing and family life.¹¹ Indeed, although in rare cases it may be reversible, female sterilization in particular is considered a permanent form of contraception, meaning that women who undergo sterilization will not be able to have children.¹²

States often have legal frameworks that specifically permit or do not otherwise prohibit the practice of forced reproductive health procedures on women with disabilities without their informed consent. For instance, under India’s Medical Termination of Pregnancy Act, 1971 (as amended in 2002), guardians can consent to abortions for women with psychosocial disabilities, leading to forced abortions.¹³ 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 allow for forced abortion of women with psychosocial disabilities.¹⁴
In Colombia, the Constitutional Court and the Ministry of Health in 2017 transformed the legal environment that allowed forced sterilization for women and girls with disabilities, instead requiring the direct consent of persons with disabilities for sexual and reproductive health services, including the provision of reasonable accommodations and support mechanisms. Although these new regulations represent a significant step toward better enforcement of the rights of women and girls with disabilities, these regulations do not alter the legal landscape for individuals under plenary guardianship. Article 6 of Act 1412 of 2010 still allows judges to order sterilization procedures for persons with disabilities who are under plenary guardianship without their consent.

**Human Rights and Medical Ethics Standards**

Informed consent is an internationally-recognized health care standard and the World Health Organization (WHO), the Council of Europe, and the International Federation of Gynecology and Obstetrics (FIGO) strongly and unanimously require informed consent as an essential component of any sexual and reproductive health-related medical intervention. In 2011, FIGO adopted guidelines specifically regarding female contraceptive sterilization, stating that only women themselves can give ethically valid consent to their own sterilization. As such, a forced procedure occurs when a person is subjected without her knowledge or consent to the procedure, or is not given a chance to consent. Furthermore, if a State or entity requires that a woman undergo sterilization in order to access to medical care or other benefits, the FIGO guidelines indicate that this is an interference with the woman’s informed consent. According to UN guidelines addressing this issue, if informed consent cannot be immediately obtained for non-life-saving measures, those measures should not be performed. According to the U.N. Interagency statement aimed at eliminating forced and involuntary sterilization, “[e]ven if a future pregnancy might endanger a person’s life or health, there are alternative contraceptive methods to ensure the individual concerned does not become pregnant immediately, and the individual concerned must be given the time and information needed to make an informed choice about sterilization,” emphasizing that “[s]terilization for prevention of future pregnancy cannot be justified on grounds of medical emergency.” This means that sterilization without consent for such purposes as menstrual hygiene or the regulation of periods would also not be valid.

Informed consent to medical procedures is also an essential aspect of ensuring the respect, protection, and fulfillment of a range of human rights, including the right to health, the right to be free from torture or ill-treatment, and the right to be free from violence, exploitation, and abuse. Concerning the right to health in particular, the Committee on Economic, Social, and Cultural Rights (ESCR Committee) recognizes that it contains a specific right to sexual and reproductive health, including family planning services, prenatal and post-natal care, emergency obstetric services, abortion, access to information, and the means to act and decide freely in this regard. States must ensure that information, goods, facilities, and services related to health care are available, accessible, acceptable, and of good quality for all persons. Furthermore, the Committee on the Elimination of Discrimination against Women (CEDAW Committee) asserts that women and girls experience higher rates of violence, harmful practices, and sexual abuse that can impact their health, especially their sexual and reproductive health, and that forced or coerced practices, such as non-consensual sterilization, mandatory pregnancy testing, or mandatory testing for sexually transmitted diseases are forms of gender-based violence. Finally, the CRPD Committee affirms 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.”

Human rights bodies and experts have also found that reproductive health procedures without informed consent constitute forms of torture or ill-treatment. In his 2013 report, the Special Rapporteur on Torture, Juan Mendez, stressed that “forced sterilization is an act of violence, a form of social control, and a violation of the right to be free from torture and other cruel, inhuman, or degrading treatment or punishment.” Furthermore, the Committee against Torture (CAT Committee) has expressed concern to
States under the Convention against Torture about circumstances where disadvantaged groups, including women with disabilities, are subjected to forced or coerced medical procedures, including forced or coerced sterilizations.  

The core of the right to equal recognition before the law as found in article 12 of the CRPD is legal capacity. The definition of legal capacity in the CRPD rejects the idea of incapacity and instead centers the exercise of the right in the realization of a person’s will and preferences, including through the provision of support. The CRPD Committee has found that safeguards must be in place to ensure that decision-making support does not subvert, either intentionally or not, the will and preferences of the person. As a result, when the will and preferences of a person cannot be determined, the CRPD Committee has found that “the ‘best interpretation of will and preferences’ must replace the ‘best interests’ determinations.” In other words, the decision must be made based on previous expressions, verbal or non-verbal, of the individual’s will and preferences, rather than on what a third party considers would be of greater benefit. As a result, States have the obligation to adopt frameworks that require the informed consent of the person who is receiving medical treatment and that ensure access to support to make that decision when needed and requested. In doing so, States must create programs and services to recognize the will and preferences of women with disabilities in particular “with regard to medical and/or therapeutic treatment, including by taking their own decisions on retaining their fertility and reproductive autonomy [and] exercising their right to choose the number and spacing of children…."

Recommendations
In order to ensure the right to health in implementing SDG Targets 5.6 regarding sexual and reproductive health and rights and Target 5.2 concerning gender-based violence, UN agencies should specifically monitor international indicators with the rights of women and girls with disabilities in mind. Furthermore, States should take the following steps:

- Develop national-level indicators for these targets that specifically monitor their implementation as related to women and girls with disabilities, including indicators about collecting and making publicly available data on the proportion of women with disabilities aged 15-49 years who make their own informed decisions regarding sexual relations, contraceptive use and reproductive health care; and data on the enforcement of new laws and regulations guaranteeing women with disabilities access to SRH care, promoting supported decision making in their access to services, and requiring their informed consent.
- Eliminate laws, policies, and practices that deprive women with disabilities of decision-making power surrounding their sexual and reproductive health, including laws that allow them to be placed under guardianship as well as laws that allow for the forced sterilization, abortion, and contraception of women with disabilities without the woman’s consent.
- Ensure that women with disabilities are empowered to give full and informed consent to sexual and reproductive health services generally, including by providing support for making decisions when needed and requested and ensuring that information provided to persons with disabilities about their health, including sexual and reproductive health, is accessible and non-biased.
- Prohibit the practice of requiring medical procedures for women, including women with disabilities, that condition their access to benefits or social protection on undergoing those procedures.
- Ensure adequate redress for women with disabilities who have been subjected to forced reproductive health procedures without their informed consent by identifying specific cases, implementing policies to guarantee access to justice, and providing reparations.

III. Ensuring Non-discriminatory Access to Sexual and Reproductive Health Information, Goods, and Services
SDG Targets 3.1, 3.7, and 3.8 and their related indicators call on States to drastically reduce maternal mortality, ensure universal health coverage, and provide universal access to sexual and reproductive health services. \(^{34}\) Furthermore, Target 5.1 calls on States to eliminate discrimination against women, while Targets 10.2 and 10.3 call on States to ensure equality and eliminate discrimination more generally. \(^{35}\)

Persons with disabilities face more barriers when seeking health coverage and when accessing health care services. \(^{36}\) In particular, women with disabilities face routine discrimination in accessing sexual and reproductive health services, based on stereotypes about their sexuality, ability to make decisions, and ability to be good parents, thus receiving less or biased information and fewer services. \(^{37}\) Furthermore, women and girls with disabilities frequently find that sexual and reproductive health information, goods, and services are inaccessible, resulting in a lack of support for a wide range of their sexual and reproductive health needs. \(^{38}\) As such, States’ implementation of the SDGs must address and should be monitored through disability- and gender-specific indicators that address these issues.

**Background**

As noted above, women and girls with disabilities face significant barriers to accessing sexual and reproductive health services, due to their inaccessibility and to discrimination and stereotypes. Common barriers include lack of training or awareness-raising among service providers on how to serve people with disabilities, \(^{39}\) laws and policies that diminish personal autonomy; failures to consider disability-related accessibility in developing programs or building service facilities; \(^{40}\) communication barriers, including both provider inability to communicate and lack of information available in alternative formats (e.g., Braille, audio, plain and simple language, and sign language interpreters); parents, caregivers, or guardians acting as gatekeepers to sexual and reproductive health information and services; heightened risk of poverty; and isolation of women and girls with disabilities in institutions. \(^{41}\) Pervasive harmful stereotypes about young women and girls with disabilities—for instance that they are asexual, cannot become pregnant, or are not capable of parenting—can further lead providers to assume they do not need access to sexual and reproductive health information, goods or services. \(^{42}\) It is also not uncommon to find that health care facilities are physically inaccessible to women with disabilities, including inaccessible examination beds for gynecological screenings and mammogram machines. \(^{43}\)

For instance, in Nigeria, the physical environment surrounding and within health care facilities is often inaccessible to wheelchair users, and health care workers frequently lack knowledge about or experience with managing care for women with disabilities. \(^{44}\) Deaf women in Nigeria also report that they do not have access to interpreters in health facilities. \(^{45}\) Furthermore, testimony collected by Colectiva Polimorfas in Colombia shows that women with disabilities encounter stereotypes and discrimination about their health and abilities, which have a significant impact on their lives. For example, Bubulina Moreno, the spokeswoman of Colectiva Polimorfas and a woman with a physical disability, reported that “the nurses always ask very intimate questions in front of my mom, disregarding completely my privacy.” \(^{46}\) The lack of access to sexual and reproductive health services and lack of accessible sexuality education for women with disabilities in Colombia leads to higher maternal and perinatal morbidity and mortality, the prevalence of sexually transmitted infections (including HIV), cervical and breast cancer, and sexual violence. \(^{47}\)

Additionally, because women with disabilities in the United States of America (U.S.) have higher rates of unemployment and poverty than the general population, they are far less likely to have private insurance to cover reproductive health goods and services, and thus often rely on government health insurance if they qualify or must purchase insurance on the open market. \(^{48}\) At the time of writing, the political environment in the U.S. was leading to instability in the health care marketplace, and while Congress contemplated drastically cutting government health insurance for low-income individuals, premiums for
private health insurance plans on the open market were likely to rise, becoming unaffordable for many women with disabilities.  

Women with disabilities also face overt discrimination in sexual and reproductive health settings. For instance, the CRPD Committee has noted that women with disabilities may be subjected to harmful stereotypes, such as that they are asexual, when accessing sexual and reproductive health information, goods, and services, and that some service providers hold prejudices or negative attitudes towards persons with disabilities. Other stereotypes assume that women with disabilities are not capable of being “good” parents and so they are “significantly overrepresented in child protection proceedings.” These stereotypes mean that women with disabilities may not be offered needed sexual and reproductive health services, including contraception, that are essential to ensuring their right to decide on the number and spacing of their children, or may more frequently be offered services permanently prevent pregnancy, including sterilization.

For instance, in the U.S., the prevalence of stereotypes and lack of provider training make health care providers significantly less likely to ask women with disabilities about their use of or need for contraceptives. Additionally, because physicians frequently see women with disabilities in the U.S. as sexually inactive and thus not in need of reproductive health care, and because transportation and health facilities are frequently inaccessible, women with disabilities are also less likely to receive needed health screenings for reproductive and breast cancer, making them vulnerable to serious health problems.

Human Rights Standards on Ensuring Non-discriminatory Access to Sexual and Reproductive Health Information, Goods, and Services

According to the ESCR Committee, in order for states to respect, protect, and fulfill the right to health, they must ensure that health information, goods, and services are available, accessible, acceptable, and of good quality (AAAQs). In particular, in order to be accessible and acceptable, health information, goods, and services must be physically accessible, economically accessible (affordable), informationally accessible, and provided free from discrimination and on the basis of informed consent. The ESCR Committee notes in particular in its General Comment No. 22 on sexual and reproductive health and rights that these requirements are applicable to sexual and reproductive health services for persons with disabilities, as their SRH needs must be given tailored attention.

Furthermore, although the right to health is a right of progressive realization, States must take immediate steps to ensure non-discrimination in the right to health and also must provide a minimum basic package of health information, goods, and services, including essential medicines such as contraception. In its recent General Comment No. 22 on sexual and reproductive health and rights, the ESCR Committee in particular calls on states to provide the fullest possible range of SRH care, including the underlying social determinants of SRH, “such as safe and potable drinking water and adequate sanitation facilities, hospitals and clinics.”

The CRPD Committee further defines what accessibility in access to health information, goods, and services means for persons with disabilities. In its General Comment No. 2, the CRPD Committee finds that accessibility must be “addressed in all its complexity, encompassing the physical environment, transportation, information, and communication, and services” and must also include a gender dimension, as this is especially important to ensure accessible reproductive health care for women and girls with disabilities. As sexual and reproductive rights are not restricted to health care, the CRPD Committee further recommends that States must remove barriers to accessing sexuality education so as to ensure the right to health for women with disabilities.
As the CEDAW Committee has noted in its General Recommendation No. 24 on the right to health, States have an obligation to ensure gender equality in health care, including by ensuring that women have access to health care that addresses their specific needs as women. Women regularly face barriers in their access to health care such as higher fees or requirements of third-party authorizations. Women with disabilities can be particularly vulnerable to these barriers, causing an increased need for 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.”

Women, due to gender stereotypes, are victims of exclusions and restrictions in their access to SRH services. In addition to addressing barriers caused by discrimination and stereotypes based on gender, States must also address the specific barriers women with disabilities experience in accessing SRH services because of discrimination based on both their gender and disability. The CRPD Committee recognizes that stereotypes about women with disabilities—including that they are asexual or hypersexual incapable, irrational, uncontrollable, or may give birth to persons with disabilities—often leads to violations of their sexual and reproductive rights. As a result, women with disabilities may not receive information about reproductive health, including in accessible formats, making them in turn more vulnerable to sexual violence and abuse. Under the CRPD, denial of reasonable accommodation, including in accessing health services, is also a form of discrimination.

Recommendations
In order to ensure the accessibility and acceptability of sexual and reproductive health information, goods, and services in implementing SDG Targets 3.1, 3.7, and 3.8, as informed by Targets 5.1, 10.2, and 10.3, UN agencies should specifically monitor international indicators with the rights of women and girls with disabilities in mind. Furthermore, States should take the following steps:

- Create national-level indicators to ensure that the health-related targets are reached for women and girls with disabilities, including by specifically measuring their rates of access to SRH services, including maternal health services; their rates of maternal mortality and morbidity; their use of and access to modern contraceptives; their participation in sexuality education programs; and coverage of SRH services under health insurance plans that women with disabilities utilize.

- Ensure the disability related accessibility of services, goods, and information by complying with international guidelines of universal design and implementing reasonable accommodations regarding:
  - Physical accessibility of buildings and equipment, including enough facilities located close to places of residence and accessible public transportation.
  - Informational accessibility, with information provided in easy-to-understand formats, Braille, sign language, and other accessible formats.
  - Communications accessibility, with health care professionals using plain language, as well as available sign-language and other kinds of interpretation, as well as allowing sufficient time in medical appointments to provide such access and accommodations.

- Ensure that sexual and reproductive health services are affordable by ensuring that women with disabilities have health insurance coverage, requiring that health insurance cover SRH services and goods, and reducing or eliminating additional fees that may prevent women with disabilities from accessing needed services or treatments.

- Hire and train health care providers about the specific health needs of women with disabilities, specifically about their sexual and reproductive health, and alternative methods of communication, in order to prevent stereotypes that pose barriers to accessing health information, goods, and services.

Thank you for your time and attention to this submission. Should you have any questions or require further information, we hope you will feel free to contact WEI at the email addresses provided below.
This submission will address the situation of women with disabilities throughout the life cycle. Any reference to “women with disabilities” should be interpreted to include girls with disabilities unless otherwise indicated.

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8 Id., ¶ 15.
9 International Disability Alliance, IDA’s Compilation of the CRPD Committee’s Conclusion Observations, July 2017.
14 Supreme Court of India, Suchita Srivastava & Anr vs Chandigarh (2009), available at https://indiankanoon.org/doc/1500783/
15 Corte Constitucional [C.C.] [Constitutional Court], octubre 19 de 2016, Sentencia T-573 de 2016 (Colom.); R. 1904/2017, mayo 31, 2017, Diario Oficial [D.O.] No. 50.263 de 13 de junio de 2017 (Colom.)
17 Informed consent has three essential components: physician disclosure of the risks and benefits of, and alternatives to, the medical procedure; the patient’s understanding of that disclosure; and voluntary patient choice.
20 Id.
eng.pdf.
25 Id. at 1.
27 Id., ¶ 12.
30 CRPD, Gen. Comment No. 3, supra note 10, ¶ 38.
34 Id., ¶¶ 20-22.
35 Id., ¶ 20.
36 CRPD, Gen. Comment No. 3, supra note 10, ¶ 44.
38 Id.
40 CRPD, Gen. Comment No. 3, supra note 10, ¶ 44.
43 Id.
46 CRPD, Gen. Comment No. 3, supra note 10, ¶ 42.
48 Id., at 14.
49 Testimony of Bubulina Moreno, on file with authors. For more information and stories about access to SRH services in Colombia, please See COLECTIVA POLIMORFAS, PROFAMILIA, WEI, SUBMISSION FOR CESCR WORKING GROUP FOR COLOMBIA (2017).
56 CRPD, Gen. Comment No. 3, supra note 10, ¶ 47.
54 Id.
57 Nancy Mele et al., Access to Breast Cancer Screening Services for Women with Disabilities, 34 J. OF OBSTETRIC, GYNECOLOGIC, & NEONATAL NURSING 453-64 (July 2005).
58 The National Center for Health Statistics found that as of 2005, 65-71% of women with disabilities have had a Pap test compared to 83% of women without disabilities. See Elizabeth Pendo, Reducing Disparities through Health Care Reform: Disability and Accessible Medical Equipment, 4 UTAH L. REV. 1057, 1065 (2010); Drew Rivera et al., Disability and Pap Smear Receipt among U.S. Women, 2000 and 2005, 42 PERSP. ON SEXUAL AND REPROD. HEALTH, 258-66 (2010).
60 Id. ¶ 12.
65 Id., ¶ 40.
66 CRPD, Gen. Comment No. 3, supra note 10, ¶ 40.
67 CEDAW Committee, General Recommendation No. 24: Article 12 of the Convention (women and health), ¶ 25, U.N. Doc. CEDAW/C/GC/24 (1999);
68 Id., ¶¶ 19-21/49
69 Id., ¶ 25.
72 Id., ¶ 40.
73 Id., ¶ 41.
74 CRPD, supra note 41, arts. 2 & 5.