     

**Submission to Special Rapporteur on the Rights of Persons with Disabilities**

**Report on the Right to Health for Persons with Disabilities**

*March 30, 2018*

Thank you for the opportunity to provide information for the Special Rapporteur on the Rights of Persons with Disabilities’ forthcoming report on the Right to Health for Persons with Disabilities. This submission was compiled by Women Enabled International (WEI) with substantive contributions from This-Ability Consulting (Kenya), Advocacy for Women with Disabilities Initiative (Nigeria), Legal Defense Assistance Project (Nigeria), Association for Women with Disabilities ONE.pl (Poland), Shanta Memorial Rehabilitation Centre (India), and Women with Disabilities India Network.

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1. Introduction

Women and girls[[1]](#endnote-1) with disabilities around the world face violations of their right to the highest attainable standard of physical and mental health (right to health) that are unique from and disproportionate to other women and to men and boys with disabilities. In the context of sexual and reproductive health and rights (SRHR) in particular, women with disabilities encounter health facilities and information that are inaccessible to them, and they are forced to work with health personnel who are not trained to provide them care and are not aware of their rights. Due to stigma and discrimination about their sexuality and capabilities, women with disabilities may not be offered needed sexual and reproductive health information, goods, and services—such as contraception or comprehensive sexuality education—and are frequently subjected to medical interventions without their consent, including forced sterilization, abortion, and contraception. These health practices not only violate their right to health but also myriad other rights, including their rights to privacy, bodily integrity, to found a family, to be free from violence, and to be free from torture or ill-treatment.

This submission highlights some of the abuses women with disabilities face in the context of sexual and reproductive health care, with examples of laws, practices, and particular cases and studies in Kenya, Nigeria, Poland, and India. This submission first pulls out some of the elements of the right to health, including SRHR, that specifically impact women, including women with disabilities. The submission then seeks to respond to the Special Rapporteur’s questionnaire by providing background information and specific examples of the barriers women with disabilities face in accessing sexual and reproductive health care, the discrimination they encounter inside and outside the health care system that leads to violations of the right to health, and abuses they face in health care settings, based on denials of free and informed consent. The submission concludes with some recommendations to the Special Rapporteur for her forthcoming report and contains annexes with more detailed information about the specific contexts in Kenya, Nigeria, Poland, and India.

1. The Right to Health for Women, including Women and Girls with Disabilities

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 (AAAQs).[[2]](#endnote-2) Although the right to health is considered a right of progressive realization, meaning that States have a duty to progressively implement the right to the maximum of their available resources, there are also certain core obligations under the right to health that all States must immediately ensure.[[3]](#endnote-3) These core obligations include, for instance, non-discrimination in the provision of health information, goods, and services and access to essential drugs as provided by the WHO Action Programme on Essential Drugs, including contraception.[[4]](#endnote-4) In its General Comment No. 14 on the right to health, the Committee on Economic, Social, and Cultural Rights (ESCR Committee) also specifies that the duty to ensure reproductive and maternal health care is of “comparable priority” to a core obligation under the right to health, as are the need to provide education and information on health and the need to ensure appropriate training for health personnel, including on human rights.[[5]](#endnote-5)

According to the Committee on the Elimination of Discrimination against Women (CEDAW Committee), the right to health requires that States ensure access to health care that women need specifically because of their sex or gender.[[6]](#endnote-6) This includes health care related to the ability or perceived ability of women to become pregnant and health care related to women’s reproductive health system.[[7]](#endnote-7) Indeed, The ESCR Committee recognizes that the right to health contains a specific right to sexual and reproductive health, including family planning services, pre- and post-natal care, skilled birth attendants, emergency obstetric services, abortion, post-abortion care, access to information, and the means to act and decide freely in this regard.[[8]](#endnote-8)

The CEDAW Committee further 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,[[9]](#endnote-9) 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.[[10]](#endnote-10) Finally, the Committee on the Rights of Persons with Disabilities (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.”[[11]](#endnote-11) These situations create unique and disproportionate risks of violations of the right to health for women and girls with disabilities.

1. Barriers to Health Care for Women and Girls with Disabilities

Women with disabilities worldwide face specific barriers to accessing needed health information, goods, and services, including sexual and reproductive health care, due to both their gender and disability. As the 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.”[[12]](#endnote-12) The CRPD Committee has found that stereotypes about women with disabilities—including that they cannot make decisions for themselves, are asexual, or cannot become pregnant—may lead health care workers to discount their needs or subject them to abuse, violating their rights to health and to found a family.[[13]](#endnote-13) The CEDAW Committee has thus 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.”[[14]](#endnote-14)

Women and girls with disabilities face numerous barriers to accessing health care, particularly sexual and reproductive health care. These barriers include physical barriers, informational and communications barriers, financial barriers, and health care personnel-related barriers, as described below.

*Physical Barriers*

Women and girls with disabilities may find that health care facilities and equipment are physically inaccessible to them, or designed without their needs in mind.

* In a 2015 study of women with physical and sensory disabilities’ interactions with the maternal health care system in **Poland**, interviewees identified that the health care system was not equipped to offer them specialized services in the context of pregnancy.[[15]](#endnote-15) Interviewees also reported that gynecological rooms and equipment were frequently not adapted to persons with disabilities; for instance, chairs and tables were not at a height accessible to women who use wheelchairs, leaving them to need assistance that at least one women considered humiliating.[[16]](#endnote-16)
* In **Kenya**, although the Persons with Disabilities Act (2003) requires that buildings be made accessible to persons with disabilities, and policies are in place to provide guidance on construction, this is not enforced, and there is not adequate budgetary allocation towards enforcement. This means that women with disabilities cannot access facilities that provide vital health care services because most centers were not constructed with people with disabilities in mind. Women with physical disabilities have cited the unhygienic nature of pit latrines, which were always dirty and not fully accessible, as a challenge they face when they visit health centers to seek sexual and reproductive health services. Furthermore, many clinics and hospitals are located far away from the residences of many women with disabilities, particularly in rural areas, necessitating long walks, which may be impossible for these women.[[17]](#endnote-17)
* A 2015 study of HIV prevalence in **Nigeria** also indicated that there were very few sexual and reproductive health services targeted at or accessible to persons with disabilities,[[18]](#endnote-18) a situation that can increase the risk of acquiring or experiencing the negative health effects of HIV.

*Informational and Communications Barriers*

Women with disabilities may also be denied needed information about their sexual and reproductive health, which is imperative for making decisions about this aspect of health. They may be denied this information because the information is not provided in accessible formats, or because they are thought not to need the information due to stereotypes about their sexuality.[[19]](#endnote-19) In particular, girls and young women with disabilities may be left out of sexuality education programs, which are necessary for ensuring that they can protect themselves from sexual violence, understand and manage their menstrual cycles, enter into healthy relationships including sexual relationships, and know how to prevent unwanted pregnancies.[[20]](#endnote-20)

* A 2013 study of girls with hearing impairments in **Nigeria** found that, because professional interpreters were not available to them in health facilities, they were not confident that they were receiving full and accurate information from their health providers.[[21]](#endnote-21)
* In **Poland**, although the State claims to provide sexuality education to persons with disabilities, that sexuality education does not meet international standards, including as established in the 2018 United Nations Educational, Scientific and Cultural Organization (UNESCO) technical guidance on comprehensive sexuality education (UNESCO guidance). The UNESCO guidance recommends that States include information specifically about persons with disabilities, including about their rights.[[22]](#endnote-22)
* In **Kenya**, women with disabilities face numerous barriers to accessing information about their health, including their sexual and reproductive health, including illiteracy, lack of information available in accessible formats, and exclusion of adolescents with disabilities from sexuality education programs due to the assumption that they do not need this information.[[23]](#endnote-23)

Women with disabilities may also have to communicate with health care personnel through family and friends, jeopardizing the confidentiality of information they provide in the context of sexual and reproductive health care, which is often quite sensitive, as well as the quality and accuracy of the information they receive about health care.

* For instance, 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.[[24]](#endnote-24) 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.[[25]](#endnote-25)
* In **Nigeria**, girls with hearing impairments reported that they were not provided with professional interpreters during visits to reproductive health facilities, instead having to rely on family members and friends to translate information for them, a situation that jeopardized the confidentiality of those services.[[26]](#endnote-26)

*Financial Barriers*

Women and girls with disabilities worldwide are less likely to receive adequate education, are more likely to be unemployed, and are more likely to live in poverty than are others, including men and boys with disabilities and other women.[[27]](#endnote-27) This means that, where health services are not covered by public health insurance schemes, women with disabilities are disproportionately unable to afford them.

* In **Kenya**, respondents stated that health centers, including those that are state owned, and local authorities charge consultation fees of huge amounts. Besides the consultation fee, patients also have to pay for the services and supplies they receive. Women with disabilities do not receive social grants from the disability fund administered by the Ministry.[[28]](#endnote-28)
* Furthermore, in **Kenya**, women with disabilities who require a personal aid for mobility have to pay for two people on public transport—and sometimes for wheelchairs, as well—making just the process of accessing the nearest health facility prohibitively expensive.[[29]](#endnote-29)
* In **Nigeria,** a woman with a spinal cord injury reported that treatment for that injury was very expensive.[[30]](#endnote-30)

*Training and Attitudes of Health Care Personnel*

Finally, women with disabilities encounter barriers to accessing sexual and reproductive health care that stem from health care personnel themselves. These barriers include a lack of training for health care providers on the lives and rights of women with disabilities and on how to provide them with adequate care.[[31]](#endnote-31) They also include attitudinal barriers, such as 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.[[32]](#endnote-32) Lack of health care provider training and discriminatory attitudes both impact the information, goods, and services women with disabilities receive in sexual and reproductive health care settings.

Frequently, sexual and reproductive health care personnel are not trained to work with women with disabilities and are not aware of their rights. This influences the care they provide to women with disabilities and can make that care more expensive or less accessible.

* Women with disabilities interacting with the maternal health system in **Poland** reported that, because they were considered a “high risk group,” they had trouble finding a doctor or midwife willing to provide them with care.[[33]](#endnote-33) In reality, pregnancy for women with disabilities is not necessarily more “high risk” than it is for other women.[[34]](#endnote-34) Furthermore, these women reported that there was generally a lack of specialized care available to them.[[35]](#endnote-35)
* In **Nigeria**, health care workers frequently lack knowledge about or experience with managing care for women with disabilities.[[36]](#endnote-36)
* In **Kenya**, women with speech impairments reported that, because doctors and nurses are so busy, they are often impatient with women who have such impairments. As a result, these women receive inadequate care.[[37]](#endnote-37) Women with intellectual disabilities in Kenya also report that health care personnel do not adequately screen them for gender-based violence and do not offer the services they need in conjunction with that violence, including emergency contraception to prevent pregnancy.[[38]](#endnote-38)
* Furthermore, in **Kenya**, women with disabilities were often not granted the privacy they required or that is usually accorded to other women in the context of sexual and reproductive health care. This serves as a deterrent among these women to visiting health centers because they feel that their privacy will be violated. Health care personnel often do not know how to relate to persons with disabilities, especially in the presence of their assistants, and often communicate with the assistants rather than with the women with disabilities themselves.[[39]](#endnote-39)

Similarly, 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.

* For instance, according to the 2015 study in **Poland** cited above, 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.[[40]](#endnote-40) 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.[[41]](#endnote-41) This treatment increased their sense of isolation, vulnerability, and lack of self-determination.[[42]](#endnote-42)
* In **Kenya**, pregnant women with disabilities cited that they were often insulted by female nurses when they visit hospitals and present for treatment.[[43]](#endnote-43)
* In **Nigeria**, a 2015 report on Plateau State found that, because women with disabilities are treated poorly by medical personnel, find health care services inaccessible, and may not be able to afford those services, they may not seek needed antenatal care when they become pregnant,[[44]](#endnote-44) a situation that can increase the risk of complications during pregnancy and labor.[[45]](#endnote-45)
1. Discrimination in the Provision of Health Care for Women and Girls with Disabilities

Multiple and intersectional discrimination against women with disabilities, based on both their gender and disability, causes many of the violations they experience in the context of the right to health, particularly sexual and reproductive health. Due to societal enforcement of discriminatory gender roles, all women may be expected to bear children and become mothers and caretakers.[[46]](#endnote-46) At the same time, due to their disability, women with disabilities are often perceived as not being able to have children or to adequately take care of children, and thus unable to fulfill this gendered role, impacting their relationships and the sexual and reproductive health care they receive.[[47]](#endnote-47)

* For instance, in **Nigeria**, women with disabilities generally report that that men want to have sex with them but not openly date them, due to shame and stigma.[[48]](#endnote-48) Women with disabilities are also considered less eligible for marriage because they are perceived as being unable to fulfill their gendered roles as wives and mothers, as they are seen as asexual, not able to give birth, and not able to undertake daily domestic tasks.[[49]](#endnote-49) Indeed, women who acquire a disability during their marriage may be abandoned by partners who cannot cope with the stigma associated with disability.[[50]](#endnote-50)
	+ One woman reported: “Most times in a home where there are ladies, the joy is always that you will get married and move out your family house because society place a lot of respect on such a woman but as a disabled woman, you are hardly considered as being an eligible candidate for that celebration or respect is hardly accorded you. Most times, if you are unable to get a place to leave you are treated as a child that is still suckling and your privacy is denied of you … Most times the society feels that as a complete woman, you should be able to conceive and bear children naturally as much as 3-5 where this is not the case you are considered an incomplete woman. Most families find it hard to permit their sons into any true relationship with a disabled woman.”[[51]](#endnote-51)
	+ Another woman reported: “There's this general notion or mentality (wrong mentality) that women living with disabilities can't live a 'normal' life or can't get pregnant or impregnate or raise a family of their own. So most times it's difficult for women living with disabilities to get into a relationship and when they eventually do, the in-laws most times kicks against such relationship and such experience can traumatized or leads to emotional and psychological depression.”[[52]](#endnote-52)
* In **Poland**, the 2015 study cited above found 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.[[53]](#endnote-53)
* In **Kenya**, the needs of persons with disabilities, including women with disabilities, still remain a peripheral issue. Persons with disabilities continue to be treated as second-class citizens. This is because of the assumption that disability is a curse or such other backward notions. The stigma causes families to keep their relatives with disabilities hidden and away from necessary services. Internalized stigma also causes women with disabilities to shy away from visiting health institutions to seek information and services.[[54]](#endnote-54)

Furthermore, stereotypes about women with disabilities—including that they are asexual or cannot control their sexuality, that they are incapable of being good parents, and that they cannot make decisions for themselves—are also forms of discrimination that impact their SRHR in myriad ways, in addition to the instances cited in Section III above

* For instance, under the Sexual Offenses Act in **Kenya**, it is assumed that many women with disabilities (those with “mental impairments”) cannot consent to sex. While the section applies to both men and women, women are disproportionately affected because culturally, all women with disabilities are seen as asexual.[[55]](#endnote-55)
* In **Poland,** several women reported that medical staff tried to convince them to have abortions or put their babies up for adoption, rather than supporting them through their pregnancies and giving them information about assistance to raise their children. This was based on the assumption held by both medical personnel and society at large that women with disabilities might pass on their disability or would otherwise not be good parents.[[56]](#endnote-56)
1. Free and Informed Consent in the Context of Health Care, particularly SRHR

Women with disabilities face more severe consequences tin the context of the right to health 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.[[57]](#endnote-57) 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.[[58]](#endnote-58) Indeed, although in rare cases it may be reversible, female sterilization is considered a permanent form of contraception, meaning that women who undergo sterilization will not be able to have children.[[59]](#endnote-59)

As the Special Rapporteur on the Rights of Persons with Disabilities noted in her 2017 report to the General Assembly, “the forced sterilization of girls and young women with disabilities represents a widespread human rights violation across the globe.”[[60]](#endnote-60) In its General Comment No. 3 on women with disabilities, the CRPD Committee further recognized that “[i]n practice, the choices of women with disabilities, especially women with psychosocial or intellectual disabilities are often ignored, [and] their decisions are often substituted by third parties, including legal representatives, service providers, guardians and family members.”[[61]](#endnote-61) When women with disabilities are deprived of legal capacity, this can “facilitate forced interventions, such as: sterilisation, abortion, [and] contraception…”[[62]](#endnote-62) These practices are frequently based on false and discriminatory assumptions about the sexuality and ability of women with disabilities to parent or are based on the desire to control their menstrual cycles[[63]](#endnote-63) and, as the Special Rapporteur noted in her 2017 report, are also considered severe human rights violations, including forms of torture or ill-treatment.[[64]](#endnote-64)

Too often, however, States fail to prevent—and sometimes legally condone—reproductive health procedures on women and girls with disabilities without informed consent.

* In **Nigeria**, the families of women with mental disabilities reported that they sometimes had contraceptive devices implanted in the women’s skin, without the women’s consent, so that these women would avoid getting pregnant if they were subjected to sexual abuse.[[65]](#endnote-65) Some families also reported that they had forcibly confined or sterilized women with disabilities for similar protective reasons,[[66]](#endnote-66) though forced sterilization of women with disabilities in Nigeria is not yet widely documented.
* In **India**, as recently as 2008, the government of Maharashtra supported a policy of forcibly sterilizing “mentally challenged” women and girls in institutions as a means of ensuring “menstrual hygiene” or the elimination of periods.[[67]](#endnote-67) There is no existing legal provision that prohibits non-consensual sterilization, and in recent years, sterilization methods using certain drugs has been tested on a large scale instead of teaching women with disabilities to manage menstrual hygiene and ensuring that they are protected from rape.[[68]](#endnote-68)
* Furthermore, in **India**, under the Medical Termination of Pregnancy Act, 1971 (as amended in 2002), guardians can consent to abortions for women with psychosocial disabilities, leading to forced abortions.[[69]](#endnote-69) 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. The Court in fact distinguished between psychosocial and intellectual disabilities, stating that, as per the law, a guardian could still provide consent for terminating pregnancies of women with psychosocial disabilities.[[70]](#endnote-70)
* In **Kenya**, a case of forced sterilization has been reported and is currently being challenged in the Kenyan courts.[[71]](#endnote-71) Evidence received by organizations of persons with disabilities[[72]](#endnote-72) points to women with intellectual disabilities and psychosocial disabilities having contraception administered to them against their will within the community,[[73]](#endnote-73) and a study by the Kenya National Commission on Human Rights on the rights of persons with disabilities found that “persons with disabilities were not being allowed to make choices on the mode of family planning with nurses dictating which methods to use.”[[74]](#endnote-74)

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.[[75]](#endnote-75) In 2011, FIGO adopted guidelines specifically regarding female contraceptive sterilization, stating that only women themselves can give ethically valid consent to their own sterilization.[[76]](#endnote-76) 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.[[77]](#endnote-77) 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.[[78]](#endnote-78) According to U.N. agency guidelines addressing this issue, if informed consent cannot be immediately obtained for non-life-saving measures, those measures should not be performed.[[79]](#endnote-79) 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.”[[80]](#endnote-80) This means that sterilization without consent for such purposes as menstrual hygiene or the regulation of periods would also be a violation of the right to informed consent.

Where women with disabilities are stripped of legal capacity, either formally or informally, they are also not permitted to make important decisions about their lives and their health, including related to their SRHR.

* In **Kenya**, there are a number of reported cases of forced sterilization,[[81]](#endnote-81) and with regards to women with disabilities, it is the guardians who are consenting to sterilization on their behalf.[[82]](#endnote-82) A Kenya’s legislative and policy framework still allows for substituted decision-making on a broad range of issues includingmarriage[[83]](#endnote-83) and makes no provision for supported decision-making.[[84]](#endnote-84) In practice, women and girls with disabilities in Kenya experience informal substitute decision-makingwhere their families make decisions for them in many spheres of life, even in cases where they are not under formal guardianship. Such decisions include reproductive health decision-making of the women with disabilities[[85]](#endnote-85) including forced sterilization, forced abortion and caesarian sections instead of vaginal delivery.
* In **India**, although the Ministry of Health issued guidelines in 2006 to prevent sterilization without informed consent, these guidelines do not address the situation of when a guardian or parent gives consent for a woman or girl with disabilities to undergo sterilization.[[86]](#endnote-86) Furthermore, these guidelines do not provide guidance on how to ensure reasonable accommodation and support to ensure that women with disabilities give their informed consent to sterilization.[[87]](#endnote-87)
1. Inclusion of Women and Girls with Disabilities in Health Care Policymaking and Programs

Despite the unique and disproportionate violations women with disabilities face in the context of the right to health, they are frequently excluded from laws, policies, and programs intended to ensure health care. They are also frequently and more broadly excluded from public participation in decisions that affect them, a situation that impacts their right to health in several respects.

* In **Poland**, according to a 2017 case study from the European Union, “[a]t the moment, women with disabilities do not exist in a public discourse as a specific group with specific needs. As a consequence, their problems are not being tackled.”[[88]](#endnote-88)
* In 2014, **Nigeria** adopted the HIV and AIDS (Anti-Discrimination) Act, which guarantees a right to be free from discrimination based on HIV status but fails to take into account the situation of persons with disabilities, particularly women with disabilities, in several respects, including by neglecting to ensure that they receive reasonable accommodation and neglecting to address issues they face disproportionately—including higher rates of sexual violence and lack of access to sexuality education—that increase the risk of HIV.[[89]](#endnote-89)
* In **Kenya**, the Reproductive Health Bill of 2014[[90]](#endnote-90) still allows guardians or parents to make the decision to undergo an abortion for a “mentally unstable person”—which includes women with intellectual or psychosocial disabilities—to undergo what amounts to a forced abortion.[[91]](#endnote-91) Furthermore, the bill does not address the issue of sterilization without the informed consent of women with disabilities, an all-too-common occurrence in Kenya.
1. Conclusions and Recommendations for the Special Rapporteur on the Rights of Persons with Disabilities

Although women and girls with disabilities make up a substantial portion of the world population, their right to health is frequently ignored, and they face severe abuses in health care settings—particularly sexual and reproductive health care settings—that deny them agency and the ability to found a family. These abuses are frequently distinct from or occur disproportionately to those experienced by men and boys with disabilities or other women.

As part of her report on the right to health, our organizations hope that the Special Rapporteur on the Rights of Persons with Disabilities recognizes the following key points related to the right to health for women and girls with disabilities:

* The scale of abuses against women and girls with disabilities in sexual and reproductive health care settings is significant and cannot be attributed solely to a State’s lack of resources. Indeed, many of these abuses—including forced sterilization, contraception, and abortion, but also physical, informational/communications, financial, and attitudinal barriers to care—occur in both developing and developed countries.
* Violations of the right to health and abuses against women and girls with disabilities in health care settings occur because of multiple and intersectional discrimination based on both their gender and disability. In particular, women and girls with disabilities face abuses in this context because they are perceived as not being able to adequately fulfill the discriminatory gendered role of being mothers and caregivers, leading to further discrimination.
* Formal and informal deprivations of legal capacity or decision-making authority disproportionately affect women and girls with disabilities in the context of the right to health, as they are more frequently subjected to reproductive health procedures and medications without their consent and with only the consent of a guardian or doctor.
* Lack of provider training contributes to violations to 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, as a means of changing attitudes and practices and encouraging the accessibility of health information and services, particularly in the context of sexual and reproductive health.
* Women and girls with disabilities are frequently left out of decision-making processes about sexual and reproductive health, and resulting laws, policies, and programs rarely reflect their priorities, rights, and lived experiences. It is imperative that women with disabilities be included in all policymaking and the design, implementation, and monitoring of programs related to health, particularly sexual and reproductive health.

Thank you for your time and attention to this submission. Please do not hesitate to contact the authors listed above should you have any questions or require further information. More details on specific country situations can be found in Annex A – Kenya, Annex B – Nigeria, Annex C – Poland, and Annex D – India, all attached.

1. Throughout this submission, the term “women” will be used to refer to women and girls of all ages, unless otherwise noted. [↑](#endnote-ref-1)
2. 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). [↑](#endnote-ref-2)
3. *Id,* **¶** 44. [↑](#endnote-ref-3)
4. *Id.* [↑](#endnote-ref-4)
5. *Id.* [↑](#endnote-ref-5)
6. CEDAW Committee, *General Recommendation No. 24: Article 12 of the Convention (women and health)*, ¶¶ 10-11, U.N. Doc. CEDAW/C/GC/24 (1999). [↑](#endnote-ref-6)
7. *Id.*, ¶ 12, [↑](#endnote-ref-7)
8. ESCR Committee, *General Comment No. 14: The right to the highest attainable standard of health (article 12 of the International Covenant on Economic, Social and Cultural Rights)*, **¶** 14, U.N. Doc. E/C.12/2000/4 (2000). [↑](#endnote-ref-8)
9. CEDAW Committee, *General Recommendation No. 24: Article 12 of the Convention (women and health)*, ¶ 12, U.N. Doc. CEDAW/C/GC/24 (1999). [↑](#endnote-ref-9)
10. CEDAW Committee, *General Recommendation No. 35 on gender-based violence against women, updating general recommendation No. 19*, ¶ 18, U.N. Doc. CEDAW/C/GC/35 (2017). [↑](#endnote-ref-10)
11. CRPD Committee, *General Comment No. 3: Article 6: Women and girls with disabilities*, ¶ 38, U.N. Doc. CRPD/C/GC/3 (2016). [↑](#endnote-ref-11)
12. 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-12)
13. CRPD Committee, *General Comment No. 3: Article 6: Women and girls with disabilities*, ¶ 38, U.N. Doc. CRPD/C/GC/3 (2016). [↑](#endnote-ref-13)
14. 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-14)
15. 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. [↑](#endnote-ref-15)
16. *Id.* [↑](#endnote-ref-16)
17. See Annex A (Kenya), pgs. 2 & 3. [↑](#endnote-ref-17)
18. Enhancing Nigeria’s HIV/AIDS Response (ENR) Programme, HIV/AIDS and Sexual Behaviours of Persons with Disabilities in Nigeria 22 (2015). [↑](#endnote-ref-18)
19. CRPD Committee, *General Comment No. 3: Article 6: Women and girls with disabilities*, ¶ 40, U.N. Doc. CRPD/C/GC/3 (2016). [↑](#endnote-ref-19)
20. See Annex C (Poland), pg. 2. [↑](#endnote-ref-20)
21. 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. [↑](#endnote-ref-21)
22. See Annex C (Poland), pg. 2. [↑](#endnote-ref-22)
23. See Annex A (Kenya), pg. 5. [↑](#endnote-ref-23)
24. See Annex A (Kenya), pg. 4. [↑](#endnote-ref-24)
25. See Annex A (Kenya), pg. 4. [↑](#endnote-ref-25)
26. 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. [↑](#endnote-ref-26)
27. CRPD Committee, *General Comment No. 3: Article 6: Women and girls with disabilities*, ¶¶ 50, 56, 58, U.N. Doc. CRPD/C/GC/3 (2016). [↑](#endnote-ref-27)
28. See Annex A (Kenya), pg. 3. [↑](#endnote-ref-28)
29. See Annex A (Kenya), pg. 4. [↑](#endnote-ref-29)
30. See Annex B (Nigeria), pg. 3. [↑](#endnote-ref-30)
31. *See, e.g.*,CRPD Committee, *General Comment No. 3: Article 6: Women and girls with disabilities*, ¶ 19, U.N. Doc. CRPD/C/GC/3 (2016). [↑](#endnote-ref-31)
32. *Id.*, ¶ 38. [↑](#endnote-ref-32)
33. 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. [↑](#endnote-ref-33)
34. *Id.* [↑](#endnote-ref-34)
35. *Id.* at 85. [↑](#endnote-ref-35)
36. Inclusive Friends & Nigeria Stability and Reconciliation Programme, What Violence Means to Us: Women with Disabilities Speak 13-14 (2015). [↑](#endnote-ref-36)
37. See Annex A (Kenya), pg. 4. [↑](#endnote-ref-37)
38. See Annex A (Kenya), pg. 5-6. [↑](#endnote-ref-38)
39. See Annex A (Kenya), pg. 4. [↑](#endnote-ref-39)
40. 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. [↑](#endnote-ref-40)
41. *Id.* [↑](#endnote-ref-41)
42. *Id.* [↑](#endnote-ref-42)
43. See Annex A (Kenya), pg. 3. [↑](#endnote-ref-43)
44. Inclusive Friends & Nigeria Stability and Reconciliation Programme, What Violence Means to Us: Women with Disabilities Speak 14 (2015). [↑](#endnote-ref-44)
45. World Health Organization, *Maternal Mortality*: *Factsheet No. 348* (Nov. 2015), http://www.who.int/ mediacentre/factsheets/fs348/en/. [↑](#endnote-ref-45)
46. *See, e.g.*, 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),*¶ 27, U.N. Doc. E/C.12/GC/22 (2016). [↑](#endnote-ref-46)
47. CRPD Committee, *General Comment No. 3: Article 6: Women and girls with disabilities*, ¶ 38, U.N. Doc. CRPD/C/GC/3 (2016). [↑](#endnote-ref-47)
48. Inclusive Friends & Nigeria Stability and Reconciliation Programme, What Violence Means to Us: Women with Disabilities Speak 12 (2015). [↑](#endnote-ref-48)
49. *Id.* [↑](#endnote-ref-49)
50. *Id.* [↑](#endnote-ref-50)
51. See Annex B (Nigeria), pg. 3. [↑](#endnote-ref-51)
52. See Annex B (Nigeria), pg. 3. [↑](#endnote-ref-52)
53. Agnieszka Wołowicz-Ruszkowska, *How Polish Women With Disabilities Challenge the Meaning of Motherhood*, in 40(1) Psych. of Women Quarterly 80, 86 (2015), *available at* http://journals.sagepub.com/doi/pdf/10.1177/ 0361684315600390. [↑](#endnote-ref-53)
54. See Annex A (Kenya), pg. 3. [↑](#endnote-ref-54)
55. See Annex A (Kenya), pg. 10. [↑](#endnote-ref-55)
56. Agnieszka Wołowicz-Ruszkowska, *How Polish Women With Disabilities Challenge the Meaning of Motherhood*, in 40(1) Psych. of Women Quarterly 80, 86 (2015), *available at* http://journals.sagepub.com/doi/pdf/10.1177/0361684315600390. [↑](#endnote-ref-56)
57. CRPD Committee, *General Comment No. 3: Article 6: Women and girls with disabilities*, **¶** 51, U.N. Doc. CRPD/C/GC/3 (2016), [↑](#endnote-ref-57)
58. UN Special Rapporteur on Violence against Women, *Report of the Special Rapporteur on violence against women, its causes and consequences*,**¶¶** 28 & 36, U.N. Doc. A/67/227 (2012). [↑](#endnote-ref-58)
59. World Health Organization, et al, *Eliminating forced, coercive or otherwise involuntary sterilization: An interagency statement* 1 (2014), *available at* http://apps.who.int/iris/bitstream/10665/112848/1/9789241507325\_ eng.pdf. [↑](#endnote-ref-59)
60. Human Rights Council, *Report of the Special Rapporteur on the Rights of Persons with Disabilities: Sexual and reproductive health and rights of girls and young women with disabilities*, **¶** 29, U.N. Doc. A/72/133 (2017). [↑](#endnote-ref-60)
61. CRPD Committee, *General Comment No. 3: Article 6: Women and girls with disabilities*, ¶ 44, U.N. Doc. CRPD/C/GC/3 (2016). [↑](#endnote-ref-61)
62. *Id.* [↑](#endnote-ref-62)
63. UN Special Rapporteur on Violence against Women, *Report of the Special Rapporteur on violence against women, its causes and consequences*,**¶¶** 28 & 36, U.N. Doc. A/67/227 (2012). [↑](#endnote-ref-63)
64. CEDAW Committee, *General Recommendation No. 24: Article 12 of the Convention (women and health)*, (20th Sess., 1999), in Compilation of General Comments and General Recommendations Adopted by Human Rights Treaty Bodies, **¶** 22, U.N. Doc. HRI/GEN/1/Rev.9 (Vol. II) (2008); CRPD Committee, *General Comment No. 1: Article 12: Equal recognition before the law,* U.N. Doc. CRPD/C/GC/1 (2014); Human Rights Committee, *Concluding Observations: Czech Republic*, **¶** 11, U.N. Doc CCPR/C/CZE/CO/3 (2013); CAT Committee, *Concluding Observations: Czech Republic*, **¶** 12, U.N. Doc. CAT/C/CZE/CO/4-5 (2012); Human Rights Council, *Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, Juan E. Mendez*, **¶** 48, U.N. Doc. A/HRC/22/53 (2013). [↑](#endnote-ref-64)
65. Inclusive Friends & Nigeria Stability and Reconciliation Programme, What Violence Means to Us: Women with Disabilities Speak 19 (2015). [↑](#endnote-ref-65)
66. *Id.* [↑](#endnote-ref-66)
67. Ashika Misra, *Is hysterectomy the final solution?,* DNA India, Jan. 30, 2008, http://www.dnaindia.com/mumbai/ report-is-hysterectomy-the-final-solution-11482. [↑](#endnote-ref-67)
68. Women with Disabilities India Network, *Meeting in Bangalore*, Feb. 4, 2012. [↑](#endnote-ref-68)
69. Medical Termination of Pregnancy Act, 1971, § 3(4)(a) (1971) (India). [↑](#endnote-ref-69)
70. Supreme Court of India, *Suchita Srivastava & Anr vs Chandigarh* (2009), *available at* https://indiankanoon.org/ doc/1500783/. [↑](#endnote-ref-70)
71. Kenya Legal and Ethical Issues Network on HIV (KELIN), “5 cases of forced and coerced sterilization filed in the High Court of Kenya” (news release) (2014), *available at* http://gem.or.ke/5-cases-of-forced-and-coerced-sterilization-filed-in-the-highcourt-of-kenya/; Petition 605 of 2014 SWK & 5 others v Medecins Sans Frontieres- France & 10 others (2016), *available at* http://kenyalaw.org/caselaw/cases/view/125001/. [↑](#endnote-ref-71)
72. See Annex A (Kenya), pg. 4. [↑](#endnote-ref-72)
73. National Survey on Disability by National Council for Population and Development (Kenya) (2007). [↑](#endnote-ref-73)
74. Kenya National Commission on Human Rights, *From Norm to Practice: A Status Report on Implementation of the Rights of Persons with Disabilities in Kenya* 25 (2014), *available at* http://knchr.org/Portals/0/Reports/Disability%20Report.pdf. [↑](#endnote-ref-74)
75. 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. World Health Organization (WHO), A Declaration on the Promotion of Patients' Rights in Europe, ICP/HLE 121, Art. 3.1 (1994); UN Office of the High Commissioner for Human Rights, *Istanbul Protocol, Manual on the Effective Investigation and Documentation of Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment*, ¶ 63, U.N. Doc. HR/P/PT/8/Rev.1 (2004) (“an absolutely fundamental precept of modern medical ethics is that patients themselves are the best judge of their own interests.”); Convention for the Protection of Human Rights and Dignity of the Human Being with Regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine, art. 5, adopted Apr. 4, 1997, Eur. T.S. No. 164 (entered into force Dec. 1, 2009); International Federation of Gynecology and Obstetrics (FIGO), Guidelines regarding informed consent, in Ethical Issues in Obstet & Gynec. 13-14 (Oct. 2009). [↑](#endnote-ref-75)
76. FIGO, *Female Contraceptive Sterilization*, 115 Int'l J. of Gynecology And Obstetrics 88, 88-89, ¶ 8 (2011). [↑](#endnote-ref-76)
77. *Id.* [↑](#endnote-ref-77)
78. *Id.* [↑](#endnote-ref-78)
79. World Health Organization, et al, *Eliminating forced, coercive or otherwise involuntary sterilization: An interagency statement* 9 (2014), *available at* http://apps.who.int/iris/bitstream/10665/112848/1/9789241507325\_ eng.pdf. [↑](#endnote-ref-79)
80. *Id.* [↑](#endnote-ref-80)
81. Mental Disability Advocacy Center, *The Right to Legal Capacity in Kenya* 5 (March 2014), *available at* http://www.mdac.info/en/kenya, [↑](#endnote-ref-81)
82. *Id.* at 46, 71 [↑](#endnote-ref-82)
83. The Marriage Act 2014, §§ 11(2)(c), 12, 66(6)(g), 73(1)(g) (Kenya). [↑](#endnote-ref-83)
84. In its Concluding Observations to Kenya on Article 12, the CRPD Committee recommended to Kenya to “eliminate all forms of formal and informal substituted decision-making regimes and replace them with a system of supported decision-making, in line with the Committee’s general comment No. 1 (2014) on equal recognition before the law.” CRPD Committee, *Concluding Observations: Kenya*, ¶ 24(a), U.N. Doc. CRPD/C/KEN/CO/1 (2015). [↑](#endnote-ref-84)
85. Kenya National Commission on Human Rights, F*rom Norm to Practice: A Status Report on Implementation of the Rights of Persons with Disabilities in Kenya* 25-26 (2014), *available at* http://knchr.org/Portals/0/Reports/Disability%20Report.pdf; Kenya National Commission on Human Rights, Realizing Sexual and Reproductive Health Rights in Kenya: A myth or a Reality? *A Report of the Public Inquiry into Violations of Sexual and Reproductive Health Rights in Kenya* 111-115 (2012), *available at* http://www.knchr.org/Portals/0/Reports/Reproductive\_health\_report.pdf. [↑](#endnote-ref-85)
86. See Annex D (India), pg. 1. [↑](#endnote-ref-86)
87. See Annex D (India), pg. 1. [↑](#endnote-ref-87)
88. European Parliament, *Study on Discrimination and Access to Employment for Female Workers with Disabilities* 21 (2017), *available at* http://www.europarl.europa.eu/RegData/etudes/STUD/2017/602067/IPOL\_STU(2017) 602067(ANN04)\_EN.pdf. [↑](#endnote-ref-88)
89. HIV and AIDS (Anti-Discrimination) Act, 2014, § 3 (Nga.) [↑](#endnote-ref-89)
90. The Reproductive Health Care Bill 2014 (Kenya), *available at* http://kenyalaw.org/kl/fileadmin/pdfdownloads/bills/2014/ReproductiveHealthCareBill2014\_\_1\_.pdf. [↑](#endnote-ref-90)
91. *Id.* at § 20. [↑](#endnote-ref-91)