

Submission to Special Rapporteur on the Rights of Persons with Disabilities Report on the Right to Health for Persons with Disabilities

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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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I. Introduction

Women and girls¹ 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.

II. 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 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 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 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

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 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 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

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 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 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 These situations create unique and disproportionate risks of violations of the right to health for women and girls with disabilities.

III. 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 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 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

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 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
- 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
- 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 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 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

- 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
- 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
- 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

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 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
- 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

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 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
- 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
- In Nigeria, a woman with a spinal cord injury reported that treatment for that injury was very expensive.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 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 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 In reality, pregnancy for women with disabilities is not necessarily more "high risk" than it is for other women.³⁴ Furthermore, these women reported that there was generally a lack of specialized care available to them.³⁵
- In Nigeria, health care workers frequently lack knowledge about or experience with managing care for women with disabilities.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 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
- 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

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 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 This treatment increased their sense of isolation, vulnerability, and lack of self-determination.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
- 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 a situation that can increase the risk of complications during pregnancy and labor.⁴⁵

IV. 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 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

- 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 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 Indeed, women who acquire a disability during their marriage may be abandoned by partners who cannot cope with the stigma associated with disability.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
 - 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
- 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
- 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

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
- 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

V. 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 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 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

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 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 When women with disabilities are deprived of legal capacity, this can "facilitate forced interventions, such as: sterilisation, abortion, [and] contraception…"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 cycles⁶³ 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

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 Some families also reported that they had forcibly confined or sterilized women with disabilities for similar protective reasons,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 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
- 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 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

• In Kenya, a case of forced sterilization has been reported and is currently being challenged in the Kenyan courts.⁷¹ Evidence received by organizations of persons with disabilities⁷² points to women with intellectual disabilities and psychosocial disabilities having contraception administered to them against their will within the community,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

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 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 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 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 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 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 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 and with regards to women with disabilities, it is the guardians who are consenting to sterilization on their behalf.⁸² A Kenya's legislative and policy framework still allows for substituted decision-making on a broad range of issues including marriage⁸³ and makes no provision for supported decision-making.⁸⁴ In practice, women and girls with disabilities in Kenya experience informal substitute decision-making where 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 disabilities⁸⁵ 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 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

VI. 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
- 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
- In **Kenya**, the Reproductive Health Bill of 2014⁹⁰ 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 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.
 - VII. 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.

- 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).
- ¹¹ CRPD Committee, *General Comment No. 3: Article 6: Women and girls with disabilities*, ¶ 38, U.N. Doc. CRPD/C/GC/3 (2016).
- ¹² CEDAW Committee, General Recommendation No. 24: Article 12 of the Convention (women and health), ¶ 25, U.N. Doc. CEDAW/C/GC/24 (1999).
- ¹³ CRPD Committee, *General Comment No. 3: Article 6: Women and girls with disabilities*, ¶ 38, U.N. Doc. CRPD/C/GC/3 (2016).
- ¹⁴ CEDAW Committee, *General Recommendation No. 24: Article 12 of the Convention (women and health)*, ¶ 25, U.N. Doc. CEDAW/C/GC/24 (1999).
- 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.

- ¹⁷ See Annex A (Kenya), pgs. 2 & 3.
- ¹⁸ ENHANCING NIGERIA'S HIV/AIDS RESPONSE (ENR) PROGRAMME, HIV/AIDS AND SEXUAL BEHAVIOURS OF PERSONS WITH DISABILITIES IN NIGERIA 22 (2015).
- ¹⁹ CRPD Committee, *General Comment No. 3: Article 6: Women and girls with disabilities*, ¶ 40, U.N. Doc. CRPD/C/GC/3 (2016).

- 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.
- ²² See Annex C (Poland), pg. 2.
- ²³ See Annex A (Kenya), pg. 5.
- ²⁴ See Annex A (Kenya), pg. 4.

¹ Throughout this submission, the term "women" will be used to refer to women and girls of all ages, unless otherwise noted.

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).

 $^{^{3}}$ *Id*, ¶ 44.

⁴ Id.

⁵ Id.

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).

⁷ *Id.*, ¶ 12,

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).

⁹ CEDAW Committee, *General Recommendation No. 24: Article 12 of the Convention (women and health)*, ¶ 12, U.N. Doc. CEDAW/C/GC/24 (1999).

¹⁶ Id.

²⁰ See Annex C (Poland), pg. 2.

- ²⁵ See Annex A (Kenya), pg. 4.
- 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.
- 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).
- ²⁸ See Annex A (Kenya), pg. 3.
- ²⁹ See Annex A (Kenya), pg. 4.
- ³⁰ See Annex B (Nigeria), pg. 3.
- 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).
- ³² *Id.*, ¶ 38.
- 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.
- ³⁴ Id.
- ³⁵ *Id.* at 85.
- ³⁶ INCLUSIVE FRIENDS & NIGERIA STABILITY AND RECONCILIATION PROGRAMME, WHAT VIOLENCE MEANS TO US: WOMEN WITH DISABILITIES SPEAK 13-14 (2015).
- ³⁷ See Annex A (Kenya), pg. 4.
- ³⁸ See Annex A (Kenya), pg. 5-6.
- ³⁹ See Annex A (Kenya), pg. 4.
- 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.
- ⁴¹ *Id*.
- ⁴² Id.
- ⁴³ See Annex A (Kenya), pg. 3.
- ⁴⁴ INCLUSIVE FRIENDS & NIGERIA STABILITY AND RECONCILIATION PROGRAMME, WHAT VIOLENCE MEANS TO US: WOMEN WITH DISABILITIES SPEAK 14 (2015).
- ⁴⁵ World Health Organization, *Maternal Mortality: Factsheet No. 348* (Nov. 2015), http://www.who.int/ mediacentre/factsheets/fs348/en/.
- 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).
- ⁴⁷ CRPD Committee, *General Comment No. 3: Article 6: Women and girls with disabilities*, ¶ 38, U.N. Doc. CRPD/C/GC/3 (2016).
- ⁴⁸ INCLUSIVE FRIENDS & NIGERIA STABILITY AND RECONCILIATION PROGRAMME, WHAT VIOLENCE MEANS TO US: WOMEN WITH DISABILITIES SPEAK 12 (2015).

- ⁵⁰ *Id*.
- ⁵¹ See Annex B (Nigeria), pg. 3.
- ⁵² See Annex B (Nigeria), pg. 3.
- 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.
- ⁵⁴ See Annex A (Kenya), pg. 3.
- ⁵⁵ See Annex A (Kenya), pg. 10.
- 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.
- ⁵⁷ CRPD Committee, General Comment No. 3: Article 6: Women and girls with disabilities, ¶ 51, U.N. Doc. CRPD/C/GC/3 (2016),
- 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).

⁴⁹ Id.

- 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.
- 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).
- ⁶¹ CRPD Committee, *General Comment No. 3: Article 6: Women and girls with disabilities*, ¶ 44, U.N. Doc. CRPD/C/GC/3 (2016).

- 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).
- 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. CAT/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).
- ⁶⁵ INCLUSIVE FRIENDS & NIGERIA STABILITY AND RECONCILIATION PROGRAMME, WHAT VIOLENCE MEANS TO US: WOMEN WITH DISABILITIES SPEAK 19 (2015).

- 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.
- ⁶⁸ Women with Disabilities India Network, *Meeting in Bangalore*, Feb. 4, 2012.
- ⁶⁹ Medical Termination of Pregnancy Act, 1971, § 3(4)(a) (1971) (India).
- ⁷⁰ Supreme Court of India, Suchita Srivastava & Anr vs Chandigarh (2009), available at https://indiankanoon.org/ doc/1500783/.
- 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-coercedsterilization-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/.
- ⁷² See Annex A (Kenya), pg. 4.
- ⁷³ National Survey on Disability by National Council for Population and Development (Kenya) (2007).
- 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.
- http://knchr.org/Portals/0/Reports/Disability%20Report.pdf.
 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

Guidelines regarding informed consent, in ETHICAL ISSUES IN OBSTET & GYNEC. 13-14 (Oct. 2009).

- 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.
- ⁸⁰ Id.
- ⁸¹ Mental Disability Advocacy Center, *The Right to Legal Capacity in Kenya* 5 (March 2014), *available at* http://www.mdac.info/en/kenya,

⁶² Id.

⁶⁶ Id.

⁽entered into force Dec. 1, 2009); INTERNATIONAL FEDERATION OF GYNECOLOGY AND OBSTETRICS (FIGO),

⁷⁶ FIGO, *Female Contraceptive Sterilization*, 115 INT'L J. OF GYNECOLOGY AND OBSTETRICS 88, 88-89, ¶ 8 (2011). ⁷⁷ Id.

 $^{^{78}}$ Id.

⁸² Id. at 46, 71

- ⁸³ The Marriage Act 2014, §§ 11(2)(c), 12, 66(6)(g), 73(1)(g) (Kenya).
- 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: Kenva, ¶ 24(a), U.N. Doc. CRPD/C/KEN/CO/1 (2015).
- ⁸⁵ Kenya National Commission on Human Rights, From Norm to Practice: A Status Report on Implementation of the Rights of Persons with Disabilities in Kenya 25-26 (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.
- ⁸⁶ See Annex D (India), pg. 1.
- ⁸⁷ See Annex D (India), pg. 1.
- 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.
- ⁸⁹ HIV and AIDS (Anti-Discrimination) Act, 2014, § 3 (Nga.)
- ⁹⁰ The Reproductive Health Care Bill 2014 (Kenva), available at
- http://kenyalaw.org/kl/fileadmin/pdfdownloads/bills/2014/ReproductiveHealthCareBill2014 1 .pdf. ⁹¹ *Id.* at § 20.

Annex A – Kenya

This information was compiled by This-Ability Consulting.

INTRODUCTION

Kenya is a state party to various international and regional human rights instruments that guarantee the right to sexual and reproductive health. The government has also developed a number of policies and established various institutions that seek to promote and protect the sexual and reproductive health rights of Kenyans. As such, Kenya is obligated to work towards the fulfillment of this right in line with these international and domestic standards. These include the Convention on the Rights of People with Disabilities, Kenyan Constitution 2010, Kenya Health Policy 2012-2030, the National Reproductive Health Policy 2007, the National Reproductive Health Strategy 2009-2015, the Adolescent Reproductive Health and Development Policy, 2003 and the current Reproductive Health Care Bill, 2014.

The Constitution of Kenya 2010, for one, guarantees the right to health care including reproductive health. It further provides that no one shall be denied emergency medical treatment and that the State shall provide appropriate social security to persons who are unable to support themselves and their dependants. (Article 43(1) (a) (2) and (3)).

In spite of this, we still are a long way from the actualization of this ideal. While the government may have made strides in the rights of women, it needs to recognize sexual and reproductive health and rights as an issue disproportionately affecting women and girls with disabilities with a focus on right to health care, right to decision making on family planning, legal capacity, right to marriage and family, violence against women with disabilities and institutionalization and access to justice as outlined in this report.

BARRIERS TO HEALTHCARE FOR WOMEN AND GIRLS WITH DISABILITIES

Women with disabilities in Kenya face numerous challenges in accessing sexual and reproductive health.

1. Cultural beliefs

There still are cultural beliefs in practice which regard women with disabilities as "damaged" and "cursed". This attitude stems from ignorance and a belief that women with disabilities are victims of curses and punishment from the gods, as a result they are considered asexual.

2. Lack of government intervention in the situation

The government has failed to promote policies that facilitate access to sexual and reproductive services by women with disabilities. Even the enacted policies in existence which would be advantageous if implemented have been ignored. For example, the provision those public buildings should be made accessible to people with disabilities by conforming to a set guideline for construction, failure of which will attract penalty.¹ This means then 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. Enactment of these policies would require a dedicated budgetary allocation which has not been done for lack of political goodwill.

¹ Persons with Disability Act 2003 (Kenya) sec. 22, *available at* <u>https://dredf.org/legal-advocacy/international-disability-rights/international-laws/kenya-persons-with-disabilities-act/</u>

3. Societal stigma

The needs of persons with disabilities, including women with disabilities, still remain a peripheral issue. People with disabilities continue to be treated as secondclass 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. This internalized stigma also causes the women with disabilities to shy away from visiting health institutions to seek information and services.

Female nurses were cited as major culprits in insulting women with disabilities when they visit hospitals when they are pregnant or present for treatment.

4. Physical barriers

Many clinics and hospitals are located far away from the residences of many of the respondents. Necessitating long walks which may be impossible. For those who rely on personal aid for mobility, the process of accessing the nearest health facility is expensive because on public transport they had to pay for two people – themselves and their assistants. In some cases, they have pay for their wheelchairs as well.

Inaccessible buildings and facilities are also cited as impediments to access sexual and reproductive services.

Women with physical disabilities cited the unhygienic nature of pit latrines which were always dirty and not user friendly as a challenge they face when they visit health centers to seek sexual and reproductive health services.

5. Financial barriers

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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.

6. Lack of privacy

Women with disabilities are often not granted the privacy they require or that is usually accorded to other women. This serves as a deterrent among these women to visiting health centers because they feel that their privacy will be violated by health staff. Health staff often are not conversant with how to relate to people with disabilities, especially in the presence of their helpers.

More often than not, they communicate to the person with a disability through the third person instead of communicating directly with the person concerned. This limits the extent to which women with disabilities could freely share confidential sexual and reproductive health information with health workers.

7. Lack of staff trained in Sign language

Deaf women highlighted that their biggest challenge is medical personnel who do not understand sign language. This prevents deaf people from getting quality and relevant information and services on sexual and reproductive health.

Women and girls with disabilities also felt that they were not being given enough attention by medical personnel when they visited the hospital and clinics. A woman with a speech impairment stated that owing to the large numbers of people they have to deal with, doctors and nurses get impatient with patients with similar impairments. As a result, people with speech disabilities do not get the opportunity to fully explain their problems.

8. Informational Barriers

The sources of information which women with disabilities have to rely on are not tailored to their needs. For example, illiteracy is one of the major factors hindering access to important information. The same applies to written material not accessible to blind women or women/girls with intellectual disabilities. Such inaccessible formats form an impossible barrier to information. This occurs also when adolescents are excluded from or not given access to sexuality education programs due to assumptions that they do not need this information, and even when they access it, most of the equipment remains out of reach for the reason that they are not designed with women with disabilities in mind.

9. Lack of inclusion

The Kenya Disability Act provides that the interests of people with disabilities be represented by the National Council for Persons with Disabilities. This council (NCPWD) then is supposed to be included in formulation of and implementation of national health policies. This has not been done and for this reason the voices and concerns of women with disabilities which would have been presented go unheard.

ACCESS TO JUSTICE

Women with disabilities face many barriers when accessing the justice system, including physical barriers. The State, to this end, has made reforms in the

judiciary like having Court User Committees, mobile courts, but there is need for further commitment with regards to women and girls with disabilities.

According to a study conducted by Kenya Association for the Intellectually Handicap (KAIH), women and girls with intellectual disabilities face numerous challenges in accessing justice² where police and health service providers do not take such cases seriously and do know how to handle them to ensure they communicate effectively and offer the required services and support.

Case Study on Gender Based Violence and Access to Health Care

Rukia (not her real name), a young lady with intellectual disability was raped by her uncle. The mother rushed her to Coast General Hospital, a government hospital in Mombasa County, to get medical assistance. It was on Saturday and she found that the gender based violence recovery center was closed. On asking for assistance from the medical personnel on duty, she was told to come back on Monday when it is opened and no medical attention was given to Rukia. As Rukia and the mother were going home, she decided to call the Director of Kenya Association of the Intellectually Handicap (KAIH) for help as she did not know what to do. It took the intervention of the Director to look for the number of the hospital or anyone working at the facility to get assistance. She had to hold the hospital personnel to account and demand for the young lady to be examined and given proper medical care including post exposure prophylaxis (PEP) and medication to prevent her from getting pregnant. The hospital had also denied her the PEP saying she should go buy it herself. Upon the organizations demanding for the same to be provided, they were able to give her the medication which is to

² Kenya Association for the Intellectually Handicapped, 'Access to the criminal justice system by persons with intellectual disabilities as victims of crime: barriers and opportunities' 2016 (on file with author).

be given free of charge. This means that they had the drugs but did not want to give her. This is the story of many sexual violence survivors with disabilities and many do not have KAIH intervening for them and demanding action. If she was to come back on Monday, evidence would have been destroyed as she would have showered therefore interfering with evidence crucial in the case, she may have gotten pregnant or contracted a sexual transmitted infection including HIV.³

Such violations of the right to access of justice are directly linked to violation of sexual and reproductive health rights.

FREE AND INFORMED CONSENT IN THE CONTEXT OF HEALTH CARE PARTICULARLY SRHR IN KENYA

The Reproductive Health Bill of 2014⁴ has a strong definition of informed consent that ensures that women themselves make the decision to undergo reproductive health procedures.⁵ However, under the section on abortion, the bill still allows guardians or parents to make the decision for a "mentally unstable person"—which includes women with intellectual or psychosocial disabilities—to undergo what amounts to a forced abortion.⁶ 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 and a serious human rights violation, including a violation of the right to found a family and a violation of the right to be free from

⁴ The Reproductive Health Care Bill 2014 (Kenya), *available at*

³ Case handled by Kenya Association for the Intellectual Handicapped (KAIH) in 2016.

http://kenyalaw.org/kl/fileadmin/pdfdownloads/bills/2014/ReproductiveHealthCareBill2014 1_.pdf accessed on 14th September 2017.

⁵ The Reproductive Health Care Bill 2014 (Kenya), sec. 2, *available at* <u>http://kenyalaw.org/kl/fileadmin/pdfdownloads/bills/2014/ReproductiveHealthCareBill2014_1.pdf</u> accessed on 14th September 2017.

⁶ The Reproductive Health Care Bill 2014 (Kenya), sec. 20, *available at* <u>http://kenyalaw.org/kl/fileadmin/pdfdownloads/bills/2014/ReproductiveHealthCareBill2014_1_pdf</u> accessed on 14th September 2017.

torture or ill-treatment.⁷

There are a number of reported cases in Kenya of forced sterilization,⁸ and with regards to women and girls with disabilities, it is the guardians who are consenting to sterilization on their behalf.⁹ Forced sterilization is a violation of women's right to bodily autonomy. Women with disabilities have a right to make an informed decision on sexual and reproductive health which includes but is not limited to family planning, safe and enjoyable sex, marriage and having a family.

Several research reports suggest that forced sterilization is a common occurrence in Kenya;¹⁰ unfortunately, findings are that the State has not taken concrete action to prohibit such practices.¹¹ In a study conducted by the Mental Disability Advocacy Centre, one of the female interviewees stated:

"I don't think I would get children. I will tell you something; you see here [lifts up the blouse and reveals a scar on her stomach] here I was made an operation. This is contraceptive, all of us had been done like this, we cannot get children. Nobody asked me. They should have asked me, because I love children [...]. I feel bad, but what can I do now.¹²

⁷ CEDAW Committee, A.S. v. Hungary case; Human Rights Council, Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, Juan E. Méndez, paras. 32 & 48, U.N. Doc. A/HRC/22/53 (2013).

⁸ Mental Disability Advocacy Center, The Right to Legal Capacity in Kenya, March 2014 pg. 5

⁹ Mental Disability Advocacy Center, The Right to Legal Capacity in Kenya, March 2014 pg. 46 and 71

¹⁰ An NGO based in Kenya, KELIN has documented instances where women with disabilities have been forcefully sterilized <u>https://profiles.uonbi.ac.ke/kihara/files/report-on-robbed-of-choice-forced-and-coerced-sterilization-experiences-of-women-living-with-hiv-in-kenya.pdf</u>.

¹¹ USPK, KAIH, MDAC, The right to Legal Capacity in Kenya (Budapest: 2014, MDAC)

¹² USPK, KAIH, MDAC, The right to Legal Capacity in Kenya (Budapest: 2014, MDAC), p. 46, 66. A full testimony from this interviewee is contained in the report

A case of forced sterilization has been reported and is currently being challenged in the Kenyan courts;¹³ this proves that indeed women in Kenya are being sterilized against their will yet nothing is being done to address this violation. Evidence received by organizations of persons with disabilities¹⁴ points to women with intellectual disabilities and psychosocial disabilities having contraception administered to them against their will within the community.¹⁵

A study conducted by the Kenya National Commission on Human Rights on the rights of persons with disabilities found that:

Others [nurses] doubted their [women with disabilities] capability to deliver through the normal procedures and instead suggested they undergo caesarean process without their consent. Further, persons with disabilities were not being allowed to make choices on the mode of family planning with nurses dictating which methods to use ¹⁶

Inquiry by KNCHR shows lack of funding contributing to not realizing reproductive health and services. The State is yet to meet its obligations of dedicating 15% of budget to health as per the Abuja Declaration.¹⁷

¹³ Kenya Legal and Ethical Issues Network on HIV (KELIN), '5 cases of forced and coerced sterilization filed in the High Court of Kenya', news article available at: <u>http://gem.or.ke/5-cases-of-forced-and-coerced-sterilization-filed-in-the-highcourt-of-kenya/</u> accessed 26th January 2017, Petition 605 of 2014 SWK & 5 others v Medecins Sans Frontieres- France & 10 others (2016) eKLR available at <u>http://kenyalaw.org/caselaw/cases/view/125001/</u> accessed 26th January 2017

¹⁴ Women Challenged to Challenge, Users and Survivors of Psychiatry – Kenya, Kenya Association of the Intellectually Handicapped who are Network members

¹⁵ National Survey on Disability by National Council for Population and Development, 2007

¹⁶ Kenya National Commission on Human Rights, 'From Norm to Practice: A Status Report on Implementation of the Rights of Persons with Disabilities in Kenya' (2014) pg. 25

<<u>http://knchr.org/Portals/0/Reports/Disability%20Report.pdf></u> accessed 30 August 2017

¹⁷ Kenya National Commission on Human Rights Realizing Sexual and Reproductive Health and Rights in Kenya: A myth or reality? (April 2012) pg. 26

Legal Capacity of Women and Girls with Disabilities

Kenya's legislative and policy framework still allows for substituted decisionmaking on a broad range of issues including marriage¹⁸ and makes no provision for supported decision-making¹⁹.

In practice, women and girls with disabilities in Kenya experience informal substitute decision-making²⁰ where 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 disabilities²¹ including forced sterilization, forced abortion and caesarian section instead of normal delivery.

This presumption of lack of legal capacity extends to making decisions to engage in intimate sexual relationships in Kenya. Section 43(4) (e) of the Sexual Offences Act presumes people with 'mental impairment' cannot give consent for intimate sexual relationships. This section denies the right of women with disabilities to exercise legal capacity with regard to making decisions on intimate sexual relationships. While the section applies to both men and women, women are disproportionately affected because culturally, all women with disabilities are seen

²¹ Kenya National Commission on Human Rights, 'From Norm to Practice: A Status Report on Implementation of the Rights of Persons with Disabilities in Kenya' (2014) pg. 25-26

¹⁸ Sections 11(2)(c), 12, 66(6)(g), 73(1)(g) of the Marriage Act, 2014

¹⁹ In its Concluding Observations to Kenya on Article 12, the UN Committee on the Rights of Persons with Disabilities 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'

²⁰ The General Comment, para 52

<<u>http://knchr.org/Portals/0/Reports/Disability%20Report.pdf></u> accessed 30 August 2017; and 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 (2012) pg. 111-115 <<u>http://www.knchr.org/Portals/0/Reports/Reproductive health report.pdf></u> accessed 30 August 2017

as asexual. There are cases (for example *Republic v Joseph Ngunjiri Nderitu*²²) where families of women with intellectual disabilities have attempted to prosecute the woman's partner under this provision (under the guise that a woman with an intellectual disability cannot give consent for a sexual relationship).

Case Study on Consent and Legal Capacity

In Kuria, Migori County there is a practice called "Nyumba Mboke" that has been normalized where married women acquire women including women and girls with disabilities for child bearing purposes with multiple partners. This situation is more prevalent for women and girls with disabilities due to their vulnerability in society where they are seen as less valuable and hold a lesser status in society. The children born out of this practice are taken away from the women with disabilities and they have no right to decide on number and spacing of children.²³

GOOD PRACTICES IN KENYA

Several players in the civil space have made strides in pursuing the rights of sexual and reproductive rights. Their approach has been to sensitize communities in order to address the underlying attitudes that shape the negative stereotypes and harmful actions against women with disabilities.

 Advantage Africa working with Kibwezi Disabled Persons Organization for example worked to improve access to justice for women with disabilities in instances of sexual violence and abuse.²⁴

²² Sexual Offence No. 21 of 2015

²³ YouTube link <u>https://www.youtube.com/watch?v=bCVw6Mv3HUU</u> accessed on 5th July 2017.

²⁴ Handicap International. Making it Work initiative on gender and disability inclusion: Advancing equity for women and girls with disabilities. Lyon: Handicap International, 2015.

- Kenya Association of the Intellectually Handicapped (KAIH) worked to break the silence around sexual-and gender-based violence against boys and girls, women and men with intellectual disabilities in Kenya.
- The Kenyan government has created a fund for the use of women with disabilities, the Uwezo Fund, and this is important because access is directly linked to financial empowerment.
- This Ability has been in the forefront of advancing the rights of women and girls with disabilities through:
 - Partnerships with organizations e.g. CREA, whom we have been working with to coordinate the establishment of a national network for women and girls with disabilities in Kenya in a bid to strengthen advocacy and build our collective voice.
 - Working with community-based groups of women with disabilities in various counties, training around leadership and advocacy skills to enable constituents engage with policymakers and influence change.
 - Adaptive Sports and SRHR using a wheelchair rugby workshop as a platform to provide access to Sexual and Reproductive Health services to women with disabilities in Nairobi. Over 200 women with disabilities received reproductive health services through partners like Family Health Options.

CONCLUSION

Our study suggests that sexual and reproductive healthcare services designed to meet the needs of women without disability might lack the flexibility and responsiveness to meet the unique healthcare needs of women with disabilities.

If Kenya is to fulfill its international obligations on the right to health for all, as well as attain the maternal health-related Sustainable Development Goals, resources must be proactively allocated to support the most vulnerable and underserved segments of the population, including women with disability.

Recommendations for change include disability-related cultural competence training for healthcare providers, making healthcare facilities more disability-friendly as well as an emphasis on patient-centered care and behavior change strategies for healthcare providers and the general public.

Annex B – Nigeria

Compiled by Advocacy for Women with Disabilities Initiative (AWWDI), Legal Defence and Assistance Project (LEDAP), and Women Enabled International (WEI)

Women with disabilities in Nigeria are subjected to social, cultural and economic disadvantages, which make it all the more difficult for them to take part in community life. Women with disabilities in Nigeria find themselves in a context where services and buildings cannot be accessed by everyone, a place where they cannot participate fully, a place where there is no respect for their human dignity and rights, and a place where they cannot have friends outside the disability group.

Stereotypes Related to Sexual and Reproductive Health

Many people in Nigeria hold the stereotype that persons with disabilities generally, and women with disabilities in particular, do not engage in sexual activity.¹ On the contrary, 71% percent of respondents to a 2013 survey on HIV and disability in Nigeria indicated that they had had sex, and indeed a higher percentage of adolescents with disabilities (40%) had had sex before age 15 than the general population (16% for women; 3% for men).² Indeed, women and girls with disabilities may find that men want to have sex with them but not openly date them, due to shame and stigma.³ 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.⁴ Indeed, women who acquire a disability during their marriage may be abandoned by partners who cannot cope with the stigma associated with disability.⁵

Violations of Sexual and Reproductive Health and Rights

In Nigeria, women with disabilities experience many barriers to accessing health care services, including sexual and reproductive health care. The physical environment surrounding and within health care facilities may be inaccessible to wheelchairs, and health care workers frequently lack knowledge about or experience with managing care for women with disabilities.⁶ Information in these facilities may also be inaccessible; for instance, deaf women report that they do not have access to interpreters in health facilities.⁷

The 2015 report from 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,⁸ a situation that can increase the risk of complications during pregnancy and labor.⁹ During labor, medical personnel in Nigeria are also more likely to assume that women with disabilities require Caesarean sections to deliver.¹⁰ Furthermore, the families of women with mental disabilities in Nigeria 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.¹¹ Some families also reported that they had forcibly confined or sterilized women with disabilities for similar protective reasons,¹² though forced sterilization of women with disabilities in Nigeria is not yet widely documented.

Women with disabilities in Nigeria may also face barriers to accessing needed sexual health information and services, making them susceptible to sexually transmitted infections including HIV. A 2015 study of HIV prevalence among persons with disabilities in Nigeria found that, although HIV prevalence was lower than for the general population, 2.4% of the women with disabilities surveyed had HIV, as compared to 1.4% of the men with disabilities.¹³ This higher rate of HIV infection for women with disabilities may be due to higher-risk behaviors that are the result of discrimination against them, including higher rates of sexual violence and lower rates of condom use.¹⁴ The study also indicated that there were very few sexual and reproductive health services targeted at or accessible to persons with

disabilities in Nigeria,¹⁵ a situation that can increase the risk of acquiring or experiencing the negative health effects of HIV.

Deaf and hard-of-hearing women in Nigeria face particular barriers to accessing needed sexual and reproductive health services and exercising their rights. A 2013 study of access to reproductive health care services for girls with hearing impairments in Ibaden, Nigeria, found that girls with hearing impairments experience a number of barriers to accessing human rights-based reproductive health services.¹⁶ In particular, communication barriers and lack of access to professional interpreters impacted their access to health services in several respects. For instance, girls reported that they missed long-awaited reproductive health appointments because they could not hear when their names were called in the waiting room, leading to embarrassment and frustration.¹⁷ Furthermore, the girls with hearing impairments reported that they often have had to rely on family or friends to communicate with health professionals on their behalves, which deprives them of patient confidentiality and also does not guarantee that the information provided to them is accurate.¹⁸ These girls also reported that high costs prevented them from accessing reproductive health services.¹⁹

In 2014, Nigeria adopted the HIV and AIDS (Anti-Discrimination) Act, which guarantees a right to be free from discrimination based on HIV status.²⁰ The Act takes some steps to ensure protection of women with disabilities from violations associated with HIV, including by outlawing cultural practices that may increase the risk of HIV transmission.²¹ However, persons with disabilities themselves are invisible in the Act, and their situations are not adequately addressed. For instance, although the Act defines discrimination against persons with HIV to include failures to reasonably accommodate their needs, the Act appears to require only that services and individuals provide reasonable accommodation based on HIV status and not other statuses such as disability, as required by the CRPD.²² Additionally, some issues faced disproportionately by women, including women with disabilities, that increase their exposure to HIV—such as lack of access to comprehensive sexuality education and increased experiences of sexual violence and sex work or prostitution—are not addressed at all in the Act, meaning that these issues are also less likely to be included in the Act's implementation and enforcement.

Individual Stories

Please note that the women who shared these stories with AWWDI asked to remain anonymous.

1. Woman with a Spinal Cord Injury

I was involved in an accident Sept. 2012 where I sustained spinal cord injury at T9-T10 incomplete injury and since then I uses wheelchair for mobility.

- Stereotype/ Discrimination: They are discrimination towards people/women living with disability. I'll use myself as a case study. I was working with Guaranty Trust Bank (GTBank) before my accident and I lost my job because of this. I was asked to resign that my service is no longer needed because am wheelchair bound and all efforts to get a new job has also proof abortive because of huge discrimination towards women living with disabilities. There is also this mentality that women living with disabilities are being seen as beggars. On several occasions, people have offered me money like they do to beggars. People living with disabilities should have equal rights with the non-disabled in all aspects. With this, women living with disabilities won't feel less of a human.
- RIGHT TO HEALTH: Most hospitals are not accessible for people like me who uses wheelchair for mobility. The treatment of Spinal Cord Injury (SCI) is very expensive to maintain, so if our treatments and medical equipment's are subsidized or free it will enhance our health. Sadly, most of our government hospitals don't have necessary equipments which sometimes results to untimely death or causes more damage to the health or physical well-being of women living with disabilities.

- RIGHT TO FAMILY: 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.
- MY CONCLUSION: Women living with disabilities are human and not an alien, so we should be entitled to equal rights as other citizens.

2. Woman with a disability shares her experience of discrimination

Disability is actually not the fault of the person affected and shouldn't be used as criteria to judge the person especially a woman. A Woman is faced with a lot of problems. There is a lot of discrimination to the woman with disability. Firstly in her family, secondly amongst her peers, and the society at large 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.

Amongst your peers or friends when they get to the stage of marriage they tend to cut all ties with you because according to them "level has changed" and its believed that you can never understand anymore what they are saying so they avoid you as if you are a sick person. 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. Your right to Loved and loved back is constantly denied of women

3. Deaf woman

"During my pregnancy, I faced barrier regarding altitude of medical personnel especially during ante natal and labour. They didn't make effort to provide communication. They just don't care. Many of the hospitals make life difficult for women with disabilities."

¹ ENHANCING NIGERIA'S HIV/AIDS RESPONSE (ENR) PROGRAMME, HIV/AIDS AND SEXUAL BEHAVIOURS OF PERSONS WITH DISABILITIES IN NIGERIA 22 (2015).

² Id.

³ INCLUSIVE FRIENDS & NIGERIA STABILITY AND RECONCILIATION PROGRAMME, WHAT VIOLENCE MEANS TO US: WOMEN WITH DISABILITIES SPEAK 12 (2015) [hereinafter INCLUSIVE FRIENDS & NSRP, WHAT VIOLENCE MEANS TO US INCLUSIVE FRIENDS & NSRP, WHAT VIOLENCE MEANS TO US].

⁴ Id.

⁵ Id.

 $^{^{6}}$ *Id.* at 13-14.

 $^{^{7}}$ *Id.* at 14.

⁸ Id.

⁹ World Health Organization, *Maternal Mortality: Factsheet No. 348* (Nov. 2015), http://www.who.int/mediacentre/factsheets/fs348/en/.

¹⁰ INCLUSIVE FRIENDS & NSRP, WHAT VIOLENCE MEANS TO US, *supra* note 3, at 14.

¹¹ *Id.* at 19.

¹² Id.

¹³ ENHANCING NIGERIA'S HIV/AIDS RESPONSE (ENR) PROGRAMME, HIV/AIDS AND SEXUAL BEHAVIOURS OF PERSONS WITH DISABILITIES IN NIGERIA 26 (2015).

¹⁴ Id.

¹⁶ 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.

¹⁷ Id. ¹⁸ Id.

¹⁹ Id.

²⁰ HIV and AIDS (Anti-Discrimination) Act, 2014, § 3 (Nga.)

²¹ *Id.*, § 3(3).

²² Id., § 6(c); Convention on the Rights of Persons with Disabilities, adopted Dec. 13, 2006, arts. 2 & 5, G.A. Res. A/RES/61/106, U.N. GAOR, 61st Sess., U.N. Doc. A/61/611, (entered into force May, 3 2008).

¹⁵ *Id.* at 22.

Annex C - Poland

This information was compiled by Association for Women with Disabilities ONE.pl and Women Enabled International.

Women with disabilities in Poland experience significant barriers to exercising their sexual and reproductive rights, including accessing sexual and reproductive health (SRH) information and services and making autonomous decisions about their sexual and reproductive health. Barriers to accessing SRH information and services in Poland frequently stem from stereotypes about women with disabilities, including that they are asexual or hypersexual, cannot become pregnant, and cannot be good parents, as well as from discriminatory attitudes towards their disability, including that they may pass along that disability to a child. For instance, a 2015 study involving interviews with women with physical and sensory disabilities in Poland 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.¹ Indeed, although Polish women with disabilities maintain the right to biological and adoptive parenthood, their reproductive rights are considered a taboo subject, as is their sexuality.² The study also revealed that women with disabilities may be deterred from applying for services to help them with caring for their children because of the fear that they will have to prove they are good parents and will not "measure up."³

Maternal Health Services

Polish women with disabilities who become pregnant or who wish to have children face numerous barriers to accessing needed care. A 2015 study on motherhood and maternal health services for women with disabilities found that the Polish health care system was not prepared "to take care of and support pregnant women with disabilities."⁴ Interviewees identified that the health care system was not equipped to offer them specialized services in the context of pregnancy, and because they were considered a "high risk group," women with disabilities reported that they had trouble finding a doctor or midwife willing to provide them with care.⁵ Indeed, women with disabilities reported that there was generally a lack of specialized care available to them.⁶ 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.⁷

Furthermore, the attitudes of health care personnel providing pregnant women with disabilities with maternal health care in Poland create significant barriers to women receiving quality care. For instance, according to the 2015 study 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.⁸ 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.⁹ This treatment increased their sense of isolation, vulnerability, and lack of self-determination.¹⁰ Furthermore, 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.¹¹

Comprehensive Sexuality Education

The government of Poland reports that, concerning its sexuality education program, "the content and forms of teaching match the needs of children with various disabilities, both in mainstream schools and special schools at different levels of education."¹² The content, as described by Poland, fails to match international standards for comprehensive sexuality education, including for inclusion of persons with disabilities. In January 2018, the United Nations Educational, Scientific and Cultural Organization

(UNESCO) updated its technical guidance on comprehensive sexuality education (UNESCO guidance), which provides that comprehensive sexuality education should aim to "equip children and young people with knowledge, skills, attitudes and values that will empower them to: realize their health, well-being and dignity; develop respectful social and sexual relationships; consider how their choices affect their own well-being and that of others; and, understand and ensure the protection of their rights throughout their lives."¹³

In particular, the UNESCO guidance notes that young people with disabilities "are all sexual beings and have the same right to enjoy their sexuality within the highest attainable standard of health, including pleasurable and safe sexual experiences that are free of coercion and violence; and to access quality sexuality education and SRH services."¹⁴ Specifically, the UNESCO guidance calls on states to ensure that comprehensive sexuality education builds skills "to treat others with respect, acceptance, tolerance and empathy," including persons with disabilities.¹⁵ It further calls on states to ensure that this education includes ongoing discussions about relationships and vulnerability, including gender and power inequalities that may be based on discrimination, including discrimination based on disability and information specifically about the SRH needs of young people with disabilities.¹⁶

As the CRPD Committee noted in its General Comment No. 4, "[p]ersons with disabilities, on an equal basis with others, must be provided with age-appropriate, comprehensive and inclusive sexuality education, based on scientific evidence and human rights standards, and in accessible formats."¹⁷ It is not clear that Poland's sexuality education program is actually being provided to persons with disabilities, particularly young persons with disabilities, let alone that it contains any of the information specifically about persons with disabilities recommended by UNESCO.

Contraception

Due to stigma, the strong influence of religion in Poland, and other social factors, all women in Poland face significant barriers to accessing contraception in order to prevent unwanted pregnancy.¹⁸ These difficulties are likely compounded for women with disabilities in Poland, because, as noted above they are perceived as asexual or unable to control their sexuality, and thus may not be offered contraception at all. Additionally, legislation in Poland has recently restricted access to emergency contraception, a method of contraception to prevent unwanted pregnancies when other methods fail, when a woman has unprotected sex, or when a woman is the victim of sexual violence.¹⁹ Given the higher risk of genderbased violence likely faced by women with disabilities, as well as the barriers they face in accessing other forms of contraception, restrictions on emergency contraception have a disproportionate impact on their ability to control their fertility and to decide on the number and spacing of their children on an equal basis with others.

Furthermore, women with disabilities in Poland may also only be offered permanent forms of contraception, such as sterilization. The issue of forced and coerced sterilization of women and girls with disabilities in Poland is not yet well documented, but given the cultural taboos surrounding motherhood for women with disabilities, the fact that many persons with disabilities are stripped of legal capacity and placed under guardianship as described in more detail below, and the seeming lack of explicit standards on sterilization and informed consent for persons with disabilities in Poland, it is likely that forced and coerced sterilization of women and girls with disabilities does occur.

Abortion

Women and girls in Poland face both legal and practical difficulties in accessing abortion, in violation of their rights to health and to reproductive autonomy. Under Poland's laws, women can access abortion only under three restrictive conditions—in cases of rape or incest, when the woman's health or life is at risk, and in cases of "severe fetal impairment."²⁰ Otherwise, abortion is illegal.²¹ In practice, it can be extremely difficult for a woman to obtain a legal abortion even under these circumstances, as doctors

frequently refuse to perform such procedures, a practice known as conscientious objection, while at the same time abusing this privilege by refusing to provide referrals to other doctors who will perform abortions, in violation of human rights and medical ethics standards.²² As a result of both this practice and the restrictive abortion law, it is estimated that tens of thousands of women in Poland seek out illegal and unregulated abortions every year, putting their health and lives at risk, while only about 1,000 legal abortions are performed each year.²³ These illegal abortions are also incredibly expensive, accounting for the average monthly wage for a Polish person (4,256 złoty),²⁴ which is significantly higher than for a woman with disabilities. Indeed, according to the European Court of Human Rights in specific cases of denial of access to legal abortion and information that could lead to legal abortion, Poland has repeatedly violated women's rights to privacy and to be free from inhuman and degrading treatment.²⁵

Current barriers to accessing abortion in Poland are compounded for women with disabilities, because of barriers to accessing sexual and reproductive health services generally, attitudes of health care professionals towards them and their decisions, and their limited incomes. Despite these human rights abuses, in January 2018, the Polish government rejected a measure that would have removed all legal restrictions on abortion within the first 12 weeks of pregnancy.²⁶ Instead, the government of Poland is currently attempting to adopt a law that would further limit access to abortion by banning abortions in cases of fetal impairment,²⁷ which account for the vast majority of legal abortions in the country,²⁸ despite massive protests from women in Poland and the insistence of disability rights advocates that they not be used as an excuse to limit women's rights and that, rather, the government should focus on ensuring the quality of life for persons with disabilities.²⁹ The passage of this bill would contribute to an already restrictive environment for the prevision of SRH information and services and would disproportionately affect women with disabilities.

- ² Id.
- 3 *Id.* at 81
- 4 *Id.* at 84.
- ⁵ *Id*.
- ⁶ *Id.* at 85.
- 7 *Id.* at 84.
- ⁸ *Id.* at 85. ⁹ *Id.*
- 10 Id.
- 10 Id. 11 Id.
- ¹¹ *Id*.

¹ 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.

¹² CRPD Committee, *Poland State Report*, ¶ 318.

¹³ UNITED NATIONS EDUCATIONAL, SCIENTIFIC AND CULTURAL ORGANIZATION (UNESCO), INTERNATIONAL TECHNICAL GUIDANCE ON SEXUALITY EDUCATION: AN EVIDENCE-INFORMED APPROACH, REVISED EDITION 17 (Jan. 2018), *available at* http://www.unaids.org/sites/default/files/media_asset/ITGSE_en.pdf.

¹⁴ *Id.* at 25.

¹⁵ *Id.* at 16.

¹⁶ *Id.* at 18.

¹⁷ CRPD Committee, *General Comment No. 4 (2016) on the right to inclusive education*, ¶ 54, U.N. Doc. CRPD/C/GC/4 (2016).

¹⁸ See, e.g., CEDAW Committee, Concluding Observations: Poland, ¶ 36, U.N. Doc. CEDAW/C/POL/CO/7-8 (2014).

¹⁹ HUMAN RIGHTS WATCH, ERODING CHECKS AND BALANCES: RULE OF LAW AND HUMAN RIGHTS UNDER ATTACK IN POLAND (2017), *available at* https://www.hrw.org/report/2017/10/24/eroding-checks-and-balances/rule-law-and-human-rights-under-attack-poland.

²⁰ The Family Planning, Human Embryo Protection and Conditions of Permissibility of Abortion Act (Jan. 7, 1993) (Poland), *available at* http://worldabortionlaws.com/map/ (unofficial English translation).
 ²¹ Id

²² Human Rights Council, Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, Anand Grover: Mission to Poland, ¶¶ 49-55. U.N. Doc. A/HRC/14/20/Add.3 (2009), available at https://documents-dds-ny.un.org/doc/UNDOC/GEN/G10/134/03/PDF/ G1013403.pdf?OpenElement; ASTRA Central and Eastern European Women's Network for Sexual and Reproductive Rights and Health, "Abuse of Conscientious Objection in Poland: Short Summary of Doctor Chazan Case" (2014), http://www.astra.org.pl/repronews/295-abuse-of-conscientious-objection-in-poland-short-summaryof-doctor-chazan-case.html; Human Rights Watch, "Dispatches: Abortion and 'Conscience Clause' in Poland" (Oct. 22, 2014), https://www.hrw.org/news/2014/10/22/dispatches-abortion-and-conscience-clause-poland

²³ "How Poland's far-right government is pushing abortion underground," THE GUARDIAN (Nov. 30, 2017), https://www.theguardian.com/news/2017/nov/30/how-polands-far-right-government-is-pushing-abortion-underground

²⁴ Id.

²⁵ See P. and S. v. Poland, No. 57375/08, Eur. Ct. H.R. (2012); RR v. Poland, No. 27617/04, Eur. Ct. H.R. (2011); Tysiac v. Poland, No. 5410/03, Eur. Ct. H.R. (2007).

²⁶ "Poland's lawmakers reject plan to ease strict abortion law," ASSOCIATED PRESS (Jan. 10, 2018), https://www.apnews.com/296623aec33140fc8002411d9d0b6ab2/Poland's-lawmakers-reject-plan-to-ease-strict-

abortion-law.

²⁷ Christian Davies, "Polish MPs back even tougher restrictions on abortion," THE GUARDIAN (Jan. 11, 2018), https://www.theguardian.com/world/2018/jan/11/polish-mps-reject-liberalised-abortion-laws-but-back-new-restrictions.

²⁸ Id.

²⁹ See, e.g., https://www.amnesty.org/en/latest/campaigns/2018/03/women-in-poland-protest-restrictions-on-abortion/

Annex D – India

This information was compiled by Shanta Memorial Rehabilitation Centre, Women with Disabilities India Network, and Women Enabled International.

Violations of Sexual and Reproductive Rights

Women with disabilities worldwide face a wide range of unique human rights abuses in sexual and reproductive health care settings, due to both their gender and disability. Stereotypes about women with disabilities mean they are disproportionately subjected to practices such as forced or coerced sterilization, contraception, and abortion.¹ In its General Comment No. 3 on women with disabilities, the CRPD Committee 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."² When women with disabilities are deprived of legal capacity, this can "facilitate forced interventions, such as: sterilisation, abortion, [and] contraception…"³ 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 cycles⁴ and are also considered severe human rights violations, including forms of torture or ill-treatment.⁵

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.⁶ In India, women with disabilities have historically been subjected to forced or coerced sterilization, due to disability-based stereotypes as well as state population policies, and forced sterilization of women with disabilities within institutions and by family is still common in India, even though it has been recognized as a human rights violation.⁷ For instance, there are several reports from the 1990s of women and girls undergoing forced sterilizations in institutions in India.⁸ Furthermore, 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.⁹ 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.¹⁰ Indeed, although the CEDAW Committee recognized in its 2014 review of India that "women with intellectual disabilities can be sterilized without their consent," in violation of CEDAW, India has not yet remedied this violation.¹¹

In 2006, the Ministry of Health issued guidelines for the sterilization of all men and women in India.¹² Under these guidelines, for sterilization to be performed, the guidelines provide that women must be "of sound state of mind so as to understand the full implications of sterilization," and women with psychosocial disabilities "must be certified by a psychiatrist, and a statement should be given by the legal guardian/spouse regarding the soundness of the client's state of mind."¹³ However, abuses may still result when women with disabilities, particularly intellectual and psychosocial disabilities, are stripped of legal capacity or otherwise denied reasonable accommodations. Concerning informed consent, the guidelines indicate that the client must sign a consent form before surgery, and that spousal consent is not needed for sterilization, though the guidelines do not comment on guardian consent. While the "informed consent" form requires confirmation that information about the procedure has been read out and explained to the person concerned in their preferred language, it does not require confirmation that support and reasonable accommodation has been given to persons with disabilities in order to ensure their full and informed consent.¹⁴ In the absence of guarantees for reasonable accommodations and a specific bar on substituted decision-making, it may still be possible for women and girls with disabilities to be sterilized without their consent and with only the consent of a guardian or parent, a situation that does not conform to international medical ethics standards from the International Federation of Gynecology and Obstetrics (FIGO).¹⁵

Additionally, 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.¹⁶ 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.¹⁷

¹⁴ *Id.* at 6.

¹ 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).

² CRPD Committee, General Comment No. 3: Article 6: Women and girls with disabilities, ¶ 44, U.N. Doc. CRPD/C/GC/3 (2016).

³ Id.

⁴ 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).

⁵ 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. CAT/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).

⁶ 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.

⁷ For instance, a 2004 survey of violence against women with disabilities in Orissa, India, found that about 6% of women with physical disabilities and about 8% of women with intellectual and psychosocial disabilities had been forcibly sterilized (Dr. Sruti Mohapatra and Mr. Mihir Mohanty, Abuse and Activity Limitation: A Study on Disabled Women Orissa. India (2004).Domestic Violence against in 16 available at http://swabhiman.org/userfiles/file/Abuse%20and%20Activity%20Limitation%20Study.pdf). These sterilizations were often the result of fears from family members that women with disabilities would be raped and become pregnant, as well as assumptions about whether women with disabilities could consent to sex and whether they could be good parents (Id. at 16). This was also a major point of discussion at the Regional Meeting of the WwD India Network organized in Hyderabad on Feb. 23-24, 2013.

⁸ See, e.g., Rajeswari Sundar Rajan, *Beyond the Hysterectomies Scandal: Women, the Institution, Family, and State in India*, in THE PRE-OCCUPATION OF POST-COLONIAL STUDIES (ed. Khan & Seshadri) 200, 201 (2000).

⁹ Ashika Misra, *Is hysterectomy the final solution?*, DNA INDIA, Jan. 30, 2008, http://www.dnaindia.com/mumbai/report-is-hysterectomy-the-final-solution-11482.

¹⁰ Women with Disabilities India Network, *Meeting in Bangalore*, Feb. 4, 2012.

¹¹ CEDAW Committee, *Concluding Observations: India*, ¶ 36, U.N. Doc. CEDAW/C/IND/CO/4-5 (2014).

¹² For instance, these guidelines indicate that women in India who undergo sterilization should be between the ages of 22 and 49—meaning that girls with disabilities should not be subjected to sterilization (Ministry of Health and Family Welfare, *Standards for Female and Male Sterilization Services* 3-4 (2006), *available at* http://nrhm.gov.in/images/pdf/guidelines/nrhm-guidelines/family-planning/std-for-sterilization-services.pdf.). ¹³ *Id.* at 3-4.

¹⁵ International Federation of Gynecology and Obstetrics (FIGO), *Female Contraceptive Sterilisation*, ¶ 7 (June 2011), *available at* http://www.figo.org/sites/default/files/uploads/wg-publications/ethics/English%20Ethical%

¹⁶ Medical Termination of Pregnancy Act, 1971, § 3(4)(a) (1971) (India).

¹⁷ Supreme Court of India, *Suchita Srivastava & Anr vs Chandigarh* (2009), *available at* https://indiankanoon.org/ doc/1500783/.

²⁰Issues%20in%20Obstetrics%20and%20Gynecology.pdf ("Only women themselves can give ethically valid consent to their own sterilisation. Family members – including husbands, parents, legal guardians, medical practitioners and, for instance, government or other public officers – cannot consent on any woman's or girl's behalf.").