



**Submission to the Special Rapporteur on Violence against Women, its Causes and Consequences:
Mistreatment of and Violence against Women and Girls with Disabilities in Reproductive Health
Care, Including Facility-based Childbirth**

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I. Introduction

Women Enabled International (WEI) and the above contributing and endorsing organizations appreciate the opportunity to provide the Special Rapporteur on Violence against Women, its Causes and Consequences (Special Rapporteur) with information to help inform her forthcoming report on mistreatment of and violence against women and girls with disabilities in reproductive health care, including facility-based childbirth.

Women and girls¹ with disabilities face significant mistreatment and violence in the provision of reproductive health care, including in facility-based childbirth. This includes forced reproductive health interventions, such as forced sterilization, abortion, and contraception, as well as physical, psychological, and verbal abuse. Furthermore, women with disabilities in some countries are at increased risk of having parental rights removed and being stripped of custody of their children, including newborns and including in childbirth facilities, which can have devastating personal consequences. There are several factors that contribute to this mistreatment and violence, including stereotypes about the sexuality of women with disabilities, their ability to parent, and their ability to make decisions for themselves, as well as a range of accessibility barriers (including physical, communications, information, and financial) and lack of provider training about their rights and lived experiences. The mistreatment and violence women with disabilities face as part of their reproductive health care, including in childbirth facilities, not only impacts their physical and emotional well-being but also deters some women with disabilities from seeking needed antenatal and postnatal care, putting their health and lives at risk.

This submission provides an overview of the causes, forms, and consequences of mistreatment of and violence against women with disabilities in reproductive health care, including childbirth facilities, with examples from several countries that illustrate these causes, forms, and consequences. The submission then provides a brief summary of human rights standards surrounding respectful reproductive health care for women with disabilities, as well as recommendations that we hope will help inform the Special Rapporteur's forthcoming report.

II. Causes, Forms, and Consequences of Mistreatment of and Violence against Women with Disabilities in Reproductive Health Care

A. Causes of Violence and Mistreatment

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

Discrimination at the intersection of gender and disability, as well as specific stereotypes about women with disabilities such as that they are asexual, cannot make decisions for themselves, cannot become pregnant, or cannot be good parents, may lead health care workers to discount their needs or subject them to abuse, violating their rights.² Indeed, while all women may face discrimination in that they may be perceived as primarily mothers and caregivers, women with disabilities are further stigmatized in that they are perceived as not being able to fulfill this otherwise discriminatory gender role.

- For instance, a 2015 study involving interviews with women with physical and sensory disabilities in **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.³ Indeed, although Polish women with disabilities have the legal right to biological and adoptive parenthood, their reproductive rights are considered a taboo subject, as is their sexuality.⁴

Sexual and reproductive health care personnel, like others in society, often hold particular stereotypes about women with disabilities that affect their attitudes towards these women, and thus the care they provide. One place where this discrimination comes into play is in access to assistive reproductive technologies (ARTs).

- For instance, in the **United States of America (U.S.)**, access to ARTs is at the discretion of the reproductive health providers. Women with disabilities are more likely to be denied access to ARTs because of discrimination and biases about disability that lead providers to believe that the welfare of a future child would be at risk.⁵ Many providers may also deny persons with disabilities access to ARTs due to “gestational concerns”—that the person’s disability presents a threat to a future child during gestation—even when there is no evidence to support these concerns.⁶

Furthermore, women with disabilities may face significant physical, financial, communications, or information barriers to accessing quality reproductive health care, including maternal health care. As Committee on the Elimination of Discrimination against Women (CEDAW Committee) noted in its General Recommendation No. 24 on the right to health, “women with disabilities, of all ages, often have difficulty with physical access to health services.”⁷ Formal and informal user fees in health facilities, as well as indirect costs for transportation and accommodation, can make accessing quality sexual and reproductive health services prohibitively expensive for women with disabilities.⁸ Finally, communications and cultural barriers between providers and persons with disabilities may inhibit access to respectful reproductive health care. For instance, Deaf women in **Nigeria** reported that communications barriers and lack of knowledge of sign language in sexual and reproductive health settings prevented them from receiving quality information and services.⁹

Lack of provider knowledge and training about the rights and lived experiences of women with disabilities can lead to misunderstandings and miscommunications, which themselves can also lead to mistreatment and violence. For instance, some providers may consider women with disabilities a “high risk” group for pregnancy and delivery, when in reality, pregnancy for women with disabilities is not necessarily more “high risk” than it is for other women.¹⁰ Many women with physical disabilities are told

that they must give birth via Caesarean section (C-section), even though in practice this is not always necessary, exposing these women to greater risks from this surgery.¹¹ Women with disabilities may also be denied needed confidentiality and privacy, because providers do not feel comfortable communicating directly with them, and as a result, they may not receive needed information about maternal health or newborn care.¹²

- In **Poland**, the 2015 study cited above found that the Polish health care system was not prepared “to take care of and support pregnant women with disabilities.”¹³ Interviewees identified that the health care system was not equipped to offer them specialized services in the context of pregnancy.¹⁴ Women with disabilities interacting with the maternal health system further reported that, because they were considered a “high risk group,” they had trouble finding a doctor or midwife willing to provide them with care.¹⁵
- Furthermore, in **Kenya**, women with disabilities have often not been granted the privacy they require or that is usually accorded to other women in the context of sexual and reproductive health care, as health care personnel often do not know how to relate to persons with disabilities, especially in the presence of their assistants, and instead communicate with the assistants rather than with the women with disabilities themselves.¹⁶ This limits the extent to which women with disabilities are willing to share private information, due to concerns about confidentiality. This also serves as a deterrent among these women to visiting health centers because they feel that their privacy will be violated.¹⁷
- 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.¹⁸

B. Forms of Violence and Mistreatment

1. Forced Reproductive Health Interventions

Women with disabilities are subjected to forced reproductive health procedures or medication, such as forced sterilization, forced abortion, and forced contraception, more often than men with disabilities or other women, frequently only with the consent of a parent, guardian, or doctor, but not with the woman’s consent.¹⁹ In its General Comment No. 3 on women with disabilities, the Committee on the Rights of Persons with Disabilities (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.”²⁰ This is because women with disabilities are more often deprived of their decision-making ability, including in reproductive health care settings, either because they are deprived of legal capacity or because others assume that they cannot make decisions for themselves. Indeed, the CRPD Committee has further found that, when women with disabilities are deprived of legal capacity, this can “facilitate forced interventions, such as: sterilisation, abortion, [and] contraception...”²¹ Additionally, these practices are frequently based on false and discriminatory assumptions about the sexuality and ability of women with disabilities to parent or are based on the desire to control their menstrual cycles.²²

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.²³ In 2011, FIGO adopted guidelines specifically regarding female contraceptive sterilization, stating that only women themselves can give ethically valid consent to their own sterilization.²⁴ 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.²⁵

Furthermore, if a State or entity requires that a woman undergo sterilization in order to have access to medical care or other benefits, the FIGO guidelines indicate that this is an interference with the woman's informed consent.²⁶ 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.²⁷ 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."²⁸ 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.

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.²⁹ 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.³⁰ 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."³¹

- Recent unpublished research conducted specifically on women with disabilities in **Poland** suggests that women with intellectual disabilities living in institutions are sterilized against their will or without their informed consent,³² an all-too-common historical and ongoing practice in institutions throughout the world.
- 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.³³ There is no existing legal provision that prohibits non-consensual sterilization, and in recent years, sterilization methods using certain drugs have been tested on a large scale instead of teaching women with disabilities to manage menstrual hygiene and ensuring that they are protected from rape.³⁴ Providers and communities also often classify sterilization of women with disabilities as a social good, because they perceive that women with disabilities cannot take care of themselves or others.³⁵
 - Although the Ministry of Health issued guidelines in 2006 to prevent sterilization without informed consent in India, 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.³⁶ 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.³⁷
- Erroneous stereotypes regarding the danger of procreation of persons with disabilities, particularly women with disabilities, are enshrined in state law in the **U.S.** As of 2015, eleven states retained statutory language authorizing a court to order the involuntary sterilization of or forced contraceptive use by a person with a disability.³⁸ Courts in the U.S. also have addressed these issues, not always consistent with the requirements of Title II of the Americans with Disabilities Act (ADA), which prohibits state and local governments from discriminating on the basis of disability in government services, programs, or activities.³⁹ Courts are divided on the legal capacity of persons with disabilities to decide about their reproductive lives, particularly regarding the forced sterilization of young women and girls with disabilities, and there is no clear judicial standard that ensures reproductive decision-making resides with these individuals.⁴⁰
- In **South Africa**, the current Sterilisation Act allows for a substitute decision-maker to consent to the sterilization of a woman with a disability over the age of eighteen who has been deemed

incapable of consenting.⁴¹ Additionally, sterilization of a person under the age of eighteen is permitted with consent from a substitute decision-maker where “failure to do so would jeopardize the person’s life or seriously impair his or her health.”⁴² As currently drafted, the language of the Sterilisation Act is excessively broad and, despite making provision for administrative review, allows for potential abuse by substitute decision-makers.⁴³ Although there has not been an in-depth study of this issue, academic research has indicated that parents of girls with disabilities in South Africa have consented to sterilization based on discriminatory notions of disability and sexuality.⁴⁴ (See Section III below for a discussion of supported decision-making vs. substituted decision-making)

Forced contraception of women with disabilities remains an under-documented phenomenon. Although forced contraception is usually reversible and only temporarily limits the ability of women with disabilities to become pregnant, it still has profound implications for their trust in the medical system, and if used for a long period of time, may also effectively take away their ability to have children.

- 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.⁴⁵
- Evidence received by organizations of persons with disabilities in **Kenya**⁴⁶ points to women with intellectual disabilities and psychosocial disabilities having contraception administered to them against their will within the community,⁴⁷ 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.”⁴⁸
- In **Serbia**, Human Rights Watch and Mental Disability Rights International Serbia have documented the forced contraception of women with disabilities living in institutions. This has included the implantation of intrauterine devices (IUDs) without the consent of the women, including under general anesthesia, and also the provision of contraceptive pills to the women without their consent. Though sometimes these institutions have the permission of guardians to provide contraception to these women, the consent of a guardian cannot substitute for the consent of the woman herself.⁴⁹
- In **Indonesia**, according to Indonesia Association of Women with Disabilities (HWDI), a recent Bill on Sexual Violence Elimination being considered in Parliament has not only failed to criminalize forced contraception of women with mental disabilities but also has perpetuated discrimination against this group. Article 104 of the Bill reads. “With regard to implanting contraceptive devices to persons with mental disability performed upon the request of their family and is based on expert opinion to protect the well being of the person in question should not be considered a crime.”⁵⁰ The Bill otherwise criminalizes forced contraception of other women and other persons with disabilities, but not persons with mental disabilities. As of January 2019, the Commission on Violence against Women, the initial drafters of the Bill, had asked the Indonesian Parliament to withdraw this provision, but at the time of writing, the Parliament had not yet taken action.

Forced abortion is also perpetrated against women with disabilities who do become pregnant. While State laws and policies frequently fail to prohibit forced reproductive health interventions on women with disabilities, forced abortion in particular is sometimes specifically permitted under law, with no repercussions for perpetrators.

- In **India**, under the Medical Termination of Pregnancy Act, 1971 (as amended in 2002), guardians can consent to abortions for women with psychosocial disabilities.⁵¹ Although the Supreme Court of India in 2009 found that guardians of women with “mild to moderate” intellectual disabilities cannot similarly provide consent to abortion on behalf of their wards, the

Court did not strike down the provisions of the Medical Termination of Pregnancy Act, 1971, that allows for forced abortion of women with psychosocial disabilities.⁵² Furthermore, the Criminal Law (Amendment) Act 2013 fails to criminalize forced or coerced sterilization or abortion for women with disabilities, meaning that it is unclear whether there are any sanctions or punishments for those who participate in these human rights violations.

- In **Kenya**, the Reproductive Health Bill of 2014⁵³ 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.⁵⁴
- In **South Africa**, the Choice on Termination of Pregnancy Act allows for substitute decision makers to consent to the termination of a woman’s pregnancy if she has been classified as “severely mentally disabled,” without a requirement to even consult with or consider the views of the woman herself, let alone obtain her informed consent.⁵⁵

2. *Mistreatment and Abuse in Maternal Health Settings*

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

- In **Nepal**, the Nepal Disabled Women Association documented a case in which a woman with a disability who underwent a C-section to deliver her baby was then put in an inaccessible room in the hospital for several days and was ignored by nursing staff when she asked for assistance for visiting the toilet. Her case is currently pending before the Supreme Court. In another case, when a woman with a physical disability went to the hospital for a delivery and was not able to push, an attending nurse started beating her abdomen and insulting her about her sexuality. The woman ultimately underwent a C-section to deliver the baby.
- In **Poland**, interviewees in the 2015 study cited above 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 woman considered humiliating.⁵⁶
- Furthermore, in **Poland**, health care providers’ attitudes towards pregnant women with disabilities ranged from indifference, to patronizing treatment, to explicitly expressing negative opinions about their plans to have children or about their disabilities.⁵⁷ 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.⁵⁸ This treatment increased their sense of isolation, vulnerability, and lack of self-determination.⁵⁹
- In **Kenya**, pregnant women with disabilities cited that they were often insulted by female nurses when they visited hospitals and presented for treatment.⁶⁰
- In **India**, women with physical disabilities are frequently criticized and taunted for getting pregnant. Providers and communities often highlight their supposed inability to look after themselves to perpetuate mistreatment.⁶¹
- In **South Africa**, a small-scale study published in 2005 on the responses women with physical disabilities received from health care workers at family planning clinics, antenatal clinics, and delivery rooms found that women were treated as asexual, asked invasive questions about their relationships, and examined in positions inappropriate for women with physical disabilities.⁶² These experiences left the women concerned that their participation in reproduction was regarded as “illegitimate” and that services were not designed to accommodate them.⁶³

Some women with disabilities are still told that they should have abortions rather than have children. Although providing women with information about abortion in general is a good medical practice, for women with disabilities, the advice to have an abortion may be provided even when pregnancies are wanted and are not high risk, reflecting deeply ingrained provider biases about the ability of women with disabilities to have and take care of children.

- For instance, in the 2015 study of maternity for women with disabilities in **Poland**, several women with disabilities 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.⁶⁴
- As part of a focus group with women with disabilities in **Nepal** to inform the 2018 CRPD Committee review of that country, several organizations documented cases in which women with physical disabilities who became pregnant were told by their doctors that they should have an abortion, because their pregnancies would be too complicated.

3. Removal of Children from Women with Disabilities

According to the CRPD Committee, “[h]armful gender and/or disability stereotypes such as incapacity and inability, can lead to mothers with disabilities facing legal discrimination. As such, they are significantly overrepresented in child protection proceedings and disproportionately lose contact and custody of their children[.]”⁶⁵ This plays out for women with disabilities both shortly after they give birth to children and also later in parenthood.

For instance, this concern is reflected in practices in the **U.S.**, where rather than being presumed to be fit parents, parents with disabilities must frequently prove their competence as parents in the face of harmful and pernicious stereotypes.⁶⁶ In the U.S., the child welfare system is generally located within state governments, rather than within the federal government. A 2012 report from the National Council on Disability (NCD) highlighted that 37 U.S. states and the District of Columbia list some forms of disability—primarily psychosocial and intellectual disability, but also physical disability—as grounds for removing a child from a disabled parent.⁶⁷ The 2012 report determined that the child welfare system’s “unfit parent” standard for removing children from parents is “one of the major threats to people with disabilities who choose to parent,” due to stereotypes about disability,⁶⁸ and that the “best interests of the child” standard in this system frequently allows biases and misperceptions about disability to color attitudes about the child-rearing abilities of parents with disabilities.⁶⁹ This then leads to “disproportionately high rates of involvement with child welfare services and devastatingly high rates of parents with disabilities losing their parental rights.”⁷⁰

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

- A 2018 study in Ontario, **Canada**, found that women with intellectual disabilities were more than 25 times more likely than other women to have their newborns taken into protective custody shortly after birth. The study found that 5.7% of newborns of women with intellectual disabilities (about 1 in 20) were discharged from the hospital directly into child protective services, as compared to 0.2% of newborns of other women (about 1 in 500).⁷¹ The study found that women with intellectual disabilities who also lived in poverty, had mental health concerns, or who had received poor prenatal care were at even higher risk of being separated from their newborns.⁷² The study noted that these separations have negative consequences for both women and babies, because “they disrupt maternal-fetal bonding and breastfeeding” and may also lead to trauma and long-term mental health issues for these women.⁷³ In a news story outlining the results of this study, a social worker also noted that there is a common misconception that women with

intellectual disabilities cannot parent, but that in reality they can do so successfully if they receive “appropriate and effective support.”⁷⁴

- Recently in the **U.S. state of New York**, a young woman with an intellectual disability had her newborn child removed from her custody by the Administration for Children’s Services (ACS) before she was discharged from the hospital. The child was removed on the basis that the woman had neglected the newborn by failing to attend parenting and treatment programs she had previously been assigned. However, ACS had failed to provide the woman with the reasonable accommodations she needed to attend these classes and further failed to accommodate her during the conference to determine the removal of her newborn, despite knowing the mother had an intellectual disability and required documented reasonable accommodations. This case was recently decided by the New York Court of Appeals, which noted that ACS has an obligation to ensure reasonable accommodations under U.S. law in cases like these.⁷⁵

This removal is likely due to pernicious stereotypes specifically about women with intellectual disabilities and their ability to parent. According to the 2012 NCD study cited above, parents with intellectual disabilities, who face a child removal rate of 40 to 80 percent in the U.S., encounter negative expectations about their parenting, including “that children will eventually be maltreated and that parenting deficiencies are irremediable.”⁷⁶ This leads to removal even when there is not any evidence of neglect or abuse.⁷⁷ Parents with intellectual disabilities are also more likely to have frequent contact with service providers or government officials, who are also more likely to report them to the child welfare system and whose allegations may be taken more seriously within that system than reports from others, such as neighbors, teachers, or other family members.⁷⁸

C. Consequences of Violence and Mistreatment

As a consequence of violence and mistreatment in sexual and reproductive health care, including the laws and policies that help perpetuate this violence, many women with disabilities may be deterred from seeking needed prenatal care or skilled birth attendance during pregnancy and delivery, a situation that puts their health and lives at risk.⁷⁹ They may also be deterred from seeking needed support for parenting, because of the fear that they will have their parental rights stripped from them.

- 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,⁸⁰ a situation that can increase the risk of complications during pregnancy and labor.⁸¹
- In **Nepal**, as a result of poor treatment, provider attitudes, and physical abuse women with disabilities face in maternal health facilities, many women with disabilities who become pregnant may not want to go to the hospital for their deliveries because of the mistreatment they expect to receive there.
- In **Poland**, a study of women with disabilities showed that they 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.”⁸²

III. Overview of International Human Rights Standards

As the CEDAW Committee and the Committee on Economic, Social, and Cultural Rights (ESCR Committee) have found, all women have a right to available, accessible, acceptable, and good quality sexual and reproductive health services, including maternal health services, as part of their rights to health and to gender equality.⁸³ Women with disabilities have the same right to respectful sexual and reproductive health care as do all women.⁸⁴ In particular, the ESCR Committee has noted that acceptable

maternal health services include those that are physically accessible, disability sensitive, and delivered without discrimination.⁸⁵ Furthermore, the ESCR Committee has found that “reasonable accommodation must be made to enable persons with disabilities to fully access sexual and reproductive health services on an equal basis, such as physically accessible facilities, information in accessible formats and decision-making support, and States should ensure that care is provided in a respectful and dignified manner that does not exacerbate marginalization.”⁸⁶ The CEDAW Committee has 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.”⁸⁷ It has also recommended that at least one State provide training to medical professionals to “raise awareness toward their own prejudices” about women with disabilities.⁸⁸

Beyond the rights enumerated for other women, women with disabilities are also guaranteed specific sexual and reproductive rights protections under the Convention on the Rights of Persons with Disabilities (CRPD).

- Concerning the right to respect for home and family, under Article 23 of the CRPD, States must ensure that “persons with disabilities, including children, retain their fertility on an equal basis with others,” must “render appropriate assistance to persons with disabilities in the performance of their child-rearing responsibilities,” and must guarantee that “[i]n no case shall a child be separated from parents on the basis of a disability of either the child or one or both of the parents.”⁸⁹
- Concerning the right to health, under Article 25 of the CRPD, States must also require that health providers give the same quality of care to persons with disabilities as to others, including on the basis of free informed consent, and must train health care providers and provide ethical standards that address “the human rights, dignity, autonomy and needs of persons with disabilities.” They must also ensure that persons with disabilities are not discriminatorily denied certain health care services and that services are located “as close as possible to people’s own communities, including in rural areas.”⁹⁰
- Concerning other related rights, under Article 12 of the CRPD, States must ensure that all persons with disabilities can exercise legal capacity on an equal basis with others and must “provide the support they may require in exercising their legal capacity.”⁹¹ The CRPD Committee has interpreted this provision to mean that States are required to abolish their systems of guardianship and instead provide support to persons with disabilities when needed and requested to make important decisions,⁹² including related to sexual and reproductive health care.⁹³ States are also required under Article 9 of the CRPD to ensure that facilities, equipment, information, and communications are accessible, are required under Article 8 to raise awareness and combat stereotypes and prejudices about persons with disabilities in order to foster respect for their rights and dignity, and are required under Article 16 to ensure their freedom from violence, exploitation, and abuse.⁹⁴

Under these provisions, the CRPD Committee has affirmed that women with disabilities have the right “to have control over and decide freely and responsibly on matters related to their sexuality, including sexual and reproductive health, free of coercion, discrimination and violence.”⁹⁵ The CRPD Committee has recommended that at least one State “recognize the sexual and reproductive health and rights of women and girls with disabilities, and [] provide them with inclusive services to help them to care for their children, to support their decision-making on matters relating to their sexual and reproductive health, contraception and sexual education for women with disabilities...,” as a means of preventing mistreatment.⁹⁶ The CRPD Committee has further recommended that at least one State “[c]onduct training to ensure that health-care practitioners are aware of the rights of persons with disabilities under the Convention and have the tools to provide appropriate advice for persons with disabilities, including on sexual and reproductive rights.”⁹⁷

Concerning forced reproductive health interventions in particular, the CRPD Committee has consistently found that these abuses violate Article 23 of the CRPD and has recommended that States exercise due diligence to prevent and prosecute these violations,⁹⁸ while other treaty bodies and human rights experts have classified forced reproductive health interventions as forms of torture or ill-treatment.⁹⁹ The CEDAW Committee has further found 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.¹⁰⁰

IV. Conclusion and Recommendations

Despite the clarity of human rights standards surrounding respectful reproductive health care for women and girls with disabilities, they still frequently face violence and mistreatment in reproductive health care, including in childbirth facilities. In order for States to ensure that women and girls with disabilities receive the reproductive health care to which they are entitled under international human rights law, they must take the following actions:

- Repeal all laws and policies that allow for reproductive health interventions to be performed on women and girls with disabilities without the informed consent of the women or girls themselves. Instead, adopt laws and policies that prohibit and criminalize forced reproductive health interventions against women and girls with disabilities and include sanctions for perpetrators of these abuses. Ensure adequate monitoring of health facilities and long-term residential care institutions to ensure that reproductive health interventions on women and girls with disabilities are never performed without their informed consent.
- Abolish systems of guardianship that deprive persons with disabilities of legal capacity and undermine their autonomy, including in reproductive health care contexts. Instead, ensure that persons with disabilities have the support they need to make important life decisions, including related to sexuality and reproduction.
- Raise awareness about the rights and lived experiences of women and girls with disabilities, highlighting their capabilities particularly as decision-makers and as parents. Provide specific training to reproductive health care providers on these rights and on how to ensure that their services are accessible to women and girls with disabilities and delivered in a respectful manner.
- Ensure that health care facilities, including childbirth facilities and equipment, are physically and financially accessible to persons with disabilities, that information is available in accessible formats, and that communications assistance is provided to all persons who need it, including persons with disabilities.
- Repeal all laws that allow for the removal of parental rights based on the disability status of the parent. Collect data on the involvement of child protection agencies in the parenting of persons with disabilities and in particular on the removal of children, including newborn children, from the custody of parents with disabilities. Ensure that staff at all levels in childbirth facilities and social welfare systems are trained on the rights of persons with disabilities and that any persistent disparities in guaranteeing the parental rights of persons with disabilities are addressed. Ensure that adequate supports for parenting are affordable and available to all, including women and girls with disabilities.
- Guarantee that sexual and reproductive health accountability mechanisms within and outside health care facilities are accessible to women with disabilities, including by ensuring that these mechanisms specifically reach out to women with disabilities to request feedback on their sexual and reproductive health care, that they provide information in accessible formats, that there are no financial barriers to accessing these mechanisms, and that women with disabilities are provided support, including communications support and legal aid, in filing claims with these mechanisms.

For further detailed recommendations on how to ensure human-rights based sexual and reproductive health care for women and girls with disabilities, please see the recent WEI and UN Population Fund (UNFPA) publication, [Women and Young Persons with Disabilities: Guidelines for Providing Rights-Based and Gender-Responsive Services to Address Gender-Based Violence and Sexual and Reproductive Health and Rights](#).

¹ This submission generally uses the term “women” to refer to all women and girls throughout the lifecycle, unless otherwise noted.

² CRPD Committee, *General Comment No. 3: Article 6: Women and girls with disabilities*, ¶ 38, U.N. Doc. CRPD/C/GC/3 (2016).

³ Agnieszka Wołowicz-Ruszkowska, *How Polish Women With Disabilities Challenge the Meaning of Motherhood*, in 40(1) PSYCH. OF WOMEN QUARTERLY 80, 86 (2015), <http://journals.sagepub.com/doi/pdf/10.1177/0361684315600390> [hereinafter Wołowicz-Ruszkowska, *Motherhood of Polish Women With Disabilities*].

⁴ *Id.*

⁵ Nat’l Council on Disability, *Rocking the Cradle: Ensuring the Rights of Parents with Disabilities and Their Children* 209-222 (Sept. 27, 2012), <https://www.ncd.gov/publications/2012/Sep272012>.

⁶ *Id.*

⁷ CEDAW Committee, *General Recommendation No. 24: Article 12 of the Convention (women and health)*, ¶ 25, U.N. Doc. CEDAW/C/GC/24 (1999).

⁸ WOMEN ENABLED INTERNATIONAL & UNFPA, WOMEN AND YOUNG PERSONS WITH DISABILITIES: GUIDELINES FOR PROVIDING RIGHTS-BASED AND GENDER-RESPONSIVE SERVICES TO ADDRESS GENDER-BASED VIOLENCE AND SEXUAL AND REPRODUCTIVE HEALTH AND RIGHTS 108 (2018), <https://womenenabled.org/wei-unfpa-guidelines.html> [hereinafter WEI & UNFPA, GUIDELINES ON GBV AND SRHR SERVICES].

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¹² WEI & UNFPA, GUIDELINES ON GBV AND SRHR SERVICES, *supra* note 8, at 108.

¹³ Wołowicz-Ruszkowska, *Motherhood of Polish Women With Disabilities*, *supra* note 3, at 84.

¹⁴ *Id.*

¹⁵ *Id.*

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¹⁷ *Id.*

¹⁸ O.S. Arulogun, M.A. Titiloye, N.B. Afolabi, O.E. Oyewole, & O.G.B. Nwaorgu, *Experiences of girls with hearing impairment in accessing reproductive health care services in Ibadan, Nigeria*, AFRICAN JOURNAL OF REPRODUCTIVE HEALTH, 17, 85–93 (2013), <https://www.ncbi.nlm.nih.gov/pubmed/24069737>.

¹⁹ CRPD Committee, *General Comment No. 3: Article 6: Women and girls with disabilities*, ¶ 51, U.N. Doc. CRPD/C/GC/3 (2016),

²⁰ *Id.*, ¶ 44.

²¹ *Id.*

²² U.N. 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).

²³ 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); U.N. Office of the High Commissioner for Human Rights, *Istanbul Protocol, Manual on the Effective Investigation and Documentation of Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment*, ¶ 63, U.N. Doc. HR/P/PT/8/Rev.1 (2004) (“an absolutely fundamental precept of modern medical ethics is that patients themselves are the best judge of their own interests.”); Convention for the Protection

of Human Rights and Dignity of the Human Being with Regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine, art. 5, adopted Apr. 4, 1997, Eur. T.S. No. 164 (entered into force Dec. 1, 2009); INTERNATIONAL FEDERATION OF GYNECOLOGY AND OBSTETRICS (FIGO), Guidelines regarding informed consent, in ETHICAL ISSUES IN OBSTET & GYNEC. 13-14 (Oct. 2009).

²⁴ FIGO, *Female Contraceptive Sterilization*, 115 INT'L J. OF GYNECOLOGY AND OBSTETRICS 88, 88-89, ¶ 8 (2011), <http://www.cehat.org/uploads/files/Female%20Contraceptive%20Sterilization%20Statement%281%29.pdf>.

²⁵ *Id.*

²⁶ *Id.*

²⁷ World Health Organization, et al, *Eliminating forced, coercive or otherwise involuntary sterilization: An interagency statement* 9 (2014), <http://apps.who.int/iris/bitstream/10665/112848/1/9789241507325eng.pdf>.

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³² Agnieszka Wołowicz, *Macierzyństwo kobiet z niepełnosprawnością intelektualną*. [Maternity of Women with Intellectual Disabilities], Unpublished research, (2018).

³³ Ashika Misra, *Is hysterectomy the final solution?*, DNA INDIA, Jan. 30, 2008, <http://www.dnaindia.com/mumbai/report-is-hysterectomy-the-final-solution-11482>.

³⁴ Women with Disabilities India Network, *Meeting in Bangalore*, Feb. 4, 2012.

³⁵ Women with Disabilities India Network, *Submission of Alternative Report (Article 6) to the Committee on the Rights of Persons with Disabilities: India 2019 (Annexure 1: Inputs from respondents from consultation with women with disabilities in Kolkata, Patna, Bhubaneswar, and Koppal)* (2018), https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=INT%2fCRPD%2fICO%2ffind%2f33879&Lang=en.

³⁶ See *Women with Disabilities Submission to the Special Rapporteur on the Rights of Persons with Disabilities on the Right to Health: Annex D (India)* 1 (Mar. 30, 2018), <https://womenenabled.org/pdfs/Annex%20D%20-%20India.docx>.

³⁷ *Id.*

³⁸ Arkansas (ARK CODE ANN. §20-49-101 (2010)); Colorado (COLO. REV. STAT. §27-10.5-130 (2012)); Delaware (DEL. CODE ANN. 16 §5712 (2013)); Georgia (GA. CODE ANN. §31-20-3 (2010)); Maine (ME. REV. STAT. 34-B §7010 (2011)); North Carolina (N.C. GEN. STAT. §35A-1245 (2010)); Oregon (OR. REV. STAT. §436.205 (2011)); Utah (UTAH CODE ANN. §62A-6-102 (2011)); Vermont (VT. STAT. ANN. 18 §8705 et seq. (2009)); Virginia (VA. CODE ANN. §54.1-2975 et seq. (1988)); West Virginia (W. VA. CODE R. §27-16-1 et seq. (2013)).

³⁹ Americans with Disabilities Act of 1990, 42 U.S.C., §§12101-12213 (2000).

⁴⁰ Courts granting nonconsensual sterilization of females with disabilities are the following: Conservatorship of Person and Estate of Maria B., 160 Cal. Rptr. 3d 269 (Cal. Ct. App. 2013); Matter of A.W., 637 P.2d 366 (Colo. 1981); Estate of C.W., 640 A.2d 427 (Pa. Super. 1994); Matter of Mildred J. Terwilliger, 304 A.2d 1376 (Pa. Super. 1982). Courts denying nonconsensual sterilization of females with disabilities are the following: Conservatorship of Valerie N., 40 Cal. 3d 143 (Cal. 1985); Matter of Romero, 790 P.2d 819 (Colo. 1990); Wentzel v. Montgomery General Hosp., 447 A.2d 1244 (Md. 1982); Matter of Truesdell, 329 S.E.2d 630, 636 (N.C. 1985).

⁴¹ Sterilisation Act, 44 of 1998, § 2(2) (S. Afr.)

⁴² *Id.*

⁴³ We concur with the analysis presented by Holness, who measures the Sterilisation Act in its present form against both the Constitution and the CRPD, and concludes that it falls short on both counts. Willene Holness, *Informed Consent for Sterilisation of Women and Girls with Disabilities in the Light of the Convention on the Rights of Persons with Disabilities*, 27 AGENDA 4, 35, 42-43 (2013).

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- ⁴⁴ See Willene Holness, *Informed Consent for Sterilisation of Women and Girls with Disabilities in the Light of the Convention on the Rights of Persons with Disabilities*, 27 *AGENDA* 4, 35-54 36 (2013); Paul Chappell, *(Re)thinking Sexual Access for Adolescents with Disabilities in South Africa: Balancing Rights and Protection*, 4 *AFRICAN DISABILITY RIGHTS YEARBOOK* 124 (2016), <http://www.adry.up.ac.za/index.php/section-a-articles-4-2016/paul-chappell>
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- ⁴⁶ See *Women with Disabilities Submission to the Special Rapporteur on the Rights of Persons with Disabilities on the Right to Health: Annex A (Kenya)* 4 (Mar. 30, 2018), <https://womenenabled.org/pdfs/Annex%20A%20-%20Kenya.docx>.
- ⁴⁷ National Survey on Disability by National Council for Population and Development (Kenya) (2007).
- ⁴⁸ 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), <http://knchr.org/Portals/0/Reports/Disability%20Report.pdf>.
- ⁴⁹ See Women Enabled International, Human Rights Watch, & Disability Rights International, *Submission to the CEDAW Committee for its Review of Serbia* (Feb. 2019), <https://womenenabled.org/pdfs/HRW%20WEI%20DRI%20Submission%20to%20CEDAW%20on%20Serbia%20FINAL%20January%2028,%202019.pdf>.
- ⁵⁰ Bill of Sexual Violence Elimination, § 104 (Indonesia) (2017).
- ⁵¹ Medical Termination of Pregnancy Act, § 3(4)(a) (1971) (India), <http://tcw.nic.in/Acts/MTP-Act-1971.pdf>.
- ⁵² Supreme Court of India, *Suchita Srivastava & Anr vs. Chandigarh Administration* (28 August 2009), <https://indiankanoon.org/doc/1500783/>.
- ⁵³ The Reproductive Health Care Bill 2014 (Kenya), http://kenyalaw.org/kl/fileadmin/pdfdownloads/bills/2014/ReproductiveHealthCareBill2014__1_.pdf.
- ⁵⁴ *Id.* at § 20.
- ⁵⁵ Choice on Termination of Pregnancy Act, 92 of 1996, § 5(5) (S. Afr.); Ashwanee Budoo, Rajendra P. Gunuth, *Termination of Pregnancy of Persons with Mental Disabilities on Medical Advice: A Case Study of South Africa*, 2 *AFRICAN DISABILITY RIGHTS YEARBOOK* 101, 103-104 (2014).
- ⁵⁶ Wołowicz-Ruszkowska, *Motherhood of Polish Women With Disabilities*, *supra* note 3, at 84.
- ⁵⁷ *Id.* at 85.
- ⁵⁸ *Id.*
- ⁵⁹ *Id.*
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- ⁷⁹ WEI & UNFPA, GUIDELINES ON GBV AND SRHR SERVICES, *supra* note 8, at 108.
- ⁸⁰ INCLUSIVE FRIENDS & NIGERIA STABILITY AND RECONCILIATION PROGRAMME, WHAT VIOLENCE MEANS TO US: WOMEN WITH DISABILITIES SPEAK 14 (2015), <http://www.nsrp-nigeria.org/wp-content/uploads/2015/09/What-Violence-Means-to-us-Women-with-Disabilities-Speak.pdf>.
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- ⁸⁴ Convention on the Rights of Persons with Disabilities, adopted Dec. 13, 2006, art. 25(a), G.A. Res. A/RES/61/106, U.N. GAOR, 61st Sess., U.N. Doc. A/61/611, (entered into force May, 3 2008) [hereinafter CRPD].
- ⁸⁵ ESCR Committee, *General Comment No. 22 on the right to sexual and reproductive health*, ¶¶ 16 & 45, U.N. Doc. E/C.12/GC/22 (2016).
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- ⁸⁹ CRPD, *supra* note 84, art. 23.
- ⁹⁰ *Id.*, art. 25
- ⁹¹ *Id.*, art. 12.
- ⁹² CRPD Committee, *General Comment No. 1 (2014): Article 12: Equal recognition before the law*, ¶ 28, U.N. Doc. CRPD/C/GC/1 (2014) (“States parties’ obligation to replace substitute decision-making regimes by supported decision-making requires both the abolition of substitute decision-making regimes and the development of supported decision-making alternatives. The development of supported decision-making systems in parallel with the maintenance of substitute decision-making regimes is not sufficient to comply with article 12 of the Convention.”).
- ⁹³ *Id.*, ¶ 35,
- ⁹⁴ CRPD, *supra* note 84, arts. 8, 9, & 16.
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