**Center for Reproductive Rights**

**Submission to the Special Rapporteur on the Rights of Persons with Disabilities - Questionnaire on the rights of persons with disabilities and bioethics**

**October 17th, 2019**

The Center for Reproductive Rights (the Center)—an international nonprofit legal advocacy organization headquartered in New York City, with regional offices in Nairobi, Bogotá, Kathmandu, Geneva, and Washington, D.C.—uses the law to advance reproductive freedom as a fundamental human right that all governments are legally obligated to respect, protect, and fulfill. Since its inception 27 years ago, the Center has advocated for the realization of women and girls’ human rights on a broad range of issues, including on the right to access sexual and reproductive health services; preventing and addressing sexual violence; and the eradication of harmful traditional practices. The Center for Reproductive Rights (“the Center”), an international non-governmental legal advocacy organization dedicated to the advancement of reproductive freedom as a fundamental human right, submits this paper to the Special Rapporteur on the Rights of Persons with Disabilities following the mandate’s questionnaire on the right of persons with disabilities and bioethics.

1. **Foundational Principles**

Questions related to bioethics and disability rights intersect with issues pertaining to sexual and reproductive health and rights (SRHR). Both SRHR and disability rights advocates coalesce around the human rights principles of non-discrimination and equality, participation, autonomy and self-determination, informed consent and accountability.

As highlighted in the Nairobi Principles on Abortion, Prenatal Testing and Disability (hereinafter ‘the Nairobi Principles’), ‘*sexual and reproductive rights, including access to safe abortion, are important priorities for both sexual and reproductive rights advocates and for women and girls with disabilities’*.[[1]](#endnote-2) The Principles also emphasize that that there is no incompatibility between guaranteeing access to safe abortion and protecting disability rights[[2]](#endnote-3), given the centrality of principles of autonomy, equality and access to health in all gender and disability-sensitive debates.

For many people with disabilities, especially individuals with developmental disabilities and other conditions that are most likely to be targeted by abortion bans, the eugenics movement is not a thing of the past but a continuing reality. It is critical to recognize that stigma, prejudice, and misconceptions about people with disabilities impacts reproductive decisions that pregnant people make, and compromises informed decision making.

It is vital that pregnant individuals receive accurate and unbiased information about disability and that governments takes proactive steps to tackle underlying and systemic ableism, stigma, and discrimination against people with disabilities while simultaneously making abortion widely available.

The enduring legacy of eugenics and the current structural system of ableism­—both rooted in disability stigma and harmful stereotypes that perpetuate ideas that the lives of persons with disabilities are somehow of less value or that persons with disabilities lack agency to decide on their lives, health and future—call for ongoing and productive conversations between the sexual and reproductive rights movement and the disability movement. These are critical to ensure the full, equal, meaningful and effective participation of women and girls with disabilities in discussions on abortion rights and to ensure that their rights are fully acknowledged and considered.[[3]](#endnote-4)

Building solidarity across social justice movements is therefore crucial but cannot be a substitute for ongoing, meaningful engagement with members of the disability rights and justice communities. Additional work is needed to appropriately recognize and support the leadership of women with disabilities, particularly women with developmental disabilities. Authentic partnership between the reproductive and disability rights and justice movements will strengthen both communities and is key not only to defeating specific legislations, but also to address concerns.

* 1. Non-discrimination and equality

People with disabilities various forms of discrimination due to stereotypes, assumptions and fears about disability. Discrimination in favor of non-disabled people is referred to as “ableism” and is often normalized. Ableism is often compounded by other forms of discrimination (based on race, ethnicity, sex, including sexual orientation and gender identity, or other status). For example, women of color with disabilities experience oppression based on multiple, intersecting identities and are disproportionately affected by restrictions on reproductive health care. LGBTQ people with disabilities also face multiple and unique barriers to reproductive health care, including a lack of provider training, provider discrimination, and denial of care. Immigrants living with disabilities similarly face distinct and overlapping barriers in accessing health care, including discriminatory cultural stereotypes and real or presumed language barriers, among other challenges.

The right to sexual and reproductive health is indivisible from and interdependent with other human rights, including the right to non-discrimination and equality.[[4]](#endnote-5) Where women’s rights to equality and non-discrimination are not fulfilled, women’s ability to access sexual and reproductive health services and make meaningful choices about their reproductive lives is limited. In addition, where women are unable to access sexual and reproductive health services, the inequalities and discrimination women face are exacerbated due to the differentiated impact that childbearing has on women’s health and lives, including in the spheres of access to education and employment. Gender inequalities create gender-specific barriers to the realization of women’s rights, including historical and systemic discrimination; gender stereotypes about women as mothers, caregivers, and child-bearers; and traditional and cultural beliefs about the role of women in society.

Both the CEDAW and CRPD Committee have highlighted States’ obligations to address the root causes of systemic discrimination against women and persons with disabilities, which includes ‘*challenging discriminatory attitudes and fostering respect for the rights and dignity of persons with disabilities, in particular women with disabilities, as well as providing support to parents of children with disabilities in this regard.*’ The two Committees have called for the repeal of discriminatory laws and policies which hinder access to sexual and reproductive health services, including discriminatory abortion laws.[[5]](#endnote-6)

The CRPD Committee recognizes that women and girls with disabilities may face multiple forms of discrimination, due to both their gender and their disability,[[6]](#endnote-7) which undermine their reproductive autonomy and threaten their ability to access their right to sexual and reproductive health. Lack of provider training, discrimination from service providers and denial of care also disproportionately impact women of color and/or members of LGBTIQs communities with disabilities. Intersectional discrimination can hinder women and girls’ ability to achieve their right to sexual and reproductive health. This discrimination creates barriers that thwart the ability of women and girls with disabilities to achieve their rights, though the ways in which different barriers affect women with disabilities have not yet been widely studied.[[7]](#endnote-8)

In its General Comment number 6, the CRPD Committee stresses that “[e]quality and non-discrimination are among the most fundamental principles and rights of international human rights law,”[[8]](#endnote-9) and in order to fulfil their obligations, “States parties are obliged to prohibit and prevent discriminatory denial of health services to persons with disabilities and to provide gender-sensitive health services, including those relating to sexual and reproductive health and rights.”[[9]](#endnote-10)

The CEDAW Committee has stated that “it is discriminatory for a State party to refuse to provide legally for the performance of certain reproductive health services for women.”[[10]](#endnote-11) Furthermore, the ESCR Committee has made clear that equality in the context of the right to health “requires at a minimum the removal of legal and other obstacles that prevent men and women from accessing and benefitting from health care on a basis of equality.”[[11]](#endnote-12)

Crucially, the Working Group on Discrimination Against Women and Girls (WGDAWG) has also established that the development, implementation and enforcement of discriminatory criminal provisions restricting and prohibiting women’s bodily autonomy undermine women’s health and human rights. The WGDAWG has stated ‘*the discriminatory use of criminal law, punitive sanctions, and legal restrictions to regulate women’s control over their own bodies constitutes a severe and unjustified form of State control and infringes on women’s dignity and bodily integrity by restricting their autonomy to make decisions about their own lives and health*.’[[12]](#endnote-13)

Furthermore, the Nairobi Principles has emphasized that *‘criminal laws and other restrictions on abortion violate international human rights law and are not the way to eliminate disability stigma or support persons with disabilities[[13]](#endnote-14).’*

According to the CRPD Committee and other treaty monitoring bodies, the principle of substantive equality, which is grounded in human rights, provides a framework by which to effectively recognize and address inequalities faced by women and girls, including those with disabilities. At its core, substantive equality requires states to identify the root causes of discrimination, such as power structures and social and economic systems reinforced by gender stereotypes and socialized gender roles, which lead to inequalities. Substantive equality also requires states to acknowledge that people experience inequality differently not only because of who they are as individuals but also because of the groups to which they belong. Finally, substantive equality requires that states measure progress on addressing inequalities by looking at equality of results for all persons, including the most marginalized, and ensuring equality of results, which may require enacting practices and policies targeting particular marginalized groups.[[14]](#endnote-15)

In that context, combating ableism and gender stereotypes at all levels, including in the provision of sexual and reproductive health information and services, creating an enabling environment for parents, and addressing the social and other determinants of health and material conditions shaping women’s and girls’ lives is central to ensuring free and informed consent and substantive equality.

* 1. Autonomy and self-determination

Ensuring women’s right to non-discrimination and substantive equality requires that women are able to exercise autonomy and self-determination, as well as make important life decisions without undue influence or coercion. Autonomy is one of the foundational principles and core legal obligations outlined in the CRPD.[[15]](#endnote-16) According to the CRPD Committee, [a]t all times, including in crisis situations, the individual autonomy and capacity of persons with disabilities to make decisions must be respected.”[[16]](#endnote-17) Thus, State parties must “review the laws allowing for guardianship and trusteeship, and take action to develop laws and policies to replace regimes of substitute decision-making by supported decision-making, which respects the person’s autonomy, will and preferences.”[[17]](#endnote-18) Other Committees, including the CESCR, CEDAW, and Human Rights Committees, have underscored that women must be able to engage in autonomous decision-making about their health, which is necessary for the achievement of reproductive health and rights.[[18]](#endnote-19) States must ensure that women and girls have full exercise of autonomy, which requires that choices are meaningful and not limited by discrimination, lack of opportunities, or possible results.[[19]](#endnote-20)

1. **International Human Rights Framework on Sexual and Reproductive Health and Rights of Women and Girls with Disabilities** 
   1. Right to sexual health and reproductive health

The right to health, including sexual health and reproductive health, is enshrined in several international treaties, with the most relevant being the International Covenant on Economic, Social and Cultural Rights (CESCR)[[20]](#endnote-21) and the Convention on the Rights of Persons with Disabilities (CRPD). In its General Comment No. 14, the CESCR Committee sets forth four interrelated and essential elements of the right to health, finding that health facilities, goods, and services must be available, accessible, acceptable, and of good quality.[[21]](#endnote-22) In its subsequent General Comment No. 22, the CESCR Committee explicitly applies these principles to the right to sexual and reproductive health.[[22]](#endnote-23) This framework has also been utilized by other treaty monitoring bodies, including the Committee on the Rights of the Child (CRC Committee) and the Committee on the Elimination of All Forms of Discrimination Against Women (CEDAW Committee).[[23]](#endnote-24)

As outlined by the CESCR Committee, the right to sexual and reproductive health includes a number of freedoms, including “the right to make free and responsible decisions and choices, free of violence, coercion and discrimination, regarding matters concerning one’s body and sexual and reproductive health.”[[24]](#endnote-25) This right also requires entitlements to, inter alia, “unhindered access to a whole range of health facilities, goods, services and information.”[[25]](#endnote-26) The CRPD and CESCR Committees underscore that women and girls with disabilities have the same right to health as all women and girls, including the right to sexual and reproductive health.[[26]](#endnote-27)

The right to sexual and reproductive health includes sexual and reproductive health care but it also extends beyond to include the underlying determinants of sexual and reproductive health.[[27]](#endnote-28) These include “access to safe and potable water, adequate sanitation, adequate food and nutrition, adequate housing, safe and healthy working conditions and environment, health-related education and information, and effective protection from all forms of violence, torture and discrimination and other human rights violations that have a negative impact on the right to sexual and reproductive health.”[[28]](#endnote-29)

The CRPD recognizes the importance of fulfilling the right to sexual and reproductive health for persons with disabilities, particularly women and girls, and includes the most expansive language on reproductive rights of any UN human rights convention. The reproductive rights specifically enumerated in the CRPD include the rights “to decide freely and responsibly on the number and spacing of their children and to have access to age-appropriate information, reproductive and family planning education,” to retain fertility on an equal basis with others, including for children and adolescents with disabilities, and to health on an equal basis with others, “including in the area of sexual and reproductive health and population-based public health programs.”[[29]](#endnote-30)

* 1. Access to sexual and reproductive health information and comprehensive sexuality education
     1. Accessibility

UN human rights bodies have recognized that states have a legal obligation to provide sexual and reproductive health information to women and girls in an accessible manner.[[30]](#endnote-31) Indeed, the Committee on Economic, Social, and Cultural Rights (ESCR Committee) has considered that fundamental to the realization of the right to health is “access to health-related education and information, including on sexual and reproductive health.”[[31]](#endnote-32) According to this ESCR Committee, accessibility of health information includes “the right to seek, receive and impart information and ideas concerning health issues” and the provision of this information without discrimination.[[32]](#endnote-33) In order to ensure that women do not face discrimination in accessing health information, the ESCR Committee has required “the removal of all barriers interfering with access to health services, education and information, including in the area of sexual and reproductive health.”[[33]](#endnote-34)

The Committee on the Elimination of all forms of Discrimination against Women (CEDAW Committee) has recognized the critical importance of reproductive health information in the exercise of decision-making autonomy, noting that “women must have information about contraceptive measures and their use, and guaranteed access to sex education and family planning services” to make informed decisions regarding their reproductive health.[[34]](#endnote-35) Additionally, the Committee on the Rights of the Child (CRC Committee) has emphasized the importance of such information for adolescents, indicating that “States parties should provide adolescents with access to sexual and reproductive information, including on family planning and contraceptives, the dangers of early pregnancy, the prevention of HIV/AIDS and the prevention and treatment of sexually transmitted diseases (STDs).”[[35]](#endnote-36) Moreover, the UN Special Rapporteur on Torture classified denial of reproductive health information as a potential form of cruel, inhuman or degrading treatment (CIDT), stating that “[a]ccess to information about reproductive health is imperative to a woman’s ability to exercise reproductive autonomy, and the rights to health and to physical integrity.”[[36]](#endnote-37)

An essential element of the right to sexual and reproductive health is that health facilities, information, goods, and services must be accessible.[[37]](#endnote-38) Because women and girls with disabilities may experience additional difficulties in accessing facilities, information, goods, and services, the needs of women and girls must be addressed through reasonable accommodation.[[38]](#endnote-39)Women and girls with disabilities are sometimes unable to access reproductive and sexual health services because of physical barriers that prevent entry into healthcare facilities or to the use of transportation.[[39]](#endnote-40)

In addition, to be able to make informed decisions about their sexual and reproductive health, women and girls must be able to obtain medically accurate information. Access to sexual and reproductive health information in healthcare settings is an issue that affects all women and girls, as laws or practices can prohibit or restrict available information or require healthcare professionals to provide unnecessary or misleading information to women about their health.[[40]](#endnote-41)

The ESCR Committee has held that ‘the dissemination of misinformation and the imposition of restrictions on the right of individuals to access information about sexual and reproductive health violated the duty to respect human rights’ and has called on States to refrain from censoring, withholding, misrepresenting or criminalizing the provision of information on sexual and reproductive health, both to the public and to individuals, adding that such restrictions impede access to information and services, and can fuel stigma and discrimination.[[41]](#endnote-42) Furthermore, the Committee has established that all individuals and groups have the right to evidence-based, scientifically and medically appropriate and up-to-date information on all aspects of sexual and reproductive health, and that such information must be provided in a manner consistent with the needs of the individual and the community, taking into consideration, for example, age, gender, language ability, educational level, disability, sexual orientation, gender identity and intersex status.[[42]](#endnote-43)

Women with disabilities may face additional barriers to accessing information about their reproductive and sexual health distinct from other women due to communication barriers, lack of sexual and reproductive health information in accessible formats, or lack of opportunity to request the information from medical professionals.[[43]](#endnote-44)

The CRPD also provides a right for persons with disabilities “to seek, receive, and impart information and ideas on an equal basis with others” through the provision of information in accessible formats.[[44]](#endnote-45) States are obligated under the CRPD to ensure that facilities and transportation, including medical facilities and emergency services, are accessible to persons with disabilities,[[45]](#endnote-46) an important part of ensuring access to needed health information.

The CRPD Committee has taken steps to ensure that the rights to health and information in the CRPD are fulfilled. The Committee has commented on “systemic barriers that make it impossible for persons with disabilities to access health services…,” including “physical barriers, a dearth of accessible materials, a lack of health-care professionals trained in the human rights model of disability …”[[46]](#endnote-47) The CRPD Committee has also expressed concern about lack of available health services, particularly in rural areas, and its effect on access for persons with disabilities.[[47]](#endnote-48)

* + 1. Comprehensive sexuality education

Comprehensive and accurate sexuality education is a key component of ensuring that sexual and reproductive rights are fulfilled, by providing needed information at an early age so that people can make decisions about their sexual and reproductive health.[[48]](#endnote-49) Sexuality education is also important as a means to empower women and girls to protect themselves from unwanted pregnancies and STIs, such as HIV and AIDS, as well as to access sexual and reproductive health services.[[49]](#endnote-50) However, according to the World Health Organization, adolescents with disabilities are more likely to be excluded from sexuality education programs than other children.[[50]](#endnote-51)

Harmful stereotypes based on gender and disability constitute a core barrier hindering women and girls with disabilities’ access to sexual and reproductive health services, including comprehensive sexuality education. For example, girls with disabilities are sometimes perceived as asexual and, thus, sexuality education is believed to be unnecessary.[[51]](#endnote-52) Conversely, girls with disabilities may also be viewed as sexually uninhibited,[[52]](#endnote-53) and, therefore, they may be actively discouraged from having sex. Existing education for girls with disabilities often depicts sex as dangerous.[[53]](#endnote-54)

Even if sexuality education is available, educational materials are seldom made available in formats such as Braille, large print, simple language, pictures, sign language[[54]](#endnote-55) or digital fully accessible formats, among others appropriate, making it difficult for persons with disabilities to access health-related information, including sexuality education.[[55]](#endnote-56) Additionally, sexuality education rarely addresses distinct sexual and reproductive health needs and issues faced by women and girls with disabilities or the historical discrimination they face in accessing these services, including as a result of being subjected to forced or coerced sterilization, contraception, or abortion.[[56]](#endnote-57)

Moreover, the information that is provided to women and girls with disabilities about sexual and reproductive healthcare and parenting may actually undermine their rights, exposing a bias in the community that persons with disabilities are not able to care for their children.[[57]](#endnote-58) Social science research has documented that women with disabilities face skepticism about their ability to care for children from family members and healthcare professionals.[[58]](#endnote-59) Parents of children with intellectual disabilities in particular may be biased against the ability of their children to become parents, sometimes resulting in abusive practices such as forced sterilization.[[59]](#endnote-60)

* 1. Access to sexual and reproductive health services – Access to Abortion

Lack of access to modern contraceptive information and services means that women and girls are often unable to protect themselves from HIV and other sexually transmitted infections (STIs) or to control their fertility and reproduction, which results in negative consequences for their health and lives.[[60]](#endnote-61) Despite that contraception and other reproductive health goods and services are important for positive health outcomes, women and girls with disabilities are less likely to receive information about HIV prevention and safe sex, and are less likely to have access to prevention methods such as condoms.[[61]](#endnote-62) Contraceptive and abortion information and services may be unavailable to individuals with disabilities due to physical barriers, lack of accessible information, stigma, and discrimination.[[62]](#endnote-63)

Accordingly, women and girls with disabilities have an increased risk for HIV, STIs, and unwanted pregnancy. Furthermore, lack of access to and information about contraception and abortion can have particularly severe physical and mental consequences for women and girls who are victims of sexual violence.[[63]](#endnote-64) Women and girls with disabilities experience violence, including sexual violence, at higher rates than other women,[[64]](#endnote-65) making access to contraception and abortion essential for the exercise of their reproductive rights.

While all women, including women with disabilities, have difficulty navigating restrictive environments to fully exercise their reproductive rights,[[65]](#endnote-66) women with disabilities are placed at a particular disadvantage because of the additional difficulties they may face in accessing sexual and reproductive health services. Procedural barriers to abortion services, such as mandatory waiting periods and third-party authorization requirements, generally increase the burden associated with accessing abortion services and exacerbate existing barriers women and girls with disabilities may face in relation to accessible transportation.

Lack of access to safe and legal abortion services has a devastating impact on women’s health and lives.

Historically, women have been denied the right to choose to terminate a pregnancy and as such, the ability to make decisions about their lives and bodies. Moreover, gaps in the implementation of abortion laws or procedural barriers placed in the way of abortion services have undermined women’s access to this reproductive health service.[[66]](#endnote-67)

Evidence has shown that women who wish to terminate their pregnancies will do so regardless of the legality of this service.[[67]](#endnote-68) However, the legal status of abortion will largely determine whether they can access abortion services in safe or unsafe conditions.[[68]](#endnote-69) In circumstances in which abortion is legally restricted, women are more likely to seek out clandestine and unsafe abortions, which are associated with increased rates of maternal mortality and morbidity.[[69]](#endnote-70) Moreover, in countries in which women are unable to access the abortion services to which they are legally entitled, they may also be forced to seek clandestine and unsafe abortions. An estimated 22 million women undergo unsafe abortions each year and 47,000 women die from unsafe abortions annually,[[70]](#endnote-71) accounting for up to 13 percent of maternal deaths worldwide.[[71]](#endnote-72)

True reproductive autonomy requires ensuring that where women face an unwanted pregnancy, abortion is an available option, if they so choose and they are provided with sufficient information and support to make this decision for themselves. This is in line with the standards from treaty monitoring bodies, which have recognized that restrictive abortion laws cause women to seek out unsafe and clandestine abortions, and repeatedly called on states to liberalize restrictive abortion laws and guarantee all women access to safe abortion services.[[72]](#endnote-73)

In countries with restrictive abortion laws, women are often unable to access abortion services in the limited circumstances they are permitted due to a variety of factors including lack of training for health care workers, lack of information about legal abortion services, and stigma around abortion.[[73]](#endnote-74) Coupled with the barriers already experienced by women with disabilities in accessing reproductive health services, including barriers to physical access, the absence of alternative formats of information and communication, lack of disability-related support services,[[74]](#endnote-75)abortion services may be virtually inaccessible for women with disabilities in practice. As a result, they may be compelled to carry to term pregnancies and enter motherhood against their will, which in turn affects all facets of their lives, including their ability to continue their education, pursue career opportunities, and participate in public life.

The CRPD contains the strongest and most explicit language of any UN human rights treaty on reproductive rights. An important aspect of ensuring reproductive rights is providing access to safe and legal abortion services to ensure that women and girls have control over their lives and bodies.

Nearly all of the UN treaty monitoring bodies have framed maternal deaths due to unsafe abortion as a violation of human rights and recognized the detrimental consequences of criminalizing or otherwise restricting abortion on women’s and girls’ lives, health, and well-being.[[75]](#endnote-76) As such, they have called on states to review and repeal laws that criminalize abortion.[[76]](#endnote-77) Among other rights, they have analyzed this issue in the context of the right to non-discrimination, noting that the problem of maternal mortality due to unsafe abortion is evidence of discrimination against women.[[77]](#endnote-78) Moreover, they have called on states to ensure access to safe abortion services where legal, recognizing that the failure to do so constitutes discrimination.[[78]](#endnote-79) Notably, the CEDAW Committee has also indicated that, in certain circumstances, forcing a woman or girl to continue a pregnancy constitutes discrimination.[[79]](#endnote-80)

The CEDAW and CRPD Committees have called on States to decriminalize abortion in all circumstances and legalize it in a manner that ‘*fully respects the autonomy of women, including women with disabilities.’[[80]](#endnote-81)*

Criminal and/or restrictive abortion laws are incompatible with states’ human rights obligations. International and regional human rights bodies have repeatedly condemned restrictive and criminal abortion laws as violating the rights to life; health; privacy; equality and non-discrimination; and freedom from cruel, inhuman or degrading treatment or punishment.[[81]](#endnote-82) These bodies have called on states to liberalize legislation criminalizing and prohibiting abortion and guarantee women access to safe abortion services.[[82]](#endnote-83) Recently, treaty monitoring bodies have progressed beyond just articulating specific grounds under which abortion should be legal and have instead urged states to generally ensure women’s access to safe abortion services.[[83]](#endnote-84)

Those opposed to abortion often attempt to apply human rights or constitutional rights prenatally, in attempt to subsume the rights of pregnant women to those of fetus. The strategy is to chip away at abortion rights by creating fetal personhood, so that fetuses are recognized as full human beings with rights under the law. An emerging trend to extend a right to life before birth, and in particular from conception, poses a significant threat to women’s human rights, in theory and in practice.[[84]](#endnote-85)

However, no international or regional human rights body has recognized that absolute right to life, as enshrined in relevant international treaties, applies prenatally.[[85]](#endnote-86)

Guaranteeing women and girls with disabilities access to the full range of sexual and reproductive information and services is essential to enabling them to exercise reproductive autonomy and self-determination.

1. **Violations of the Sexual and Reproductive Rights of Women with Disabilities**
   1. Forced or coerced sterilization

Autonomy and equality are key principles for protecting women’s sexual and reproductive rights. There is broad consensus amongst the treaty monitoring bodies which recognizes that forced sterilization violates human rights and calls for an end to the practice. The CRPD Committee considers forced or coerced sterilization as a violation of the rights to bodily integrity, family and fertility, health, and legal capacity,[[86]](#endnote-87) noting that women with disabilities are subjected to high rates of forced sterilization because they are denied control over reproductive decision-making.[[87]](#endnote-88) The Committee Against Torture (CAT Committee) has found that forced sterilization violates women and girls’ right to be free from torture or ill-treatment.[[88]](#endnote-89) The CEDAW Committee has identified forced sterilization as a form of gender-based violence,[[89]](#endnote-90) and has called for complaints about forced sterilization to be duly investigated and for the provision of remedies and redress that are “adequate, effective, promptly granted, holistic and proportionate to the gravity of the harm suffered.”[[90]](#endnote-91) Other Committees, including the CRPD, CESCR Committee, and CRC Committees, have called on states to prohibit forced sterilization and provide reparations for women who have been victims of forced sterilization.[[91]](#endnote-92)

Women with disabilities are often forced to undergo sterilization,[[92]](#endnote-93) which takes away their reproductive capacity without free and informed consent. Forced or coerced sterilization of women and girls with disabilities is often used as a way to control menstrual cycles.[[93]](#endnote-94) It may also occur because of misconceptions and discriminatory attitudes about the ability of women with disabilities to take care of children.[[94]](#endnote-95) Forced or coerced sterilization is deeply rooted in stereotypes about women and girls with disabilities and constitutes a form of control over sexuality and reproduction, under the paternalistic assumption of the practice being for ‘their own good’.[[95]](#endnote-96)

Women and girls with disabilities are particularly vulnerable to forced sterilizations performed under the auspices of legitimate medical care or as the result of decisions made by their parents, guardians, or doctors without the individual woman’s consent. The Special Rapporteur on Violence against Women called forced sterilization of women with disabilities a form of violence and classified it as a “global problem.”[[96]](#endnote-97) The UN Special Rapporteur on the Right to Health recognized that “[f]orced sterilizations, rape and other forms of sexual violence, which women with mental disabilities are vulnerable to, are inherently inconsistent with their sexual and reproductive health rights and freedoms.”[[97]](#endnote-98)

Despite that forced sterilization is a gross violation of human rights, many countries permit the practice on women and girls with disabilities. For instance, in the United States, the question of whether people with disabilities can exercise their legal capacity to provide consent remains a contentious legal issue, as courts are divided on the issue[[98]](#endnote-99) and at least ten states have statutory language authorizing a court to order the involuntary sterilization of a person with a disability.[[99]](#endnote-100) In France, five young women with mental disabilities brought suit in the European Court of Human Rights after they were forcibly sterilized.[[100]](#endnote-101) In Colombia, the Constitutional Court validated the practice of surgical sterilization of minors with intellectual and psychosocial disabilities. In its decision, the Court explained, “The decision to undergo surgical sterilization ensures more dignified living conditions for those who cannot make decisions related to the exercise of their reproductive freedom and that may be exposed to forced pregnancies in detriment of their dignity and personal integrity.”[[101]](#endnote-102)

Research has indicated that parents of children with intellectual disabilities may consider sterilization for their children because of perceptions that their children would not be good parents themselves, that other means of contraception would not be effective at preventing unwanted pregnancies, or that pregnancy may result from sexual abuse.[[102]](#endnote-103) In reality, however, parents may feel they need to sterilize their children because the parents lack support in caring for children with disabilities undergoing menstruation,[[103]](#endnote-104) or because support services are not available in the community for persons with disabilities who decide to have children.

* 1. Forced Abortion

Women and girls with disabilities have been subject to forced abortion as a result of discriminatory beliefs about who should have children or unjustifiable state policies.

Although the issue of forced abortion for women and girls with disabilities is not yet widely studied, news reports indicate that when women and girls, particularly with intellectual or mental disabilities, become pregnant, they are sometimes forced or coerced into undergoing an abortion.[[104]](#endnote-105) The European Disability Forum (EDF) noted in a submission to OHCHR on sexual and reproductive rights that “[i]n some countries where therapeutic sterilization of women with disabilities has become illegal, the practice of coerced abortion of women with intellectual or psychosocial disabilities or women and girls with intensive support needs has become even more common….”[[105]](#endnote-106) EDF explains that, because of the widespread societal notion that women with disabilities should not become mothers,[[106]](#endnote-107) “women with disabilities sometimes have to argue with the medical personnel that they actually want to keep their baby [and] often feel pushed by their own families, or persons close to them/personnel in the institutional setting where they live to undergo an abortion.”[[107]](#endnote-108) Women and girls with disabilities who live in institutional settings may be particularly vulnerable to forced abortion.[[108]](#endnote-109)

Women and girls with disabilities also frequently face pressure from doctors, guardians, social service workers, parents and society to terminate their pregnancies.[[109]](#endnote-110) This pressure stems from misconceptions and discriminatory beliefs about their ability to raise a family and the inheritability of certain disabilities.

The CRPD Committee has considered forced sterilization and forced abortion as violations of the rights to bodily integrity, family and fertility, health, and legal capacity.[[110]](#endnote-111) Where states and third parties seek to control the fertility of women and girls with disabilities, they perpetuate misconceptions and discriminatory attitudes about their childrearing and decision-making abilities.

States must guarantee that women and girls with disabilities are able to achieve their sexual and reproductive rights, which includes the right to make free and responsible decisions and choices, free of violence, coercion and discrimination, regarding matters concerning one’s body and sexual and reproductive health.[[111]](#endnote-112)

We are grateful for this opportunity to input in the Special Rapporteur’s report. Should the mandate need any additional information, please do not hesitate to reach out to Rebecca Brown, Senior Director for Global Advocacy at [rbrown@reprorights.org](mailto:rbrown@reprorights.org).

1. Nairobi Principles on Abortion, Prenatal Testing and Disability [hereinafter Nairobi Principles], <https://nairobiprinciples.creaworld.org/principles/>. [↑](#endnote-ref-2)
2. *Id*. [↑](#endnote-ref-3)
3. *Id.* [↑](#endnote-ref-4)
4. Committee on Economic, Social and Cultural Rights, *General Comment No. 22: on the right to sexual and reproductive health (article 12 of the International Covenant on Economic, Social and Cultural Rights)*, para. 7, U.N. Doc. E/C.12/GC/22 (2016) [hereinafter ESCR Committee, *Gen. Comment No. 22*], [↑](#endnote-ref-5)
5. *Guaranteeing sexual and reproductive health and rights for all women, in particular women with disabilities*, Joint statement by the Committee on the Rights of Persons with Disabilities and the Committee on the Elimination of All Forms of Discrimination against Women, 29 August 2018,*available at* <https://www.ohchr.org/EN/HRBodies/CRPD/Pages/CRPDStatements.aspx>. [↑](#endnote-ref-6)
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89. *Id..* at para. 18. [↑](#endnote-ref-90)
90. CEDAW Committee, *Concluding Observations: Slovakia*, para. 33(d), UN Doc. CEDAW/C/SVK/CO/5-6 (2015); *see also* CEDAW Committee, *Gen. Recommendation No. 33 on women’s access to justice*, para. 19(d), U.N. Doc. CEDAW/C/GC/33 (2015); CEDAW Committee, *Concluding Observations: Barbados*, paras. 41-42 U.N. Doc. CEDAW/C/BRB/CO/5-8 (2017). [↑](#endnote-ref-91)
91. *See* CEDAW Committee, *Concluding Observations: Ukraine*, para. 44 (b), U.N. Doc. CEDAW/C/UKR/CO/8 (2017); *Finland,* paras. 28-29, U.N. Doc. CEDAW/C/FIN/CO/7 (2014); *Belgium*, para. 35, U.N. Doc. CEDAW/C/BEL/CO/7 (2014); *Montenegro,* paras. 40-41, U.N. Doc. CEDAW/C/MNE/CO/2 (2017); *Thailand,* para. 39, U.N. Doc. CEDAW/C/THA/CO/6-7 (2017); *Hungary*, paras. 32-33. U.N. Doc CEDAW/C/HUN/CO/7-8 (2013); CRC Committee, *Concluding Observations: Brazil*, paras. 51-52,U.N. Doc. CRC/C/BRA/CO/2-4 (2015); *Romania*, para. 32, U.N. Doc. CRC/C/ROU/CO/5 (2017); CESCR Committee, *Concluding Observations: Australia*, paras. 45-46, U.N. Doc. CESCR/C/AUS/CO/5 (2017). [↑](#endnote-ref-92)
92. For purposes of this paper, forced sterilization refers to the situation in which a person is sterilized after expressly refusing the procedure, without her knowledge or is not given an opportunity to provide consent. Coerced sterilization occurs when financial or other incentives, misinformation, or intimidation tactics are used to compel an individual to undergo the procedure. [↑](#endnote-ref-93)
93. *See, e.g.,* Susan Brady et al., Human Rights and Equal Opportunity Commission, The Sterilisation of Girls and Young Women in Australia: Issues and Progress*,* A report commissioned bythe Federal Sex Discrimination Commissioner and the Disability Discrimination Commissioner (2001) [hereinafter Sterilisation of Girls and Young Women in Australia]; *see also,* WHO*,* Eliminating Forced, Coercive And Otherwise Involuntary Sterilization: An Interagency Statement, OHCHR, UN Women, UNAIDS, UNFPA, UNICEF And WHO, 6 (2014), *available at* <https://www.unaids.org/sites/default/files/media_asset/201405_sterilization_en.pdf>. [↑](#endnote-ref-94)
94. Against her Will, 42, at 6. [↑](#endnote-ref-95)
95. WHO*,* Eliminating Forced, Coercive And Otherwise Involuntary Sterilization: An Interagency Statement, OHCHR, UN Women, UNAIDS, UNFPA, UNICEF And WHO 5 (2014), *available at* <https://www.unaids.org/sites/default/files/media_asset/201405_sterilization_en.pdf>. [↑](#endnote-ref-96)
96. SRVAW, *Rep. of the Special Rapporteur* (2012), , at para. 28. [↑](#endnote-ref-97)
97. Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, *Rep. of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health,* *Advancement of Women*, para. 38, U.N. Doc. E/CN.4/2005/51 (Feb. 11, 2005) (by Paul Hunt). [↑](#endnote-ref-98)
98. *Compare* Matter of A.W., 637 P.2d 366 (Colo. 1981); Estate of C.W., 640 A.2d 427 (Pa. Super. Ct. 1994); Matter of Terwilliger, 450 A.2d 1376 (Pa. Super. Ct. 1982); *and* Conservatorship of Person and Estate of Maria B., 160 Cal. Rptr. 3d 269 (Cal. Ct. App. 2013); *with* Wentzel v. Montgomery General Hosp., Inc., 447 A.2d 1244 (Md. 1982); Matter of Truesdell, 329 S.E.2d 630 (N.C. 1985); Conservatorship of Valerie N., 40 Cal. 3d 143 (Cal. 1985); *and* Matter of Romero, 790 P.2d 819 (Colo. 1990). [↑](#endnote-ref-99)
99. Arkansas (Ark. Code Ann. §20-49-101 (2016)); Colorado (Colo. Rev. Stat. §25.5- 10-233 (2016)); Delaware (16 Del. Code Ann. §5712 (2016)); Georgia (Ga. Code. Ann. §31-20-3 (2016)); Maine (34-B Me. Rev. Stat. §7010 (2016)); North Carolina (N.C. Gen. Stat. §35A-1245 (2010)); Oregon (Or. Rev. Stat. §436.225 (2016)); Utah (Utah Code Ann. §62A-6-102 (2016)); Vermont (18 Vt. Stat. Ann. §8705 (2016)); Virginia (Va. Code Ann. §54.1-2975 (2016)). [↑](#endnote-ref-100)
100. Gauer and Others v. France, No. 61521/08 Eur. Ct. H.R. (2012). [↑](#endnote-ref-101)
101. *See* Press Release*, Organizations in several countries reject decision of the Colombian Constitutional Court allowing for sterilization of minors with disabilities without their consent*, Center for Reproductive Rights (Mar. 18, 2014), *available at* <https://reproductiverights.org/press-room/Organizations-in-several-countries-reject-decision-of-the-Colombian-Constitutional-Court>. [↑](#endnote-ref-102)
102. Hoangmai H. Pham and Barron H. Lerner, *In the Patient’s Best Interest? Revisiting Sexual Autonomy and Sterilization of the Developmentally Disabled*, 175 Western Journal of Medicine 283 (2001). [↑](#endnote-ref-103)
103. Although parents may have concerns handling girls with disabilities who are undergoing menstruation, many requests for sterilization of girls with disabilities actually occur before menstruation even begins. *See, e.g.,* Sterilisation of Girls and Young Women in Australia,. [↑](#endnote-ref-104)
104. *See* *Mentally Disabled Woman Escapes Forced Abortion*, The Telegraph, (Jan. 10, 2013), *available at* [*https://www.telegraph.co.uk/news/health/news/9793790/Mentally-disabled-woman-escapes-forced-abortion.html*](https://www.telegraph.co.uk/news/health/news/9793790/Mentally-disabled-woman-escapes-forced-abortion.html); Robin Marty, *Court Battle Ensues Over Pregnant Mentally-Disabled Woman in Nevada*, Rewire.News, (Nov. 5, 2012), *available at* <http://rhrealitycheck.org/article/2012/11/05/court-battle-ensues-over-disabled-woman-abortion/>. [↑](#endnote-ref-105)
105. European Disability Forum, EDF input to the general discussion of the CESCR on sexual and reproductiverights p.6 (2010) [hereinafter EDF Input] and “Parenthood and intellectual disability, discourses on birth control and parents with intellectual disabilities 1967-2003”, J. Areschoug, September 2005. [↑](#endnote-ref-106)
106. *Id.* at 6; *See also* Melissa Masden, *Pre-Natal Testing and Selective Abortion: The Development of a Feminist Disability Rights Perspective* (1992), *available at* http://wwda.org.au/issues/eugenic/eugenic1995/masden1/. (“There are...strong social sanctions against women with a disability as parents.”). [↑](#endnote-ref-107)
107. EDF Input*,* at p.6. [↑](#endnote-ref-108)
108. *See* Jane Maxwell et al., A Health Handbook for Women with Disabilities at p.306 (2007). [↑](#endnote-ref-109)
109. Anne Finger, *Forbidden Fruit*, 233 New Internationalist (July 5, 1992), *available at* https://newint.org/features/1992/07/05/fruit; *see also* Carolyn Frohmader*, Moving Forward and Gaining Ground: The Sterilisation of Women and Girls with Disabilities in Australia*, Women With Disabilities In Australia 6-7 (2012), *available at* http://wwda.org.au/wp-content/uploads/2013/12/Moving\_Forward\_Gaining\_Ground.pdf; *See generally* Law Students for Reproductive Justice, Women with Disabilities, para. 3 (2008), *available at* http://lsrj.org/documents/factsheets/08-09\_Women\_with\_Disabilities.pdf. [↑](#endnote-ref-110)
110. CRPD Committee, *Concluding Observations: Spain*, paras. 37-38, U.N. Doc. CRPD/C/ESP/CO/1 (2011); *China*, para. 34, U.N. Doc. CRPD/C/CHN/CO/1 (2012); *Argentina*, paras. 31-32, U.N. Doc. CRPD/C/ARG/CO/1 (2012); *Peru*, para. 35, U.N. Doc. CRPD/C/PER/CO/1 (2012). [↑](#endnote-ref-111)
111. *See* ESCR, *Gen. Comment No. 22*, at para. 5. [↑](#endnote-ref-112)