HUMAN RIGHTS WATCH

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Members of the United Nations Committee on Economic, Social and Cultural Rights
Office of the United Nations High Commissioner for Human Rights (OHCHR) Palais Wilson
52 rue des Pâquis
CH-1201 Geneva, Switzerland

Re: Day of General Discussion on the Right to Sexual and Reproductive Health

Dear Committee Members:

We write in advance of the Committee on Economic, Social and Cultural Rights' upcoming Day of General Discussion to highlight areas of concern we hope will inform your consideration of a General Comment on sexual and reproductive health, in relation to Articles 10(2) and 12 of the International Covenant on Economic, Social and Cultural Rights (ICESCR).

First of all, we would like to congratulate you on taking on this important topic. Our research and experience shows that where access to sexual and reproductive health services, information, and choices are limited, severe suffering often ensues. For example, women's overall health and wellbeing generally diminish where they are not allowed even the most basic tools to space births. Moreover, the majority of preventable maternal mortality have been linked to limitations in equal access to quality care.

In fact, a comprehensive and human-rights based approach to sexual and reproductive health is absolutely necessary for the full enjoyment not only of the rights contained in articles 10(2) and 12 of the ICESCR, but of a range of related human rights such as the rights to privacy, freedom of thought and religion, freedom to receive and impart information, equal protection under the law, (articles 17, 18, 19, and 26 of the International Covenant on Civil and Political Rights), non-discrimination in access to health care, equal access to family planning for rural women, and the right to decide freely and responsibly on the number and spacing of children (articles 12, 14 (b), and 16(e) of the Convention on the Elimination of All Forms of Discrimination against Women and articles 5, 9 and 23 of the

Convention on the Rights of Persons with Disabilities) and equal recognition before the law (Article 12 of the Convention on the Rights of Persons with Disabilities).

In addition, some human rights violations in the area of sexual and reproductive health constitute consistent barriers to the exercise of other human rights, such as the rights to education, work, physical integrity, and the right to enjoy the benefits of scientific progress. In short, the design and implementation of adequate policies on sexual and reproductive health are both essential to and a product of a comprehensive human rights policy. We therefore encourage the Committee to reach out to fellow experts from other treaty-monitoring bodies, to ensure jurisprudential coherence and to reflect the interdependence and indivisibility of human rights, which is so pertinent to this issue.

Addressing sexual and reproductive health from a human rights perspective also requires an approach that promotes the very values that originated the concept of human rights. In the words of the Office of the High Commissioner on Human Rights: "The practical implications of the human rights values of dignity and non-discrimination result in a set of working principles that form the basis of a human rights based approach. The treaty bodies and United Nations experts have clarified the importance of seven such principles: accountability, participation, transparency, empowerment, sustainability, international cooperation and non-discrimination."[1]

In the following, we will address a few aspects of some of these principles, as they relate to sexual and reproductive health: accountability, sustainability, and equality.

Accountability

Accountability has two main components: redressing past grievances, and correcting systemic failure to prevent future harm. The Special Rapporteur on the right to the highest attainable standard of health has elaborated upon the meaning of accountability in the context of providing health care: "What it means is that there must be accessible, transparent and effective mechanisms of accountability in relation to health and human rights…. Accountability is also sometimes narrowly understood to mean blame and punishment, whereas it is more accurately regarded as a process to determine what is working (so it can be repeated) and what is not (so it can be adjusted)." [2]

Accountability to correct systemic failures in the implementation of a sexual and reproductive health program—such as frequent contraceptive supply problems, or

[1] Office of the United Nations High Commissioner for Human Rights, "Report of the Office of the United Nations High Commissioner for Human Rights on preventable mortality and morbidity and human rights," April 16, 2010, A/HRC/14/39, para. 32.

[2] Special Rapporteur on the right to health, "Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, Paul Hunt," January 17, 2007, A/HRC/4/28, para. 46.

the inability to prevent unwanted pregnancies—cannot be achieved without regular monitoring of the health system and the underlying physical and socio-economic determinants of health that affect an individual's health and ability to exercise their rights.[3] States should develop "appropriate indicators to monitor progress made, and to highlight where policy adjustments may be needed."[4] Monitoring helps states parties develop a better understanding of the "problems and shortcomings encountered" in realizing rights, providing them with the "framework within which more appropriate policies can be devised." [5]

Monitoring is also a basic component of the state obligation to adopt and implement a national public health strategy and plan of action, including right to health indicators and benchmarks by which progress can be closely monitored.[6] Data based on appropriate indicators should be disaggregated on the basis of the prohibited grounds of discrimination to monitor the elimination of discrimination, as well as ensure that vulnerable communities are benefiting from healthcare schemes.[7]

Sustainability

The protection of the right to reproductive and sexual health requires a long-term investment in health policies and programs to further the empowerment of those individuals who are particularly at risk for violations of their rights, and to build the trust that is necessary to ensure continuance of care. Such sustainability has been highlighted as key to successful initiatives to guarantee both the underlying physical determinants of health, such as water and healthcare access itself.[8]

Equality

The protection and promotion of reproductive and sexual health is, at the most fundamental level, an issue of sex equality: the biological difference between women and men creates different basic health needs and experiences that must be acknowledged and understood by the state and reflected in the design of an equitable health care system. In addition, women are in practice more likely than

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[3] Office of the High Commissioner on Human Rights, "Report of the Office of the High Commission on Human Rights on preventable maternal mortality and morbidity and human rights," April 16, 2010, A/HRC/14/39, para. 36.

[4] Special Rapporteur on the right to health, "The right of everyone to the enjoyment of the highest attainable standard of physical and mental health," September 2006, A/61/338, para. 28 (e).

[5] Committee on Economic, Social, and Cultural Rights, "Reporting by States Parties," General Comment 1, E/1989/22, 1989, para. 3.

[6] Committee on Economic, Social, and Cultural Rights, "Substantive Issues Arising in the Implementation of the International Covenant on Economic, Social, and Cultural Rights," General Comment No. 14, The Right to the Highest Attainable Standard of Health, 2000, E/C.12/2000/4 (2000), para. 43 (f).

[7] Ibid., General Comment No. 20, Non-Discrimination in Economic, Social and Cultural Rights (art 2, para 2), June 10, 2009, E/C.12/GC/20, para. 41.

[8] Office of the High Commissioner on Human Rights, "Report of the Office of the High Commission on Human Rights on preventable maternal mortality and morbidity and human rights," April 16, 2010, A/HRC/14/39, para. 42.

men to experience personal hardship where sexual and reproductive health rights are ignored, primarily because women are more likely to suffer social disadvantage flowing from economic, career, and other de facto life changes when they have children. Where women are compelled to continue unwanted pregnancies, such consequences forcibly put women at a disadvantage.

Specific subgroups of the population, in addition, have specific needs and face unique challenges in accessing and enjoying reproductive and sexual health services. These needs and challenges must be recognized and addressed by state policies that seek to fulfill their obligations under the Covenant. In recent research, Human Rights Watch has documented the significant barriers women with disabilities face in their enjoyment of these rights. For a fuller analysis of the right to reproductive and sexual health as it relates to women with disabilities, please see the annex of this letter.

Based on our research, Human Rights Watch makes the following recommendations with regard to a General Comment on the obligations of States Parties vis-à-vis the right to sexual and reproductive health. States Parties should be required to:

- Systematically gather data and information on implementation of sexual and reproductive health programs. Including, at the minimum: age, sex, level of education, special needs, disability (if any), distance to service provider, services needed and incidence of abuse (if any). This data should be analyzed and published in an annual public report on the implementation of health care programs.
- Ensure training of health professionals with regard to the content of relevant laws, regulations, and guidelines on reproductive health.
- Develop and implement regulations that enable women and girls with disabilities to effectively enjoy their reproductive rights, including the right to accessible health information and services.
- Make sexual and reproductive health services accessible and available for all. This includes physical access, adequately trained staff, transportation and dissemination of information about the services in accessible formats.
- Work with prosecutors to file criminal charges against public officials who are criminally negligent in discharging their functions as related to women's and girls' reproductive health, such as, for example, those who deny access to legal abortion services to women whose life or health is threatened by their pregnancy, or those who deny life-saving treatment—such as chemotherapy—to pregnant women.
- Combat stigma and discrimination against women with disabilities through awareness raising and media campaigns on the right to sexual and reproductive health for all women.
- Undertake the eradication of violence against women. Women must have access to proper and effective reporting methods when they are survivors of

abuse. States Parties must also guarantee that all women have equal access to justice.

Human Rights Watch looks forward to continuing this dialogue with the Committee and are happy to share our research and experience with you.

Best regards,

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Human Rights Watch

ANNEX

1. DEFINITIONS AND ELEMENTS OF THE RIGHT TO SEXUAL AND REPRODUCTIVE HEALTH IN THE CONTEXT OF PERSONS WITH DISABILITIES

Our recent report on Argentina documents the many obstacles women and girls, including women with disabilities, face in getting the reproductive health care services to which they are entitled, such as contraception, voluntary sterilization procedures, and abortion after rape. The most common barriers to care include long delays in providing services, unnecessary referrals to other clinics, demands for spousal permission contrary to law, financial barriers, and in some cases outright denial of care.

Our research in northern Uganda documents how women with disabilities lack equal access to care in maternal health, rehabilitation, family planning, and reproductive health, including HIV testing, treatment and prevention. This is due to poverty, stigma, difficulty in negotiating safe sex, lack of accessible information and mobility and communication barriers.

In both Argentina and Uganda, laws intended to protect women's right to sexual and reproductive health are not fully implemented.[9] For more extensive discussion of these issues, please refer to our reports.[10]

A. Accessibility

Accessibility is at the core of exercising the right to sexual and reproductive health, and includes (a) physical access and (b) access to information.
(a) Physical accessibility requires that health facilities, goods, and services be within safe physical reach for all sections of the population, especially vulnerable and marginalized groups such as women with disabilities. Physical accessibility requires equitable distribution of health facilities and personnel within the country. Equal access may require States to take extra measures to ensure that facilities and services are accessible for all. An assessment of northern Uganda conducted by Women's Refugee Commission together with UNFPA found that there are not enough reproductive health clinics or workers in the north, particularly for emergency obstetric care, leading to poor services for pregnant women.[11]

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[9] See Human Rights Watch, "As If We Weren't Human": Discrimination and Violence against Women with Disabilities, and "Illusions of Care": Lack of Accountability for Reproductive Rights in Argentina

[10] Human Rights Watch, "Illusions of Care": Lack of Accountability for Reproductive Rights in Argentina, ISBN: 11-56432-669-1, August 2010, available at http://www.hrw.org/en/reports/2010/08/10/illusions-care-0 Human Rights Watch, "As If We Weren't Human": Discrimination and Violence against Women with Disabilities, ISBN: 1-56432-674-8, August 2010, available at: http://www.hrw.org/node/92611

[11] Women's Refugee Commission, "Reproductive Health in Northern Uganda," August 2009, http://www.womensrefugeecommission.org/images/stories/RH_N._Uganda_10_28_09.pdf (accessed June 20, 2010). Women's Refugee Commission, "We Want Birth Control: Reproductive Health Findings in Northern Uganda," June 2007, http://womensrefugeecommission.org/programs/five-country-focus/821-uganda (accessed July 5, 2010).

Women and girls with disabilities are often invisible in the reproductive health system. In the case of Argentina, this invisibility is reflected in the absence of logistical measures that would accommodate access for women and girls with disabilities to the system. Access to services and information is complicated for able-bodied individuals and can be nearly impossible for those with physical disabilities, in particular in resource-poor settings. Two women with disabilities in Uganda who were raped said that they did not undergo HIV testing afterward because they were unable to reach a health clinic.
Barriers to access include long distances to travel, and a lack of ramps, accessible beds and toilets. In one instance in northern Uganda, health care personnel verbally abused women for not being able to climb up onto the delivery bed, which was high and on wheels. A nurse asked her why she was not able to get on this bed if she was able to get on a bed when she got pregnant.[12]

(b) Access to sexual and reproductive health services is often impeded by insufficient information on health services that are available and legal. In Argentina, women are often unaware of the circumstances in which they could legally obtain an abortion. The few individuals who do solicit legal abortions are stonewalled by complicated procedures and hostile service providers in the health and justice systems. Many women with crisis pregnancies go directly to underground service providers, though some end up in the courts arguing for their right to health care.[13] Very few women who were interviewed in Argentina knew that abortion might be legal in some circumstances. With the exception of a woman with a physical disability that severely restricts her mobility, none who were entitled to a legal abortion, were informed of this fact by the medical providers they turned to for help.[14] Guidelines on access to legal abortion, such as those issued by the Argentine National Health Ministry in 2005 and republished in 2010, can provide relief for some women in distress. However, Human Rights Watch research indicates that the guidelines so far have been selectively implemented and routinely ignored. Moreover, experience from other countries with similar normative frameworks show that the general criminalization of abortion contributes to the stigmatization of legal abortion services, even where guidelines exist.[15]

For women with a broad range of disabilities, very little accessible information exists in most countries, particularly on contraception, HIV and other issues related to

[12] Human Rights Watch interview with Honorable Nalule Safia Juuko, member of parliament representing women with disabilities, Kampala, May 25, 2010.

[13] Human Rights Watch, "Illusions of Care": Lack of Accountability for Reproductive Rights in Argentina, pp. 21-22, ISBN: 11-56432-669-1, August 2010, available at http://www.hrw.org/en/reports/2010/08/10/illusions-care-0

[14] Human Rights Watch, "Illusions of Care": Lack of Accountability for Reproductive Rights in Argentina, pp. 23, ISBN: 11-56432-669-1, August 2010, available at http://www.hrw.org/en/reports/2010/08/10/illusions-care-0

[15] See Human Rights Watch, The Second Assault: Obstructing Access to Legal Abortion After Rape in Mexico, March 2006, Vol. 18, No. 1(B); and Human Rights Watch, My Rights, and My Right to Know: Lack of Access to Therapeutic Abortion in Peru, July 2008, ISBN 1-56432-347-1.

sexual and reproductive health. Access to information for persons with disabilities requires sign language interpreters for the deaf, Braille signage, easy to understand information for persons with intellectual disabilities, among alternative formats of communication. In some countries, like Uganda, the law requires that sign language be included in curricula for medical personnel, and the provision of interpreters in hospitals and Braille for drug labels. However, this law is not fully implemented.[16]

B. *Non-discrimination*

States Parties to the ICESCR have the duty to provide the highest attainable standard of health.[17] States are obligated to take special measures to make obstetric services available, accessible, and of adequate quality. Failure to make efforts to do so is a form of discrimination against women. Importantly, both the Convention on the Elimination of Discrimination Against Women (CEDAW) and the Convention on the Rights of Persons with Disabilities (CRPD) require states to take steps to eliminate discrimination by not only state actors, but also private actors, including any person, organization, or private enterprise.[18]

Myths and stereotypes persist regarding the sexual lives and reproductive capacities of women with disabilities. "Everything that has to do with sex [for persons with disabilities] is taboo," said a disability rights activist from Argentina.[19] Another activist concurred: "A parent to a kid with Down's syndrome [for example] … is going to say, 'My child … does not have children, does not have abortions…. My child does not even have sex….' They infantilize you."[20] The activist told Human Rights Watch that some doctors thought her incapable of remembering to take her daily contraceptive pill because she is blind.

Experiences at health centers in Uganda vary widely for women with disabilities; while many said that they were treated well by hospital staff and were satisfied with the services, other women were ignored at health centers and were discouraged from seeking reproductive health or family planning. Some nurses and staff made derogatory remarks to women with disabilities; for example one health worker questioned why a woman with a disability would have a baby, since she would be

[16] Persons with Disabilities Act, 2006, sec. 7.

[17] ICESCR, Article 12.

[18] Secretariat for the Convention on the Rights of Persons with Disabilities of the Department of Economic and Social Affairs; United Nations Population Fund; Wellesley Centers for Women, "Disability Rights, Gender, and Development -- A Resource Toll for Action", (2008), p. 19. Convention on the Elimination of All Forms of Discrimination against Women, articles 2, 3, and 5. Convention on the Rights of Persons with Disabilities, art. 5.

[19] Human Rights Watch interview with Silvia Valori, activist on the rights of persons with disabilities, Buenos Aires, March 4, 2010.

[20] Human Rights Watch interview with Verónica González, journalist, Buenos Aires, March 5, 2010.

unable to take care of the child.[21] A deaf woman said that when she was hospitalized during delivery, a nurse asked her how she was able to have sex.[22]

The Convention on the Rights of Persons with Disabilities explicitly recognizes that women with disabilities face multiple types of discrimination, and confers on States parties the obligation to ensure that all persons with disabilities can effectively exercise their rights to "decide freely and responsibly on the number and spacing of their children …. [,] to have access to age-appropriate information, reproductive and family planning education … and [that] the means necessary to enable them to exercise these rights are provided."[23] The Convention further specifies that States parties must "[p]rovide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health and population-based public health programmes."[24] The CRPD reinforces the right to health free of discrimination and requires that the government provide health services near where people live, including in rural areas.

2) CROSS-CUTTING ISSUES AND GROUPS IN FOCUS: *Women with Disabilities and HIV*

Women with disabilities are particularly vulnerable to HIV infection. In northern Uganda, 9 percent of women are living with HIV, compared to 7 percent of men.[25] Women are more likely than men to be tested and know their status due to maternity-related health services.[26] A 2004 World Bank study suggests that persons with disabilities globally are infected with HIV at a rate of up to three times greater than non-disabled people due to risk of physical abuse, inability to negotiate safe sex, isolation, general poverty, and lack of access to services and information.[27]

Our research, as well as research from others, has found that women with disabilities are frequently abandoned by their partners and may be at greater risk of HIV infection because of sexual violence, inability to negotiate condoms, unstable relationships and property rights abuses. One woman with a disability in northern Uganda told Human Rights Watch that when she suggested to her partner that they undergo HIV testing before having sex, he agreed, but then under the guise of taking

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[21] Human Rights Watch interview with Joy, woman with physical disability, Gulu district, May 15, 2010.

[22] Human Rights Watch interview with Victoria, deaf woman, Lira district, May 24, 2010.

[23] Convention on the Rights of Persons with Disabilities, U.N. Doc. A/61/611, entered into force on May 3, 2008. Convention on the Rights of Persons with Disabilities, arts. 6 and 23(b).

[24] Convention on the Rights of Persons with Disabilities, art. 25(a).

[25] Uganda Ministry of Health, "HIV/AIDS Sero-Behavorial Study, 2004-2005," March 2006.

[26] See Human Rights Watch, "Uganda – Just Die Quietly: Domestic Violence and Women's Vulnerability to HIV in Uganda," Vol. 15, No. 15(A), August 13, 2003, http://www.hrw.org/en/reports/2003/08/12/just-die-quietly-0.

[27] World Bank Social Development Department, "Social Analysis and Disability: A Guidance Note, Incorporating Disability-Inclusive Development into Bank-Supported Projects," March 2007, http://siteresources.worldbank.org/EXTSOCIALDEV/Resources/3177394-1175102311639/3615048-1175607868848/SA-Disability-Title&Preliminary.pdf (accessed June 20, 2010).

her to the health center, he took her to a friend's house. The friend asked why they were planning to get tested. He said, "She is a disabled woman. She is not going to have HIV." Then the man raped her. He subsequently raped her three more times.[28]

After rape, women with disabilities find it especially difficult to get post-exposure prophylaxis and other necessary treatment, such as emergency contraception. These services must be reached quickly, generally within 120 hours of an attack, which may be particularly difficult for women with disabilities that impact their mobility. Several women with disabilities who stated that they had been raped said that they still had not undergone HIV testing for various reasons. Two rape survivors with physical disabilities in northern Uganda could not travel the long distances to health centers.[29] Staff told one woman with physical and communicative disabilities in Uganda who was raped to go to police instead.[30]

Confidentiality in HIV testing is especially problematic for the deaf, who may be forced to bring a family member to interpret the results. The availability of health center staff trained in sign language would be an important step towards expanding voluntary counseling and testing among the deaf.[31]

Strategies to reduce the risk of HIV transmission from mother to child may be especially difficult for women with disabilities. Aside from initial difficulties in accessing the necessary drugs for prevention of mother to child transmission, delivering in a health center or hospital may not be an option for women with restricted mobility, and the enduring poverty associated with disability may make formula feeding difficult.[32]

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[28] Human Rights Watch interview with Lucy, woman with physical disability, Gulu district, April 15, 2010.

[29] Human Rights Watch interview with Angela, woman with physical disability, Amuru district, May 17, 2010; Human Rights Watch interview with Charity, woman with physical disability, Amuru district, April 15, 2010.

[30] Human Rights Watch interview with Irene, woman with physical and communicative disability, Gulu district, April 14, 2010.

[31] Efforts at increasing the number of sign language interpreters should be paired with increased education in formal sign language for deaf women and girls.

[32] Breastfeeding by mothers with HIV increases the risk of HIV transmission to the infant. UNAIDS recommends that "when replacement feeding is acceptable, feasible, affordable, sustainable and safe, avoidance of all breastfeeding by HIV infected mothers is recommended. Otherwise, exclusive breastfeeding is recommended during the first months of life and should then be discontinued as soon as it is feasible." UNAIDS, "Nutrition and Food Security," http://www.unaids.org/en/PolicyAndPractice/CareAndSupport/NutrAndFoodSupport/ (accessed July 5, 2010).