

Human Rights Watch Submission on the Child's Right to Health

September 2012

Human Rights Watch welcomes the opportunity to provide input to the Office of the High Commissioner for Human Rights (OHCHR) for its report on the right of the child to the enjoyment of the highest attainable standard of health. Human Rights Watch has carried out extensive research on the right to health, including the child's right to health, around the globe. The following recommendations are based on our research findings and analysis of research on public health and human rights from other sources.

Children face violations of their right to health for a number of reasons. These include:

- a lack of attention to broader children's rights in health policy;
- a lack of attention to children's medical needs (pediatrics) in public health strategies;
- insufficient health worker training on pediatric and child rights issues;
- government failure to provide adequate information on health and healthcare;
- lack of proper grievance mechanisms and accountability in health systems;
- economic barriers to health care, including user fees and transport costs;
- government failure to address causes of childhood ill-health, including environmental threats and poor sanitation.

Human Rights Watch therefore calls upon the OHCHR to recommend measures to address these and other barriers to child health care.

A Child Rights' Approach to Health

The child's right to health is closely related to other rights, such as freedom from discrimination, the right to survival and development, primary consideration of the best interests of the child, and protection from abuse and neglect. Children who suffer discrimination, violence, neglect, abuse, child marriage or other violations of their rights under the CRC are particularly vulnerable to violations of their right to health. For example, Human Rights Watch has documented health rights violations against e.g., children living with HIV, migrant children, and children in conflict with the law. The right to health is also closely related to the protection of the right to freedom of expression, the right to education, and to health information. The right to seek, receive, and impart information is an integral component of the right to health. Human Rights Watch's research on health and children's rights has found that governments often deny comprehensive and accurate information to children and their parents or guardians.

Human Rights Watch therefore recommends that the report:

- Recognizes the link between children's right to health and other rights, and makes recommendations on how States can ensure that children suffering from discrimination, violence, neglect, abuse, child marriage or other violations of their rights can realize their right to health. This should include measures to train health workers in child rights, and to ensure that they are able to identify violations and act upon them. Particular attention should be paid to the positive role community health workers can play in this regard.
- Underscores the importance of comprehensive health information provided without discrimination, and the negative impact of censorship and intentionally misrepresented information on health.

Health Challenges for Children

Girls' Right to Health

Female Genital Mutilation

According to the WHO, between 100 and 140 million girls and women around the world have undergone some form of female genital mutilation (FGM). The practice is typically carried out on young girls, from infants to adolescents. International human rights law recognizes FGM as a violation of the human rights of girls and women, including their right to health, to be free from violence, to life and physical integrity, to non-discrimination, and to be free from cruel, inhuman, and degrading treatment.

FGM has immediate and long-term effects on physical and mental health. FGM is furthermore medically unnecessary and irreversible. Human Rights Watch has found that girls are often unaware what is about to happen to them, and that they experience great pain during the procedure and afterwards. Immediate serious consequences of FGM include, but are not limited to, hemorrhaging, sepsis, and septic shock. Long-term complications include anemia, cyst formation, difficulty passing urine, menstrual disorders, painful sexual intercourse, sexual dysfunction, infertility, and elevated risk of complications during childbirth. FGM has been linked with depression, anxiety, post-traumatic stress disorder, and other mental health problems.

Human Rights Watch therefore recommends that the report:

- Explicitly defines FGM as a violation of the right to the highest attainable standard of health of the child and call for a ban on FGM.
- Recommends the putting into place of long-term and comprehensive strategies to end FGM, including through education, training, public awareness campaigns and gathering of statistics.

Access to Sexual and Reproductive Healthcare and Patient Grievance Mechanisms

Reproductive and sexual health care is a vital part of the right to health for adolescents and adults, yet there are significant barriers to accessing such health care, especially in developing countries and among marginalized populations. The need for such services for adolescents is immense: girls between 10 and 14 years old are five times more likely to die in pregnancy or childbirth than women aged 20 to 24. In developing countries, over 200 million married women and girls lack access to modern contraceptives.

Human Rights Watch has documented a range of obstacles to sexual and reproductive health care around the world, including lack of evidence-based sexuality education and information, shortages of health professionals, high costs, requirements for parental consent for access to contraceptives or legal abortions, lack of autonomy to seek health services, negative attitudes and abusive behaviors of health providers, criminal penalties for seeking reproductive health services (especially abortion), and community stigma relating to sexuality. Human Rights Watch has also documented that child marriage exposes girls to increased sexual and reproductive health risks.

Unfortunately, some countries have dysfunctional mechanisms for patients to lodge grievances or seek redress for such abuse or negligence. These States have neglected to inform patients of their rights and what to do when those rights are violated. Where individuals do successfully submit grievances, health authorities do not always conduct impartial, transparent, and efficient inquiries into specific complaints and how they may relate to broader systemic problems.

Human Rights Watch therefore recommends that the report:

- Includes a specific list of obligations in the field of reproductive and sexual health, including a call to ensure girls and women have informed and free access to safe and legal abortion services, ensure access to a full range of modern contraceptive methods to adolescents and adults, and facilitate access to full, complete, and accurate information on sexual and reproductive health.

- Recommends measures for improved accountability of sexual and reproductive health services, such as the establishment of accessible grievance mechanisms; impartial, transparent, and efficient inquiries into grievances; clear standards and guidelines; mechanisms for tracking health budgets and spending; and data collection to track patient complaints and address systemic problems in the provision of sexual and reproductive health care.

Post-Rape Care and Virginit

The gaps in reproductive health care for girls may be particularly serious for girls who are victims of sexual violence. Human Rights Watch has documented the situation of girls who have been victims of sexual violence, but have received no or inadequate reproductive, psychological, or other services, such as HIV post-exposure prophylaxis and emergency contraception. Besides inadequate health care for sexual violence survivors, some countries have unscientific, inhuman, and degrading testing practices to gather forensic evidence of rape. In India, Human Rights Watch has documented the continued use of the “two-finger test,” an invasive practice with no basis in science that involves a doctor inserting fingers into a rape victim's vagina to determine the presence or absence of the hymen and the so-called “laxity” of the vagina, with the aim of establishing the irrelevant issue of whether the victim is “habituated” to sex. In 2011 in Egypt, Human Rights Watch found that girls and women were subject to forced virginity tests by government doctors after being detained by the military for protesting. Previously, Human Rights Watch documented similar tests, without consent, in Libya, Turkey, Indonesia, the Occupied Palestinian Territories, and Jordan.

Human Rights Watch therefore recommends that the report:

- Highlights the urgent need for holistic state policies and programs that focus on the health needs of survivors after sexual assault, including psychological, sexual, and reproductive healthcare.
- Explicitly defines virginity tests as a child rights violation, and calls on States to prevent and eliminate all forms of forced virginity tests, and to establish special guidelines regarding the forensic examination of child survivors of sexual abuse to minimize invasive procedures and eliminate unscientific practices.

Forced Sterilization

Girls from marginalized populations—such as girls with disabilities, girls living with HIV, Roma girls, indigenous and other minority girls—are vulnerable to forced sterilization, performed under the auspices of legitimate medical care and with the consent of others in their name. Across the globe, forced sterilization is performed on young girls and women with disabilities for various purposes, including eugenics-based practices of population control, menstrual management and personal care, and pregnancy prevention (including pregnancy that results from sexual abuse). The practice of forced sterilization is part of a broader pattern of denial of the human rights, including reproductive rights of women and girls with disabilities. Forced sterilization is an act of violence, a form of social control, and a violation of the right to be free from torture and other cruel, inhuman or degrading treatment or punishment.

Human Rights Watch therefore recommends that the report:

- Explicitly calls for an end to forced sterilization of girls, and for redress for those sterilized without consent;
- Calls for measures to address this practice, such as investigations, public education, and training for health care providers about this issue.

Children with Disabilities

There are an estimated 150 million children with disabilities in the world. These children are more likely to experience violence and abuse than their non-disabled peers. They also face a number of challenges in accessing health care.

Accessibility of Health Services

Children with disabilities often encounter various problems in accessing health care, including discrimination, lack of adequate health care, physical barriers, and lack of accessible information about available services. For example, in northern Uganda Human Rights Watch found that health facilities lack ramps, accessible beds and toilets, and sign language interpreters—barriers for both children and adults. Health care workers often do not receive adequate training on how to care for children with disabilities. Children with disabilities and their parents are also often subject

to derogatory remarks or verbal abuse by health care workers. As a result of these many barriers, children with disabilities often do not get proper diagnosis or treatment.

Human Rights Watch therefore recommends that the report:

- Calls on States to make health facilities, goods, information, and services available and accessible to children with diverse disabilities, including those who live in rural communities.
- Recommends measures on the rights and dignity of persons with disabilities, including children, be integrated into existing trainings of healthcare workers and other medical professionals.
- Recognizes state obligations to cooperate with disabled persons' organizations in planning and implementation of health education programs and the delivery of health services.

Abuse and Neglect in Institutions

Children with disabilities living in state-run institutions are often subject to gross violations of their dignity and right to health, bodily integrity, and informed consent. For example, Human Rights Watch found that Ghana's main psychiatric hospital has inappropriately sedated patients with psychotropic drugs, left children lying naked on the ground, and confined children in rooms littered with human waste.

Children with disabilities also face abuse in private institutions. Because there are very few mental health services available in their communities, many families in Ghana also send children with mental disabilities (mental health problems) for healing at so-called prayer camps, spiritual healing centers run by churches that are not regulated by the government. Human Rights Watch observed children with mental disabilities as young as 9 chained to trees or in unventilated rooms, where they were left for days or weeks at a time, forced to fast, and did not have access to medications for mental or physical health conditions.

Human Rights Watch therefore recommends that the report:

- Calls on States to prevent and eliminate all forms of violence, abuse, exploitation, and non-consensual medical treatment of children with disabilities, and to provide appropriate living conditions for children with disabilities living in institutions, including adequate food, water, and sanitation facilities.
- Recommends measures to improve accountability, including accessible grievance mechanisms for children with disabilities or their parents or guardians to report barriers to care and mistreatment by institution staff.

Children's Right to Information about their HIV Status

Children have the right to age-appropriate information about their HIV status, but are often not told when they are HIV positive. Human Rights Watch's research in Kenya shows the disastrous effects of poor disclosure policies. Children who do not know they are HIV-positive may be less likely to take their medication regularly, which can lead to drug resistance and premature death. Children who become sexually active may unknowingly infect partners with the HIV virus. If adults withhold such important information for years, children may sense a problem and live in great anxiety. Later, they may also be more likely to internalize stigma and feel betrayed by those who have hidden their status. Some children are confronted with the news of their illness through public comments from others, and experience additional trauma and depression.

Human Rights Watch therefore recommends that the report:

- Recognizes the issue of disclosure of HIV status as a child rights issue, and recommends the consideration of disclosure to children starting at age six, depending on each child's cognitive and emotional maturity, family dynamics, and the clinical context.
- Underscores the importance of health worker training on disclosure to children.

Children's Environmental Health

Children around the world are exposed to toxic chemicals and other environmental threats. Human Rights Watch has documented children's exposure to lead, mercury, and other toxic chemicals in the context of mining, industrial production, and agriculture. Children are disproportionately affected by such chemicals because of their increased vulnerability; toxic exposures in children can lead to life-long physical and intellectual disabilities. For example, in

Nigeria, Mali, and Papua New Guinea, children in poor rural communities have been severely affected by mercury or lead exposure linked to artisanal gold mining. In China, children in poor rural communities have suffered serious lead poisoning from lead smelters and battery factories. Governments have repeatedly neglected their obligation to protect communities from adverse human rights and environmental effects, including by failing to adequately regulate the private sector. In some cases, governments are also directly responsible for abuses. The right to information and participation is violated when governments or businesses fail to inform the population about their actions and risks to child health, and take crucial decisions without community participation.

Human Rights Watch therefore recommends that the report:

- Highlights the disproportionate impact of many environmental policies and practices on children and the right to non-discrimination.
- Develops recommendations for the prevention and treatment of children's exposure to toxic chemicals.
- Recognizes the link between hazardous child labor and environmental health, and urges measures to end children's exposure to hazardous chemicals in activities such as artisanal mining.
- Develops recommendations on the substantive and procedural content of a child's right to a healthy environment.
- Highlights the child rights responsibilities of businesses.

Pediatric Palliative Care

Although curative care must clearly be a primary focus of health services for children, it is paramount that such services also effectively protect children with chronic conditions from unnecessary suffering. Worldwide, the availability of palliative care for children is almost universally worse than it is for adults. As a result, millions of children each year experience severe pain and other distressing symptoms without access to appropriate treatment. Human Rights Watch has documented cases of children who suffered from severe pain that could have been treated with simple interventions and inexpensive medications, but were not.

Governments often fail to take even basic steps to improve the availability of palliative care, particularly children's palliative care. In many countries, health policies fail to address the needs of children with incurable illnesses, and healthcare workers do not get adequate training on children's palliative care. Due to this lack of training, healthcare workers are frequently reluctant to use opioid analgesics on children even when pain is severe. It is therefore critical that countries make specific provisions to ensure the availability of pediatric palliative care with adequately trained staff. In addition, countries need drug control regulations that do not interfere with the availability and accessibility of strong pain medications like morphine, including pediatric formulations of palliative care medicines.

Human Rights Watch therefore recommends that the report:

- Calls on States to ensure that palliative care services are fully integrated into treatment programs for children with chronic illnesses so these symptoms are adequately treated. Treatment guidelines for cancer, HIV/AIDS, neurological, and other relevant conditions should include guidance on the provision of pediatric palliative care. These services should also address the psychological, social, and spiritual needs of the children, their parents or guardians, their siblings, and other relatives.
- Calls on States to ensure that end-of-life care is available for children who suffer from untreatable conditions or treatment failure. Such services should require adequate training of staff in pediatric palliative care provision, including communication skills to discuss prognosis and care options with patients, parents or guardians, siblings, and other relatives.
- Highlights the importance of access to essential medicines that are controlled under international or national law.
- Makes recommendations for health care worker training in children's palliative care.

Children's Health in Detention

Human Rights Watch has documented abuses against children in drug detention centers in Laos and Cambodia, and in Zambian prisons, which include the denial of health care, unsanitary living conditions, and torture and other cruel, inhuman, and degrading treatment.

Human Rights Watch therefore recommends that the report:

- Calls on States to release children currently being detained in drug detention centers, as their continued detention cannot be justified on legal or health grounds, and calls on States to prevent and eliminate all forms of institutional violence against children.
- Encourages improved access to voluntary, community-based drug dependency treatment options for children, and ensure that such services are accessible, medically appropriate, and include components of education.
- Calls on States and international health donors to develop and support drug control policies that exclude support for institutions that violate the right to health.

Conversion Therapy for Children

Conversion therapy, also sometimes called reparative therapy, is defined as counseling and psychotherapy aimed at changing a patient's sexual orientation. Conversion therapy is based on the idea that homosexuality is an illness or disorder, an idea which has been rejected by professional organizations. Furthermore, in labeling homosexuality as a disorder and, in some cases, as a child's personal and moral failure, efforts to convert lesbian, gay, or bisexual youth have the potential to cause serious psychological harm to their subjects.

Human Rights Watch therefore recommends that the report:

- Identifies conversion therapy as a violation of a child's right to health.
- Calls on States to promote education on human sexuality and sexual health that includes respect for diversity and for non-heterosexual persons.

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Human Rights Watch, *World Report 2009* (New York: Human Rights Watch, 2009) *Abusing Patients*, http://www.hrw.org/sites/default/files/reports/wr2009_web_1.pdf.

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Human Rights Watch, *Unjust and Unhealthy: HIV, TB, and Abuse in Zambian Prisons*, April 2010, <http://www.hrw.org/reports/2010/04/27/unjust-and-unhealthy-0>.