

Pregnant Women Living with HIV/AIDS: Protecting Human Rights in Programs to Prevent Mother-to-Child¹ Transmission of HIV

As governments around the world respond to the AIDS pandemic, pregnant women are increasingly at the center of global prevention efforts. The availability of medications that can block the transmission of HIV during pregnancy, childbirth and the postnatal period has created new opportunities to slow the spread of the virus. Governments have begun establishing programs to facilitate access to these medications for pregnant women.² These initiatives, known as Prevention of Mother-to-Child Transmission (PMTCT) programs, enable pregnant women to reduce significantly the chances that their infants will be born with HIV.

While the benefits of PMTCT programs are immense—for individual women, their children,³ and societies alike—it is crucial that governments implement them with a keen awareness of the experiences of all women living with HIV/AIDS and with respect for their human rights. PMTCT programs are primarily conceived as prevention programs for infants. This focus on prevention leaves the concerns of women living with HIV/AIDS largely invisible. In any health-care setting in which women are under the care of providers, however, women receiving treatment have rights as patients. Ultimately, an approach that respects the human rights of women will ensure that their infants and families are better served.

This briefing paper addresses the fundamental human rights standards that governments must uphold in creating PMTCT programs. These standards include requirements of informed consent, provider-patient confidentiality, and health-care access without discrimination. The briefing paper concludes with recommendations for government action to ensure that women are treated with dignity and respect through every phase of HIV/AIDS prevention, treatment, and care. If PMTCT programs fail to protect the rights of the women involved, not only will they reinforce women's marginalization, but they will ultimately prove ineffective.

HIV/AIDS and its Toll on Women

Heterosexual women are the group showing the greatest increases in prevalence of HIV/AIDS. UNAIDS estimates that, in sub-Saharan Africa, women are more likely—at least 1.3 times—to be infected with HIV than men. Among younger age-groups, such as those aged 15–24 years, women are three times as likely to be infected as men. In Eastern Europe, rates of infection are rising among women: In Russia, the country in the region hardest hit by the pandemic, 38% of the newly diagnosed HIV cases in 2003 were among women, compared with 24% in 2001. Asia is also seeing increases in the number of women living with HIV/AIDS, with HIV transmission between spouses becoming a more prominent mode of transmission than in the past. In the United States, African-American women account for an increasing share of new infections, and AIDS has become one of the three leading causes of death among African-American women aged 35–44.

Source: UNAIDS & WHO, AIDS EPIDEMIC UPDATE DECEMBER 2004 7–9 (2004), available at <http://www.unaids.org/wad2004/report.html>.

I. Background

A. DISCRIMINATION AGAINST WOMEN AND HIV/AIDS

Commentators have long pointed to the nexus between HIV/AIDS and gender discrimination.⁴ Women are physiologically more susceptible than men to HIV infection through unprotected vaginal intercourse,⁵ and the vast majority of women living with HIV are infected in this way. Women's physiological vulnerability to HIV infection is compounded by pervasive sexual and domestic violence, and by women's entrenched social and economic inequality within their marriages and intimate relationships.⁶ HIV transmission between spouses is becoming more prevalent and there are indications that married women have a higher risk of infection than unmarried women. For example, adolescent brides in some African countries are being infected with HIV at a higher rate than their sexually active unmarried counterparts.⁷

Women have also suffered disproportionately from discrimination against people living with HIV/AIDS. The pandemic has led to increased gender-based violence as HIV-positive women are assaulted, prevented from having children, dismissed from employment, disowned, shunned by their families and communities, and sometimes even killed.⁸ Women are more likely than men to be held responsible for spreading the disease and to be labeled as promiscuous.⁹ Fearing violence, stigma, and ostracism, many women avoid taking HIV tests, thereby denying themselves crucial information about their health and excluding themselves from programs to prevent HIV transmission to their newborns.¹⁰

B. PREVENTION OF MOTHER-TO-CHILD TRANSMISSION OF HIV (PMTCT)

“When I was found [to be HIV] positive, no one talked to me about my well-being. The doctor told me to do MTP [medical termination of pregnancy] as I had no right to pass on the infection to my baby.”

Woman in Mumbai, India, from PANOS & UNICEF, STIGMA, HIV/AIDS AND PREVENTION OF MOTHER-TO-CHILD TRANSMISSION (unnumbered page) (2001) available at <http://www.ohchr.org/english/issues/hiv/introhiv.htm>.

PMTCT programs are an effort to reduce the rate of transmission of HIV from a woman to her fetus or newborn during pregnancy, delivery, or the postpartum period. Across the globe, approximately 2.2 million children are currently living with HIV.¹¹ The major cause of HIV/AIDS among children is transmission of HIV during pregnancy, delivery, and breast-feeding.¹² Infant and child mortality has noticeably increased in many sub-Saharan countries due to HIV infection—both as a direct result of vertical transmission (which increases child morbidity), and as a consequence of the general impact of HIV-related deaths on the health-care delivery system.¹³

In the absence of treatment, an infant’s risk of acquiring HIV from a mother living with HIV/AIDS ranges from 15% to 30% among women who do not breast-feed their infants.¹⁴ The risk of transmission increases when a woman has a higher viral load (e.g., she is newly infected with HIV or is at an advanced stage of the disease), or if an infant is directly exposed to the mother’s infected body fluids during birth.¹⁵ If an infant born to an HIV-positive mother does not contract the virus during pregnancy or childbirth, studies estimate that the child has a 5–20% chance of acquiring the virus from the mother’s milk if he or she is breastfed.¹⁶

PMTCT programs have been scaled up as quickly as possible to prevent the tragedy of children contracting HIV from their mothers, either in utero, during childbirth, or through breast-feeding. PMTCT programs attempt to prevent transmission of HIV through the following strategies:

- a) preventing HIV infection among all people, particularly among women of childbearing age (through promoting HIV/AIDS education, expanding condom access, and improving women’s status);
- b) preventing unwanted pregnancies among HIV-positive women (through family planning and improved reproductive health services); and
- c) reducing the transmission of HIV during pregnancy, childbirth, and the postpartum period (via the provision of antiretrovirals, safe delivery practices such as cesarean sections, and support and counseling on infant-feeding methods).¹⁷

The third strategy is the most common approach used by programs that specifically focus on pregnant women living with HIV/AIDS.

Since 1994, clinical trials in several countries have shown that the transmission rate of HIV can be drastically reduced through the administration of a short course of the drug zidovudine to pregnant women and their infants. More recently, a 1999 study in Uganda showed that nevirapine could also be used to decrease mother-to-child transmission, and that it is similar in effectiveness to zidovudine.¹⁸ The potential for the reduction of mother-to-child transmission is considerable: Antiretroviral prophylaxis around the time of delivery, for example, can reduce transmission two-fold in breast-feeding populations.¹⁹ With the adoption of these antiretroviral treatments, mother-to-child transmission rates have declined in the United States and other industrialized countries to 2%.²⁰

Many countries are currently implementing PMTCT pilot projects or programs. Recent international initiatives have increased the number of PMTCT programs in the Eastern and Southern parts of Africa and have established additional programs in the Caribbean, parts of Western and Central Africa, parts of Eastern Europe, and parts of Central and Southeast Asia.²¹ However, many countries still do not have PMTCT programs, and those that do have experienced difficulty in increasing access to PMTCT services.²² For example, 34% of HIV-positive pregnant women in Botswana get PMTCT treatment—a statistic on the higher end—while only 0.1% of HIV-positive pregnant women in Guyana do.²³ Only an estimated 1% of HIV-positive pregnant women in countries heavily affected by the HIV/AIDS pandemic have access to PMTCT services.²⁴

II. PMTCT Programs and Women's Human Rights

“Where individuals and communities are able to realize their rights—to education, free association, information and, most importantly, non-discrimination—the personal and societal impact of HIV and AIDS are reduced. ...The protection and promotion of human rights are therefore essential in preventing the spread of HIV and to mitigating the social and economic impact of the pandemic.”

Office of the United Nations High Commissioner for Human Rights, *HIV/AIDS and Human Rights* at <http://www.ohchr.org/english/issues/hiv/introhiv.htm> (last visited July 28, 2005).

PMTCT programs implicate certain fundamental human rights regarding liberty, security of person, privacy, health, and freedom from discrimination.²⁵ These rights are undermined where women are denied the opportunity to give informed consent to HIV testing and treatment, where their confidentiality is not respected, and where their involvement in PMTCT programs serves to reinforce discrimination and stigma associated with HIV/AIDS.

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A. INFORMED CONSENT

“The people in charge of the program [to prevent mother-to-child transmission] tell us not to give all the information [because they say it might confuse women]. Maybe 2% [of the women] are given all the information. In fact, the other day there was a [pregnant] woman who said to me ‘For my child, I will do anything. But they have to give me all the information.’ ”

Human Rights Watch interview with HIV/AIDS counselor [name withheld] at a public hospital, Santiago, Dominican Republic, January 19, 2004, HUMAN RIGHTS WATCH, A TEST OF INEQUALITY: DISCRIMINATION AGAINST WOMEN LIVING WITH HIV IN THE DOMINICAN REPUBLIC 30 (2004) available at <http://hrw.org/reports/2004/dr0704/dr0704.pdf> (last visited June 16, 2005).

Respect for an individual’s right to give informed consent derives from the concept of physical integrity, which is formally protected in guarantees of the rights to security of the person,²⁶ liberty,²⁷ privacy,²⁸ and health.²⁹ Women’s right to physical integrity requires that their decisions regarding health interventions—HIV testing and treatment among them—be respected. And to make appropriate decisions about their health, women must have access to reliable information about the proposed treatment or testing protocol.

In its resolution on the rights of persons with mental illness, the United Nations General Assembly defines informed consent as consent to a medical intervention that is “obtained freely, without threats or improper inducements.”³⁰ Before giving consent, a patient must be provided with “adequate and understandable information in a form and language understood by the patient” on matters such as the purpose of the treatment, alternative treatments and “possible pain or discomfort, risks and side-effects of the proposed treatment.”³¹ Further, the United Nations Committee on the Elimination of Discrimination against Women discusses the right to informed consent in connection with article 12, the article on health, in the Convention on the Elimination of All Forms of Discrimination against Women. The committee expresses this right as follows:

“Women have the right to be fully informed, by properly trained personnel, of their options in agreeing to treatment or research, including likely benefits and potential adverse effects of proposed procedures and available alternatives.”³²

Informed consent must be guaranteed prior to testing and treatment for HIV/AIDS. Counseling should be part of every woman’s decision to learn her HIV status and participate in PMTCT programs.

1. TESTING AND INFORMED CONSENT

“If [a woman] finds herself HIV-positive, she is signing three deaths: psychological death, social death, and later physical death. Don’t you think that is a lot?”

Woman in Koudougou, Burkina Faso, from PANOS & UNICEF, STIGMA, HIV/AIDS AND PREVENTION OF MOTHER-TO-CHILD TRANSMISSION (unnumbered page) (2001) available at <http://www.ohchr.org/english/issues/hiv/introhiv.htm>.

As programs to prevent mother-to-child transmission of HIV become increasingly available, there is a strong incentive to raise enrollment in those programs by scaling

up HIV testing of pregnant women. Expanding women’s access to HIV testing during pregnancy is a necessary component of any campaign to prevent mother-to-child transmission. It is crucial, however, that efforts to increase testing be complemented by similar commitments to pretest counseling. Governments should not lose sight of each woman’s right to make informed decisions about her health care, including her decision to learn her HIV status. Where women are forced to take an HIV test or are tested without their knowledge and informed consent, their basic human rights are severely compromised.

Compulsory HIV testing, the most obvious threat to the right to informed consent, “can constitute a deprivation of liberty and a violation of the right to security of person,” according to the International Guidelines on HIV/AIDS and Human Rights, promulgated to help states translate human rights principles into concrete practices in the context of HIV/AIDS.³³ The guide-

lines warn that “there is *no public health justification* for such compulsory HIV testing” as “[r]espect for the right to physical integrity requires that testing be voluntary and that no testing be carried out without informed consent.”³⁴ UNAIDS further maintains that testing can be conducted only with informed consent—consent that is both informed and voluntary.³⁵

UNAIDS and WHO define four different types of testing and categorize them by whether the testing is initiated by the client (voluntary testing) or the provider (diagnostic testing, routine offer of testing to all clients, and mandatory testing).

- Voluntary testing refers to testing at the patient’s request.
- Diagnostic testing refers to testing that is indicated whenever a patient show signs or symptoms consistent with HIV-related diseases or AIDS.
- Routine offer of testing refers to testing that is offered whenever a patient is being assessed for sexually transmissible infections, when a pregnant patient is seen in the context of enrollment in a PMTCT program, or a patient is seen in a health-care setting where HIV is prevalent and antiretroviral treatment is available.
- Mandatory testing refers to testing that is compulsory. UNAIDS and WHO discuss mandatory testing only for testing blood to be used for transfusions or the manufacture of blood products, and in rare circumstances where a patient is unconscious, where his or her guardian or parent is absent, and HIV-status is needed for optimal treatment.

Source: UNAIDS & WHO, *Policy Statement on HIV Testing* (2004), available at http://www.unaids.org/html/pub/una-docs/hivtestingpolicy_en_pdf.htm.

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Even where not compulsory, routine provider-initiated testing, which has been increasingly supported as a means to ensure higher rates of testing among pregnant women,³⁶ may threaten women's right to give informed consent. Though UNAIDS and WHO maintain that "for provider-initiated testing...patients retain the right to refuse testing, i.e., to 'opt-out' of a systematic offer of testing," many physicians erroneously believe that provider-initiated testing, specifically routine testing, does not require them to seek informed consent.³⁷ Similarly, many women—particularly those who are young or who lack financial resources and access to education—may not understand that they have a right to refuse testing.³⁸ Full consent is called into even greater question when the first time women are offered testing is during labor and delivery, as happens in many countries to women who do not receive prenatal care.³⁹ The stress and pain of childbirth can make it difficult for any woman to consider fully the implications and potential consequences of HIV testing. In these ways, "opt-out" testing becomes indistinguishable from mandatory testing, as women are routinely tested without their full knowledge or consent. Characterizing a medical test as "routine" does not affect health professionals' obligation to seek informed consent from the women who are being tested.⁴⁰

In the Dominican Republic, women's human rights are regularly violated when it comes to HIV testing and treatment, according to a report from Human Rights Watch. Several women reported that doctors and other health-care professionals required HIV tests as a condition for receiving services. In public facilities offering prenatal care, women received little or no counseling prior to being tested for HIV.

Source: HUMAN RIGHTS WATCH, *A TEST OF INEQUALITY: DISCRIMINATION AGAINST WOMEN LIVING WITH HIV IN THE DOMINICAN REPUBLIC 29* (2004) available at <http://hrw.org/reports/2004/dr0704/dr0704.pdf>.

If provider-initiated testing of women seeking prenatal care is to become the norm, it must be coupled with comprehensive measures to ensure that HIV-positive women and girls have the opportunity to give informed consent. First, testing protocols must ensure that the offer to test is prefaced with an offer of pretest counseling. Once a patient has agreed to be counseled, she should be informed of the benefits of HIV testing, the right to refuse testing, the availability of follow-up services, and, in the case of a positive test result, the implications of that result for the patient's partner or family.⁴¹ Following counseling, providers must ensure that the patient has sufficient time to consider whether or not to undergo testing. Under no circumstance should the provision of prenatal care be conditioned on HIV testing. Once the patient has given a clear indication that she consents to be tested, the screening can take place. Providers should make referrals for posttest counseling on HIV prevention and, for those who test positive, for medical and psychosocial support.⁴²

Governments that embrace provider-initiated testing should not abandon efforts to promote patient-initiated voluntary counseling and testing models. In addition, provider-initiated testing should not be reserved for pregnant women only. Where HIV infection carries stigma and there is resistance to testing in the general population, targeting pregnant women for testing may only marginalize them further, while their partners may refuse testing themselves. As UNAIDS and WHO recommend, all patients in a setting where HIV is prevalent and antiretroviral treatments are available should be offered HIV testing and counseling.⁴³

2. TREATMENT AND INFORMED CONSENT

PMTCT programs must provide pregnant women with the opportunity to decide freely whether to accept antiretroviral therapy. The standard for informed consent to PMTCT treatment must abide by the general standard for consent as laid out above—i.e., informed consent is consent to a medical intervention that is “obtained freely, without threats or improper inducements.”⁴⁴ PMTCT programs, as their name indicates, focus on *prevention*. As a result, the fact that HIV-positive women are patients receiving a health service is frequently overlooked. These programs must not disregard their duty of care to the woman being treated, as well as the rights of these women as patients. In all cases, adequate counseling must be a precondition to women’s participation in PMTCT programs.

To ensure an informed decision, women must be counseled on the risks and benefits of taking antiretroviral medication, both for themselves as patients and for their fetuses and infants. They must also receive information on the risks and benefits of alternatives to breast-feeding, as well as the likelihood of transmission of HIV to their fetus or newborn, both with treatment and in the absence of treatment. Furthermore, women must be informed of the fact that although drug therapy may reduce the risk of vertical transmission, it does not eliminate that risk.⁴⁵ This information is important because it allows pregnant women to have realistic expectations of how they (and their fetus) might benefit from drug therapy.

Informed consent to undergoing antiretroviral therapy to reduce mother-to-child transmission is also important because the treatment may affect the health of the pregnant woman. The long-term side effects of temporary exposure to nevirapine or zidovudine must be further researched, as previous studies have shown that there is a small chance of resistance to these drugs—especially after their use during more than one pregnancy. Researchers state that the risks of antiretroviral treatments are outweighed by their benefits in preventing mother-to-child transmission of HIV.⁴⁶ However, pregnant women must be fully informed of the medical uncertainties and potential risks involved. Recent news articles have revived this debate with reports that even one dose of nevirapine during pregnancy can cause resistance, thus undermining efforts to treat HIV-positive women with the drug after childbirth.⁴⁷ It is clear that the

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full implications of administering drugs to pregnant women to reduce transmission of HIV are not yet known.

Finally, pregnant women should be aware that their access to medication may be dependent upon their participation in a PMTCT program. As presently conceived, most PMTCT programs are aimed solely at protecting the health of fetuses and newborns,⁴⁸ rather than treating women living with HIV/AIDS. It is important that pregnant women understand, through counseling, that access to antiretrovirals may end shortly after they have given birth. As noted by UNAIDS:

“The fact that antiretrovirals can serve two separate purposes—as [a] vaccine for infants against MTCT [mother-to-child transmission] of HIV, and as treatment for HIV infected individuals—is, of course, very significant. But the issue of antiretroviral treatment for infected people must be considered separately from the issue of antiretroviral drugs used for the prevention of MTCT. It requires debate and policy decisions outside the scope of MTCT policy-making.”⁴⁹

Each woman has the right to understand the advantages and risks of getting tested and enrolling in a PMTCT program, and the decision to be tested and enroll should be her decision alone. A woman who refuses to be tested for HIV or participate in a PMTCT program should not be subjected to punitive action or denial of care,⁵⁰ as happened, for example, to an HIV-positive woman in the United States who had her parental rights suspended when she insisted on breast-feeding her child.⁵¹

B. CONFIDENTIALITY OF CARE

“When the patient comes to our ward, it’s written on the file ‘HIV’ in big letters. Anybody can see it. It’s kept next to the patient. Anybody can see it.”

Ward-boy working in a private hospital in Mumbai, India, UNAIDS, HIV AND AIDS-RELATED STIGMATIZATION, DISCRIMINATION AND DENIAL: FORMS, CONTEXTS AND DETERMINANTS, RESEARCH STUDIES FROM UGANDA AND INDIA 24 (2000) available at http://www.unaids.org/html/pub/publications/irc-pub01/jc316-uganda-india_en_pdf.pdf.

Privacy and confidentiality guarantees are essential for PMTCT programs to effectively protect and promote women’s human rights. For many women, the fear of disclosure of their HIV status prevents them from seeking health services. The stigma attached to HIV can lead to severe consequences for women, such as abandonment by partners, rejection by other family members, blame for bringing the disease into the family, eviction, loss of economic support, physical and emotional abuse, and other forms of discrimination.⁵²

The right to privacy is upheld in many international legal instruments, including the International Covenant on Civil and Political Rights.⁵³ In the context of health status and HIV/AIDS, the Programme of Action of the International Conference on Population and

Development states that governments should “ensure that the individual rights and the confidentiality of persons infected with HIV are respected.”⁵⁴ The International Guidelines on HIV/AIDS and Human Rights call on states to enact general confidentiality and privacy laws, ensuring that HIV-related information is protected.⁵⁵

Health-care providers play an essential role in protecting patients’ privacy. The Ethical Committee of the International Federation of Gynecology and Obstetrics (FIGO) states that physicians have an obligation to “respect and guard the individual patient’s right to privacy and the confidentiality of their health information. This includes avoiding the casual sharing of any information about individual patients in any setting.”⁵⁶

In Ukraine, when pregnant women were found to be HIV-positive during routine prenatal blood tests, many reported that nurses would disclose their status to other members of their community.⁵⁷ As a result, many women would be subjected to abuse, rejection, and abandonment, and a number were forced to leave their homes.⁵⁸ Similarly, it has been reported in Mumbai, India that health-care workers, when they learn that a woman has tested positive for HIV, insist on disclosing this information to the woman’s husband in the belief that the woman herself will not understand.⁵⁹ The information is sometimes shared with other family members, as well.⁶⁰

Breaches of confidentiality may also be indirect. FIGO notes that “the title of a clinic or institution may inadvertently breach a patient’s right to confidentiality.”⁶¹ A woman who has to go to a specially designated facility to access PMTCT services may reveal her HIV status to the community. PMTCT programs that stand apart and label themselves as such, without being integrated into routine reproductive health-care programs, can breach a woman’s right to privacy. Similarly, where breast-feeding is the norm, a woman who is seen bottle-feeding her infant in a hospital setting may be assumed to be participating in a PMTCT program.⁶²

Not only do breaches of confidentiality violate women’s human rights, but there are strong public health arguments for securing confidentiality. The possibility that a person’s HIV status may be made public without an individual’s consent will seriously discourage people from obtaining a test or the necessary treatment. In the Dominican Republic for example, a woman chose not to undergo an operation to remove an ovarian cyst because the operation required an HIV test.⁶³ She feared the consequences of testing positive and of having the results leaked to her family. Jeopardizing her health to avoid disclosure, she refused the test and the operation. A year after her diagnosis, she still had not had the cyst removed.⁶⁴

C. MISTREATMENT OF WOMEN SEEKING CARE IN PMTCT PROGRAMS— DISCRIMINATION AND STIGMA

“The nurses treat you like an animal, if you are ever admitted, the nurses will never help you. When you disturb them a lot they will call you names and ask you pointedly whether you want to infect them.”

Woman living with HIV/AIDS in Nigeria, Center for the Right to Health, *Human Rights and HIV/AIDS: Experiences of People Living with HIV/AIDS in Nigeria* (2001) at <http://www.crhonline.org/pubdetail.php?pubid=2>.

Some of the most egregious examples of discrimination against people living with or suspected to have HIV/AIDS are reported in health-care settings.⁶⁵ Uninformed doctors and nurses, fearful of HIV, often violate patients’ right to nondiscrimination. Examples include the denial of care and drugs to HIV-positive patients, unreasonable delays in providing consultations or care, neglectful treatment (e.g., leaving HIV-positive patients in the corridor), and insults from health staff toward persons living with HIV/AIDS.⁶⁶

Article 1 of the Universal Declaration of Human Rights provides that “all human beings are born free and equal in dignity and rights.”⁶⁷ Human rights law guarantees freedom from discrimination on grounds such as “race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.”⁶⁸ The Commission on Human Rights explains that in provisions dealing with nondiscrimination, “other status” must be “interpreted to include health status, including HIV/AIDS.”⁶⁹

The FIGO Committee for the Ethical Aspects of Human Reproduction and Women’s Health clearly delineates the standard for equality in health care as it pertains to women’s reproductive health. FIGO’s ethical guidelines require that women be treated equally when receiving reproductive health care, which places a duty on providers to respect women’s rights.⁷⁰ It is especially important that providers respect the rights of women living with HIV/AIDS, who face a “double” burden of discrimination based on the intersection of HIV-related stigma with gender-related inequality.

Moreover, empowering women is essential to fight the HIV/AIDS pandemic and to reduce discrimination and stigma. The impact of being labeled HIV-positive is immense for many women. Within the health-care system, women living with HIV/AIDS have been refused admission to deliver their babies. For example, one woman in India was kept waiting so long for her cesarean that she eventually had to deliver vaginally.⁷¹ Such treatment discourages women living with HIV/AIDS from attending clinics and prevents them from taking advantage of the many benefits that PMTCT programs can offer. In Nigeria, for example, reports reveal that comprehensive PMTCT programs could prevent 246 cases of vertical transmission a day.⁷² Unfortunately, the stigma surrounding HIV-positive status means that many women are unwilling to be

tested, and therefore many of these infections are not prevented.⁷³ In some health clinics in Nigeria, it is reported that nurses do not tolerate mothers who bottle-feed their children in the postnatal wards, and scold any women they see doing so.⁷⁴

III. Recommendations for Governments Carrying Out PMTCT Programs

The following recommendations are aimed at policymakers engaged in the oversight of PMTCT programs. These recommendations are grounded in the basic human rights principles addressed in this briefing paper. Members of civil society, who play a crucial role in ensuring governments' compliance with human rights norms, can advocate for adherence to these recommendations. They can do so by engaging with national health ministries, lobbying before legislative bodies, and litigating on behalf of women whose rights have been violated in PMTCT programs.

- **Remember that the woman is the patient.** Do not allow prevention goals to outweigh the rights of women as patients in a health-care setting. Respect for women's dignity and rights encourages informed decision-making among women, who will be more willing to participate in programs once they know their decisions will be respected.
- **Ensure informed consent and confidentiality.** Ensure that PMTCT programs follow strict guidelines regarding informed consent and confidentiality. Where provider-initiated testing is the norm, develop protocols that emphasize counseling prior to soliciting patients' consent to testing.
- **Reduce stigma.** Integrate future PMTCT programs within prenatal care facilities. Undertake community-wide education and information initiatives in order to combat the fear and myths surrounding HIV/AIDS.
- **Increase providers' understanding of human rights.** Increase training for health-care providers on the links between human rights and HIV/AIDS programming—particularly with regard to PMTCT programs. Ensure that PMTCT programs follow FIGO guidelines that protect women's rights to informed consent, confidentiality, and nondiscrimination.
- **Advance and protect women's human rights.** Promote women's status in both the home and the public sphere. Ensure that government clinics promote and protect women's rights and provide protection for women living with HIV/AIDS who might suffer abuse.

IV. Conclusion

A lack of respect for human rights fuels the spread of HIV and exacerbates the impact of the HIV/AIDS pandemic. Strategies for HIV prevention, treatment, support, and care are hindered when they are carried out in an environment where human rights are not respected.⁷⁵ Governments must ensure that women's rights are respected when women access treatment, care, and testing services. Medical, health, and informational services must promote the dignity and equality of pregnant women living with HIV/AIDS. For PMTCT programs, this means ensuring that programs meet the requirements of informed consent to testing and treatment and that they operate with respect for the right to privacy and confidentiality. Finally, all HIV testing or treatment programs must respect women's dignity, and work to reduce the stigma and discrimination related to HIV/AIDS.

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ENDNOTES

- 1 A note on terminology: The phrase “prevention of mother-to-child transmission” is the one most commonly used to refer to programs aimed at preventing HIV infection in fetuses and newborns during pregnancy, childbirth or the postnatal period. This terminology is increasingly being questioned by advocates who note that it can imply that pregnant women and mothers living with HIV/AIDS are solely responsible for preventing transmission of HIV to their newborn infants. Alternative phrasing, including “prevention of parent-to-child transmission” has been advocated by several groups. See HUMAN RIGHTS WATCH, A TEST OF INEQUALITY: DISCRIMINATION AGAINST WOMEN LIVING WITH HIV IN THE DOMINICAN REPUBLIC (2004), available at <http://hrw.org/reports/2004/dr0704/> [hereinafter HUMAN RIGHTS WATCH, A TEST OF INEQUALITY]. Others have advocated for the term “perinatal” transmission. See MARIA DE BRUYN, IPAS, HIV/AIDS AND REPRODUCTIVE HEALTH: SENSITIVE AND NEGLECTED ISSUES 29 (2005), available at http://www.ipas.org/publications/en/HIVLITREV_E05_en.pdf. Because this briefing paper focuses narrowly on the rights of women in regimes commonly referred to by governments and the UN system as “prevention of mother-to-child transmission” programs, this terminology has been used throughout.
- 2 WORLD HEALTH ORGANIZATION (WHO), ANTIRETROVIRAL DRUGS FOR TREATING PREGNANT WOMEN AND PREVENTING INFECTION IN INFANTS: GUIDELINES ON CARE, TREATMENT AND SUPPORT FOR WOMEN LIVING WITH HIV/AIDS AND THEIR CHILDREN IN RESOURCE-CONSTRAINED SETTINGS 7 (2004), available at <http://www.unaids.org> [hereinafter WHO, ANTIRETROVIRAL DRUGS]. The guidelines state that “Over the past few years, considerable efforts have been made to introduce and expand programs to prevent mother-to-child transmission of HIV.” *Id.* at iv.
- 3 See *Treatment Action Campaign et al v. Minister of Health et al*, (South Africa, High Court, Transvaal Provincial Division, CCT 8/02, Case No. 21182/2001). In this case, access to PMTCT programs is recognized as an exercise of women’s right to health care. The court opines that “The Constitution requires government to devise and implement within its available resources a comprehensive and coordinated program to realize progressively the rights of pregnant women and their newborn children to have access to health services to combat MTCT of HIV.” *Id.* at 74.
- 4 UNAIDS & WHO, AIDS EPIDEMIC UPDATE DECEMBER 2004 4 (2004), available at <http://www.unaids.org/wad2004/report.html> [hereinafter UNAIDS & WHO, AIDS EPIDEMIC UPDATE]; HUMAN RIGHTS WATCH, POLICY PARALYSIS: A CALL FOR ACTION ON HIV/AIDS-RELATED HUMAN RIGHTS ABUSES AGAINST WOMEN AND GIRLS IN AFRICA 1 (2003), available at <http://www.hrw.org/reports/2003/africa1203/> [hereinafter HUMAN RIGHTS WATCH, POLICY PARALYSIS].
- 5 UNAIDS & WHO, AIDS EPIDEMIC UPDATE, *supra* note 4, at 11.
- 6 UNAIDS & WHO, AIDS EPIDEMIC UPDATE, *supra* note 4, at 10, 12.
- 7 Shelley Clark, *Early Marriage and HIV Risks in Sub-Saharan Africa*, 35(3) STUDIES IN FAMILY PLANNING 149 (2004); Lawrence K. Altman, *HIV Risk Greater for Young African Brides*, N. Y. TIMES, Feb. 29, 2004, at § 1, 3.
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- 11 UNAIDS & WHO, AIDS EPIDEMIC UPDATE, *supra* note 4, at 1. The number of children living with HIV/AIDS is estimated to be in the range of 2.0-2.6 million.
- 12 *Id.* at 14.
- 13 Chewe Luo, *Strategies for Prevention of Mother-to-Child Transmission of HIV*, 8(16) REPRODUCTIVE HEALTH MATTERS 144 (2000).
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- 21 AVERT, *Preventing Mother-to-Child Transmission of HIV*, at <http://www.avert.org/motherchild.htm> (last visited June 16, 2005).
- 22 UNAIDS, PROGRESS REPORT ON THE GLOBAL RESPONSE TO THE HIV/AIDS EPIDEMIC, 2003 at 64 (2003), available at http://www.unaids.org/ungass/en/global/UNGASS_Report_2003_en.pdf [hereinafter UNAIDS, PROGRESS REPORT].
- 23 *Id.* at 65.
- 24 UNAIDS & WHO, AIDS EPIDEMIC UPDATE, *supra* note 4, at 14.
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Protecting Human Rights in Programs to Prevent Mother-to-Child Transmission of HIV

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- 26 See Universal Declaration of Human Rights, *adopted* Dec. 10, 1948, art. 3, G.A. Res. 217A (III), at 71, U.N. Doc. A/810 (1948) [hereinafter Universal Declaration]; International Covenant on Civil and Political Rights, G.A. Res. 2200A (XXI), U.N. GAOR, 21st Sess., Supp. No. 16, U.N. Doc A/6316 (1966), arts. 6(1), 9(1), 999 U.N.T.S. 171 (*entered into force* Mar. 23, 1976) [hereinafter Civil and Political Rights Covenant]; Convention on the Rights of the Child, *adopted* Nov. 20, 1989, arts. 6(1), 6(20), G.A. Res. 44/25, annex, U.N. GAOR, 44th Sess., Supp. No. 49, at 166, UN Doc. A/44/49 (1989), *reprinted in* 28 I.L.M. 1448 (*entered into force* Sept. 2, 1990) [hereinafter Children's Rights Convention]; *Programme of Action of the International Conference on Population and Development*, Cairo, Egypt, Sept. 5-13, 1994, paras. 7.3, 7.15, 8.34, U.N. Doc. A/CONF.171/13/Rev.1 (1995) [hereinafter ICPD *Programme of Action*]; *Beijing Declaration and the Platform for Action, Fourth World Conference on Women*, Beijing, China, Sept. 4-15, 1995, paras. 96, 106, 108, U.N. Doc. A/CONF.177/20 (1995) [hereinafter *Beijing Declaration and Platform for Action*].
- 27 Universal Declaration, *supra* note 26, art. 3; Civil and Political Rights Covenant, *supra* note 26, art. 9.
- 28 See Civil and Political Rights Covenant, *supra* note 26, art. 17(1); Children's Rights Convention, *supra* note 26, arts. 16(1), 16(2); ICPD *Programme of Action*, *supra* note 145, para. 7.45; *Beijing Declaration and Platform for Action*, *supra* note 26, paras. 106, 107.
- 29 United Nations Committee on Economic, Social and Cultural Rights, Gen. Comment No. 14, *The Right to the Highest Attainable Standard of Health*, para. 9, U.N. Doc. E/C.12/2000/4 (2000), available at [http://www.unhchr.ch/tbs/doc.nsf/\(Symbol\)40d009901358b0e2c1256915005090be?Opendocument](http://www.unhchr.ch/tbs/doc.nsf/(Symbol)40d009901358b0e2c1256915005090be?Opendocument).
 "The Committee interprets the right to health, as defined in article 12.1, as an inclusive right extending not only to timely and appropriate health care but also to the underlying determinants of health, such as . . . access to health-related education and information." *Id.* para. 11. It also states: "The obligation to fulfil (*facilitate*) requires States *inter alia* to take positive measures that enable and assist individuals and communities to enjoy the right to health [including] . . . (iv) supporting people in making informed choices about their health." *Id.* para. 37.
- 30 *Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care*, G.A. Res. 199, U.N. GAOR, 46th Sess., Supp. No. 49 at Principle 11, 2, U.N. Doc. A/RES/46/119 (1992) available at <http://www.unhchr.ch/html/menu3/b/68.htm>.
- 31 *Id.*
- 32 United Nations Committee on the Elimination of Discrimination against Women, General Recommendation No. 24, *Women and Health*, Feb. 2, 1999, para. 20, available at [http://www.unhchr.ch/tbs/doc.nsf/\(Symbol\)/77bae3190a903f8d80256785005599ff?Opendocument](http://www.unhchr.ch/tbs/doc.nsf/(Symbol)/77bae3190a903f8d80256785005599ff?Opendocument)
- 33 UN HUMAN RIGHTS GUIDELINES, *supra* note 25, para. 113.
- 34 *Id.* (emphasis added). A 2004 UNAIDS/WHO joint policy statement supports mandatory HIV screening in blood that is destined for transfusion or for manufacture of blood products. In addition, mandatory screening is required of donors prior to all procedures involving transfer of bodily fluids or body parts, including artificial insemination and organ transplants. UNAIDS & WHO, UNAIDS/WHO POLICY STATEMENT ON HIV TESTING (2004), available at http://www.unaids.org/html/pub/unadocs/hivtestingpolicy_en_pdf.htm.
- 35 *Id.*
- 36 MARIA DE BRUYN, *supra* note 1, at 29.
- 37 HEALTH CANADA, HIV TESTING AND PREGNANCY: MEDICAL AND LEGAL PARAMETERS OF THE POLICY DEBATE 84 (1999), available at <http://www.aidslaw.ca/Maincontent/issues/testing/e-preg.pdf>.
- 38 MARIA DE BRUYN, *supra* note 1, at 29.
- 39 *Id.* at 30.
- 40 HEALTH CANADA, *supra* note 37, at 84.
- 41 UNAIDS/WHO POLICY STATEMENT ON HIV TESTING, *supra* note 34 at 2.
- 42 *Id.*
- 43 *Id.*
- 44 *Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care*, G.A. Res. 199, *supra* note 30.
- 45 WHO, ANTIRETROVIRAL DRUGS, *supra* note 2 at 4, noting that "The risk of MTCT can be reduced to below 2% by interventions that include antiretroviral (ARV) prophylaxis given to women during pregnancy and labour and to the infant in the first weeks of life, obstetrical interventions including elective caesarean delivery (prior to the onset of labour and membrane rupture) and completely avoiding breastfeeding." (citations omitted).
- 46 *Id.* at 2; see also, Founding Affidavit of Treatment Action Campaign, filed on 21 August 2001 at Pretoria High Court in the matter between *Treatment Action Campaign et al. v. Minister of Health et al.* at 12.
- 47 Lawrence K. Altman, *Infant Drugs For HIV Put Mothers at Risk*, N.Y. TIMES, Feb. 10, 2004, at A22.
- 48 WM El-Sadr et al., "The MTCT-Plus Initiative: A Successful Model Of Care and Treatment for HIV-Infected Families In Resource-Limited Countries," Conference Posters International AIDS Conference, Bangkok 2004, available at http://www.mtctplus.org/pdf/MTCTPlus_Model_of_Care.pdf. MTCT-Plus programs, in contrast, aim to provide "lifelong care and treatment to HIV seropositive pregnant and postpartum women, their partners, and their children." *Id.*
- 49 UNAIDS, PREVENTION OF HIV TRANSMISSION FROM

- MOTHER TO CHILD: STRATEGIC OPTIONS 14 (1999), available at http://www.unaids.org/html/pub/publications/irc-pub05/prevention_en_pdf.pdf.
- 50 PUBLIC HEALTH SERVICE TASK FORCE, RECOMMENDATIONS FOR USE OF ANTIRETROVIRAL DRUGS IN PREGNANT HIV-1-INFECTED WOMEN FOR MATERNAL HEALTH AND INTERVENTIONS TO REDUCE PERINATAL HIV-1 TRANSMISSION IN THE UNITED STATES (2005), available at http://aidsinfo.nih.gov/guidelines/perinatal/PER_022405.pdf.
- 51 CNN, *HIV-infected mother battles to breast-feed baby*, Feb. 1, 1999, available at <http://www.cnn.com/HEALTH/9902/01/baby.azt/>.
- 52 WHO, GENDER DIMENSIONS OF HIV STATUS DISCLOSURE TO SEXUAL PARTNERS: RATES, BARRIERS AND OUTCOMES: A REVIEW PAPER 18-19 (2003), available at <http://www.who.int/gender/documents/en/genderdimensions.pdf>; Kingsley Obom-Egbulem, *Stigma impairs access to Nigeria's PMTCT programme*, JOURNALISTS AGAINST AIDS – NIGERIA, July 30, 2003, available at <http://www.nigeria-aids.org/MsgRead.cfm?ID=1651> (last visited June 16, 2005).
- 53 See Civil and Political Rights Covenant, *supra* note 26, art. 17(1).
- 54 ICPD Programme of Action, *supra* note 26, para 8.29; 8.34.
- 55 UN HUMAN RIGHTS GUIDELINES, *supra* note 25, para 30(c). The UN Guidelines further state that governments have an obligation to: “guarantee that adequate safeguards are in place to ensure that... confidentiality is protected, particularly in health and social welfare settings, and that information on HIV status is not disclosed to third parties without the consent of the individual.” *Id.* para 5.
- 56 INTERNATIONAL FEDERATION OF GYNECOLOGY AND OBSTETRICS (FIGO), RECOMMENDATIONS ON ETHICAL ISSUES IN OBSTETRICS AND GYNECOLOGY BY THE FIGO COMMITTEE FOR THE ETHICAL ASPECTS OF HUMAN REPRODUCTION AND WOMEN’S HEALTH 17 (2003), available at http://www.figo.org/content/PDF/ethics-guidelines-text_2003.pdf. Emphasis added. Considering information about STIs, FIGO maintains that “[w]hen information on the health state of a patient has serious implications for the health of others, the physician has an obligation to consult the individual and obtain permission to make the information appropriately available.” *Id.*
- 57 PANOS & UNICEF, HIV/AIDS AND PREVENTION OF MOTHER-TO-CHILD TRANSMISSION: A PILOT STUDY IN ZAMBIA, INDIA, UKRAINE AND BURKINA FASO 29 (2001), available at http://www.unicef.org/evaldatabase/index_14340.html.
- 58 *Id.*
- 59 *Id.* at 33.
- 60 *Id.*
- 61 FIGO, *supra* note 56, at 18.
- 62 Joan MacNeil, Family Health International, *Preventing Mother-to-Child Transmission of HIV* (2005) at <http://www.fhi.org/en/HIVAIDS/pub/Archive/articles/IOH/ioh11/ioh11-10.htm>; HUMAN RIGHTS WATCH, POLICY PARALYSIS, *supra* note 4, at 75, 76.
- 63 HUMAN RIGHTS WATCH, A TEST OF INEQUALITY, *supra* note 1, at 30.
- 64 *Id.*
- 65 PANOS & UNICEF, *supra* note 57, at 29.
- 66 *Id.*
- 67 Universal Declaration, *supra* note 26, art. 1.
- 68 Universal Declaration, *supra* note 26, art. 2.
- 69 OFFICE OF THE UNITED NATIONS HIGH COMMISSIONER FOR HUMAN RIGHTS, THE PROTECTION OF HUMAN RIGHTS IN THE CONTEXT OF HUMAN IMMUNODEFICIENCY VIRUS (HIV) AND ACQUIRED IMMUNODEFICIENCY SYNDROME (AIDS), para. 16 (2003), available at http://ap.ohchr.org/documents/E/CHR/resolutions/E-CN_4-RES-2003-47.doc.
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- 71 PANOS & UNICEF, *supra* note 57, at 30.
- 72 Kingsley Obom-Egbulem, *supra* note 52.
- 73 *Id.*
- 74 *Id.*
- 75 Office of the United Nations High Commissioner for Human Rights, *Introduction to HIV/AIDS and Human Rights*, available at <http://www.ohchr.org/english/issues/hiv/introhiv.htm> (last visited June 17, 2005).