BREAKING THE CYCLE

Ensuring Equitable Access to HIV Treatment for Women and Girls

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Breaking the Cycle: Ensuring Equitable Access to HIV Treatment for Women and Girls

Janet Fleischman
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Introduction

Recent international initiatives to provide antiretroviral (ARV) treatment in resource-poor countries have changed the landscape of the HIV/AIDS debate and signal an unprecedented new phase in the struggle against HIV/AIDS. With an estimated 40 million people living with HIV/AIDS and 14,000 new infections every day,[1] access to treatment is a challenge of global proportions. In sub-Saharan Africa alone, almost 4.5 million people need antiretroviral treatment, yet only 100,000 currently receive it.[2] To develop effective treatment programs, national governments, international donors, and community stakeholders should ensure equitable access to HIV treatment and care, notably for acutely vulnerable populations such as women and girls.

Integrating a gender approach in the rollout of treatment programs is a matter of urgency. In the worst affected countries of sub-Saharan Africa, women and girls account for 58 percent of those living with HIV/AIDS,[3] and girls ages 15 to 19 are infected at rates up to four to seven times higher than boys, a disparity

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[1] World Health Organization (WHO), *Treating 3 Million by 2005: Making it Happen, the WHO Strategy* (Geneva: WHO, December 2003), p. 3, http://www.who.int/3by5/publications/documents/en/3by5StrategyMakingItHappen.pdf.
[2] WHO, *Treating 3 Million by 2005*, p. 5.
[3] UNAIDS/WHO, *AIDS Epidemic Update 2002* (Geneva: UNAIDS/WHO, December 2002), http://www.unaids.org/worldaidsday/2002/press/epiupdate.html.

linked to sexual abuse, coercion, discrimination, and impoverishment.[4] In addition, gender-related barriers to health care are compounded by HIV/AIDS. The threats that HIV-positive women face upon disclosing their status, especially when they are the first to be identified as being HIV positive and are blamed for bringing the virus into the household, in turn heighten their risk of violence, abandonment, and other forms of stigma and discrimination. Treatment initiatives provide an opportunity to address the violence and inequities that put women and girls at particular risk of HIV transmission and thereby to break the cycle that has led to the disproportionate impact on women and girls.

Despite the dangers of their subordinate status, women—especially pregnant women—may face fewer barriers than men to knowing their HIV status. This is due to the increasing amount of testing conducted in antenatal clinics and to mother-to-child transmission (MTCT) programs. Yet many women in the most heavily stricken regions do not have access to adequate antenatal care; only 1 percent of women have access to MTCT services;[5] and nonpregnant women and adolescent girls are often out of reach. Accordingly, there is a compelling need to reinforce and expand the entry points to the health system for women by integrating voluntary counseling and testing (VCT) and treatment into reproductive health, family planning, and youth clinics. Curbing the AIDS epidemic requires a broader focus beyond medical interventions; programs that inform, protect, and empower women and girls are an essential way to reinforce the medical and health approaches to combating HIV/AIDS.

The U.S. President's Emergency Plan for AIDS Relief (PEPFAR)[6] is an historic initiative to support HIV/AIDS treatment, care, and prevention in 12 African and 2 Caribbean countries.[7] In developing the PEPFAR strategy, the Bush administration has a unique opportunity to ensure that programs targeting women and girls are effectively integrated into HIV treatment and prevention. Indeed, for the administration to meet its goals of treating 2 million HIV-positive individuals, preventing 7 million new infections, and caring for 10 million people,[8] it will

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[4] Janet Fleischman, *Suffering in Silence: The Links Between Human Rights Abuses and HIV Transmission to Girls in Zambia* (New York: Human Rights Watch, January 2003), p. 1.

[5] UNAIDS/Global Coalition on Women and AIDS, "AIDS Treatment—A Focus on '3 by 5'" (media backgrounder), February 2, 2004.

[6] PEPFAR and the accompanying legislation, the United States Leadership Against HIV/AIDS, TB, and Malaria Act of 2003, are expected to lead to an unprecedented increase in U.S. funding. Over five years, the Bush administration plans to spend $15 billion to combat HIV/AIDS, TB, and malaria. Approximately $10 billion of these funds are targeted for 12 sub-Saharan and two Caribbean countries.

[7] Other important initiatives include: WHO's "3 by 5" campaign, designed to get 3 million people on treatment by 2005; funding for ARV treatment from the Global Fund for HIV/AIDS, TB, and Malaria, the World Bank, and from private foundations such as the Bill and Melinda Gates Foundation, the Clinton Foundation HIV/AIDS initiative, and the Nelson Mandela Foundation; private organizations such as Médecins sans Frontières and Partners in Health; and national treatment programs in Brazil, Botswana, and in the early stages of design and implementation in other countries.

[8] Ambassador Randall L. Tobias, U.S. global AIDS coordinator, "Remarks at the Wilson Center," Washington D.C., December 11, 2003, http://www.state.gov/s/gac/rl/rm/27133.htm.

have to address the gender dimensions of HIV/AIDS as a strategic priority, especially the acute vulnerabilities of women and girls in the target countries. That women's subordinate status fuels the epidemic in the worst-affected countries is known and increasingly accepted; what is needed now is the political will, economic resources, and programmatic ingenuity to apply this knowledge as part of a comprehensive response to the epidemic.

Recommendations for U.S. Policy

There is now broad consensus on the centrality of gender in combating HIV/AIDS. This is reflected in part by the extensive commitments made by the U.S. government and other donors to the prevention of mother-to-child transmission and in the subsequent recognition that women identified in such programs should also be treated. It is now time to move to the next phase, which requires proactive strategies to enable women and girls to have meaningful access to prevention and treatment programs. In the worst affected countries, women have become active and motivated players in HIV/AIDS programs, and they offer new ways to help mobilize communities and to reach their partners. The challenge is no longer simply a lack of resources; the political will is now required to use available resources and programs to initiate innovative strategies to ensure that women and girls are a focal point for prevention and treatment.

The legislation passed by Congress, the United States Leadership Against HIV/AIDS, TB, and Malaria Act of 2003, focuses on the gender dimension of HIV/AIDS in several sections. It requires the administration to establish a comprehensive, integrated, five-year strategy and to include specific objectives, multi-sectoral approaches, and strategies to provide treatment and promote prevention, with a particular focus on the needs of women. For example, in its report to Congress, the administration is expected to include "[a] description of specific strategies developed to meet the unique needs of women," including empowering women in interpersonal situations; empowering young people and children, including orphans and victims of the sex trade, rape, sexual abuse, assault, and exploitation; encouraging men to be responsible in sexual behavior; increasing women's access to employment opportunities, income, productive resources, and microfinance; and educating women and girls about the spread of HIV/AIDS. The legislation calls for 55 percent of the funds authorized to be used for treatment of individuals with HIV/AIDS, and it sets the targets of having at least 500,000 people on treatment by the end of fiscal year 2004, 1 million by the end of FY 2005, and 2 million by the end of FY 2006.[9]

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[9] The legislation contains some elements that have been subject to considerable debate and raise concerns about how the funding on programs targeting women and girls will be allocated. Of particular concern is a provision requiring 33 percent of the prevention funds be used for abstinence-until-marriage programs. There is little dispute that abstinence is a component of broader prevention efforts, though it is often incompatible with the realities of abuse and inequality that women and girls face. The earmark was established in advance of a country planning process or cost analysis and may therefore divert funds from other prevention programs known to be effective, including VCT, MTCT, ensuring a safe blood supply, preventing drug

In particular, the new U.S. strategy should:

- **Integrate gender into treatment programs.**
  - Develop mechanisms and benchmarks to ensure gender equity in U.S.-funded treatment programs and to proactively seek out women for treatment programs. Benchmarks should include gender specific information on: the percentage of individuals infected; the number of infected people with access to ARVs; and the percentage of adherence, including the social support and continuous provision of drug access. Establish targets to ensure that at least 50 percent of those on treatment are women and girls and develop strategies to reach nonpregnant women, including adolescent girls and sex workers.
  - Design treatment programs to address the obstacles that women and girls face in accessing health care, ranging from cost of treatment, transportation, and child care, to appropriate appointment schedules, reduction in waiting times, sufficient women health workers, and guarantees of privacy and confidentiality. Treatment and prevention programs should provide counseling, referrals, and follow-up about the risk of abandonment or violence after disclosing their status, including links to safe shelters for women.
  - Train health workers to recognize signs of gender-based violence and to provide appropriate counseling and referral services to social, legal, and community-based support groups. Train and employ women as health care providers to increase the confidentiality and comfort level of women and girls seeking treatment.
  - Encourage couple counseling at VCT and MTCT sites to better ensure the involvement of male partners.
  - Provide post-exposure prophylaxis for rape victims and strengthen support services for survivors of rape and sexual violence.
  - Integrate HIV/AIDS and sexually transmitted infection (STI) services and treatment into family planning centers and reproductive health clinics. Similarly, integrate family planning services or referrals into HIV/AIDS programs.

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abuse, and improving women's social and economic status. In addition, the formulation "abstinence until marriage" does not reflect that marriage itself can be a risk factor, since married women are often unable to protect themselves or to negotiate condom use. Furthermore, this language may hamper important efforts to prevent the practice of child marriage, which is common in many of the PEPFAR countries and is associated with significant health risks. The legislation also includes a requirement that funding recipients have a policy opposing prostitution, which many observers fear may undermine outreach efforts to sex workers, an extremely high-risk group. The Bush administration's FY 2005 budget request calls for a reduction in child-survival and reproductive-health accounts, raising concerns that the administration is not prioritizing strategies to reach women and girls.

- **Strengthen programs focused on women and girls.**
  - Expand training of law enforcement and judicial personnel, as well as educators and health care providers, on the link between gender-based violence and HIV/AIDS, in the enforcement of women's and children's rights, and in investigating and prosecuting sexual violence, child abuse, domestic violence, and violence against sex workers.
  - Support legislative and judicial reform programs to repeal laws that violate women's rights, including property and inheritance rights; to amend laws to include crimes of sexual abuse, including marital rape; to enact legislation to prohibit domestic violence; and to ensure legal protection for people living with HIV/AIDS or those orphaned or widowed due to HIV/AIDS.
  - Expand economic empowerment for women through access to micro-credit programs, job and skills training, and assistance with property and inheritance rights.
  - Increase girls' access to education by supporting the elimination of school fees and related costs and provide bursaries and scholarships targeting girls.
  - Provide comprehensive HIV/AIDS and sexual education information beginning in primary schools. Integrate HIV/AIDS education into curricula, with special attention to the needs of girls. This should include addressing gender norms.
  - Establish gender advisory groups in the target countries. The advisory groups would provide input and guidance for the development and implementation of national PEPFAR plans, including treatment and prevention programs. Their expertise can ensure that PEPFAR programs recognize and address the specific effects of the epidemic on women and girls in each country. The groups should include representatives from civil society, including women's groups, networks of women living with HIV/AIDS, service providers, and other organizations with gender expertise.
  - Ensure that the technical assistance and interagency core teams that support the development of plans and programs in each of the PEPFAR countries include gender experts and women living with HIV/AIDS.
  - Issue formal instructions to the embassies and USAID missions in all target countries to ensure that programs focusing on gender equity in treatment and the gender dimension of the epidemic are integrated in their country plans, and include clear criteria upon which their programs will be evaluated.

  - In addition to incorporating these components into current and future procurements, create a new request for proposals to ensure that these targets are covered adequately in U.S.-funded HIV/AIDS programs.

- **Engage civil society and support community mobilization.**
  - Identify and support programs aimed at community mobilization for treatment preparedness, including mechanisms for delivery of ARVs, information and education campaigns, reduction of stigma and discrimination, advocacy, adherence, social support, and referrals to other social and economic resources.
  - Rapidly scale up programs through immediate support to nongovernmental organizations that work to reduce women and girls' vulnerability to HIV/AIDS and expand community mobilization. Assistance should be targeted to groups providing services that improve the social status and reduce the economic dependence of women and girls and facilitate their access to treatment. Where possible, these services should be linked to HIV/AIDS treatment centers, MTCT sites, and clinics providing reproductive health care.
  - Create a discretionary fund for U.S. embassies in the target countries specifically aimed at getting resources to women's groups, organizations of people living with HIV/AIDS, and other civil society groups that provide services to women and girls affected by AIDS. Given the emergency situation, ensure that reporting requirements are as flexible as possible.

- **Bolster data collection and indicators.**
  - Require U.S.-funded HIV/AIDS programs, including ARV treatment programs, to collect gender-specific data wherever possible about counseling, treatment, outcome, and adherence, and to improve data collection systems to better measure the relevant status and well-being of women and girls. Develop systems for anonymous tracking of domestic violence among persons in treatment.

- **Intensify public diplomacy.**
  - Engage in high-level public diplomacy focused on gender equity in treatment and the gender dimension of the crisis as a central part of the HIV/AIDS crisis. High-ranking administration officials, notably U.S. ambassadors, should engage with host country leadership to ensure that the gender dimension is integrated into HIV/AIDS programs in prevention, care, and treatment. Support leadership at the national, local, and community levels that highlights and integrates a gender analysis into HIV/AIDS programs, including violence against women, cross-generational sex, property and inheritance rights.

Links between Abuses against Women and Girls and HIV/AIDS

The AIDS crisis is fueled by women's social, economic, and biological vulnerabilities.[10] The alarming infection rate among women and girls results in part from widespread human rights abuses, including rape within and outside marriage, sexual violence and coercion, cross-generational sex, economic dependency, and discriminatory access to education, health care, and property and inheritance rights. Human Rights Watch underscored the new dangers of these abuses in the era of AIDS: "All of these human rights abuses have existed for a long time and many have been life-threatening, but with HIV/AIDS they are lethal on a massive scale."[11]

These abuses require programs that can and should be addressed through medical interventions, but also go beyond them to address the discrimination and violence that women and girls face. Dr. Helene Gayle, director of the Bill and Melinda Gates Foundation's HIV, TB, and Reproductive Health Program, summarized the importance of broader interventions for women: "We know that HIV is a virus that causes AIDS, that it is the virus that has the most direct impact, but we recognize that people and communities are vulnerable because of broader societal issues, of which gender inequality is perhaps one of the greatest."[12]

In an article published for the launch of a new initiative by the Joint United Nations Program on HIV/AIDS (UNAIDS), called the Global Coalition on Women and AIDS, Dr. Peter Piot, the director of UNAIDS, and Emma Thompson, the British actress, stressed the importance of focusing on the roots of women's vulnerability to HIV/AIDS: "To address AIDS effectively, we first have to understand how women are being treated and why. A comprehensive strategy is needed to boost girls' access to education—particularly secondary education—strengthen legal protection for women's property and inheritance rights, eradicate violence against women and girls, and ensure they have fair access to HIV care and prevention services."[13]

HIV/AIDS is a disease that attacks the fault lines in our societies, clearly evident when analyzing gender and AIDS. The stigma and silence surrounding discussions of sex, sexually transmitted infections, prostitution, and intravenous drug use, combined with the unequal status of women and male dominance in power relations, form a fatal mix. Ultimately, effective responses to HIV/AIDS

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[10] Janet Fleischman, *Fatal Vulnerabilities: Reducing the Acute Risk of HIV/AIDS among Women and Girls*, a report of the CSIS Task Force on HIV/AIDS (Washington D.C.: CSIS, February 2003).
[11] Human Rights Watch, *Policy Paralysis: A Call for Action on HIV/AIDS-Related Human Rights Abuses Against Women and Girls in Africa* (New York: Human Rights Watch, 2003), p. 3.
[12] "Scale Up Treatment—But Don't Forget Prevention, Says Gayle," *AllAfrica.com*, December 1, 2003, http://allafrica.com/stories/200312010064.html.
[13] Peter Piot and Emma Thompson, "HIV Efforts are Failing Women and Girls," February 2, 2004, http://www.unaids.org.

will have to address the structures and policies that perpetuate the abuse and discrimination faced by women and girls that leave them vulnerable to infection and that undermine their ability to cope and to access treatment once infected.

ARV Treatment

Treatment with antiretroviral therapy can transform HIV/AIDS from a devastating and deadly disease to a chronic illness and enable people living with HIV/AIDS to attain an improved quality of life. Patients are usually able to return to their work and are likely to experience fewer opportunistic infections.

Treatment is also an indispensable element of prevention and therefore should be part of a broader comprehensive approach that combines prevention, care, and treatment. In Brazil, for example, where ARV treatment and treatment for opportunistic infections are guaranteed and where social mobilization has been strong, experience indicates that the availability of treatment can lead to a significant reduction in new infections. This suggests that treatment is critical to broader programs to stop the spread of HIV/AIDS.[14]

Despite the fact that broadening access to ARVs still presents many challenges involving expense, administration, compliance, and sustainability, it provides hope that HIV-positive people can lead active, healthy lives.[15] Dr. Joseph O'Neill, U.S. deputy coordinator of global AIDS, recognized the sea change that has taken place in U.S. policy on ARVs in resource-poor settings: "We've moved in the last couple of years from the concept of treatment being impossible to treatment being difficult…and that shift is enormous."[16]

In recent years, the prospect of treatment has sparked a global treatment access movement that has mobilized communities, pressured governments and pharmaceutical companies, and contributed to the reduction in prices of AIDS drugs and laboratory tests.[17] The government of Brazil led the way in 1996, becoming the first developing country to guarantee universal access to ARVs,

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[14] Alan Berkman, "Confronting Global AIDS: Prevention and Treatment," *American Journal of Public Health*, vol. 91, no. 9 (September 2001).

[15] Gilbert Kombe and Owen Smith, *The Costs of Anti-Retroviral Treatment in Zambia* (Bethesda, Md.: Partners for Health Reformplus Project and Abt Associates Inc., October 2003), pp. 1, 13.

[16] CSIS HIV/AIDS Task Force conference, "Botswana's Strategy to Combat HIV/AIDS: Lessons for Africa and President Bush's Emergency Plan for AIDS Relief," Washington, D.C., November 12, 2003, http://www.kaisernetwork.org/health_cast/uploaded_files/111203_csis_implications_tr.pdf.

[17] In early 2000, the price of ARVs for one patient for a year was $10,000 to $12,000. By the end of 2000, the prices had dropped to $500 to $800 per person per year in low-income countries. As of May 2003, the least expensive brand name combination recommended by WHO was about $675 per person per year, and the least expensive generic combination recommended by WHO was under $300 per person per year. See http://www.unaids.org/en/in+focus/topic+areas/antiretroviral+therapy.asp. In October 2003, former U.S. president Bill Clinton and his foundation brokered an agreement with four generic drug companies to cut the cost of some ARVs by up to one-half for distribution to several countries in Africa and the Caribbean, bringing the cost to $132 per patient per year. See Lawrence K. Altman, "Clinton Group Gets Discount for AIDS Drugs," *New York Times*, October 24, 2003.

pushed by civil society action and multi-sectoral mobilization.[18] Groups like the Treatment Action Campaign in South Africa have transformed the debate about treatment, and groundbreaking work by international organizations such as Médecins sans Frontières (MSF) and Partners in Health have demonstrated the feasibility and effectiveness of treatment in developing countries.

The World Health Organization (WHO) recommends treatment for those diagnosed with AIDS and those with CD4 counts below 200 or who fulfill guidelines of a clinical diagnosis if no CD4 tests are available.[19] Yet WHO has also acknowledged that additional social and economic criteria will need to be developed and included "treatment and human rights" and "equity" in the guiding principles of its "3 by 5" campaign, noting that "special attention will be given to protecting and serving vulnerable groups in prevention and treatment programs" and that "the Initiative will make special efforts to ensure access to antiretroviral therapy for people who risk exclusion because of economic, social, geographical, or other barriers."[20] However, specific strategies have not yet been articulated to address the deep-rooted gender inequities in the context of treatment.

Obstacles to Treatment

The uptake in treatment is influenced by financial, physical, and social factors, and reflects many of the long-standing barriers that women have faced in accessing health care. However, in an era of HIV/AIDS, these factors are often exacerbated by threats of violence and abandonment, especially loss of economic support and fear of isolation and discrimination.

Traditional obstacles to health care for women include cost for services and drugs, distance to a health facility, and quality of care. In the case of maternal mortality, these factors have been described as the "three delays": delay in decisions to seek treatment (by the individual, the family, or both, depending on the decisionmakers and the status of women); delay in reaching health facilities (including travel time and cost of transportation); and delay in receiving treatment (including shortages of equipment, trained personnel, and competence of personnel).[21] These same delays apply to women's access to quality HIV/AIDS care and treatment.

In many developing countries, the differential use of health services relates to gender and socioeconomic status. Indeed cost and distance often work together to affect the decisionmaking process, since longer distances mean higher

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[18] Paulo Teixeira, "The Challenges for Access to ARVs in Developing Countries," Second IAS Conference on HIV Pathogenesis and Treatment," Paris, July 15, 2003, http://www.kaisernetwork.org/health_cast/uploaded_files/Teixiera_IAS_071503.pdf.

[19] WHO and UK Department for International Development, *Provision of Antiretroviral Therapy in Resource-limited Settings: A Review of Experience up to August 2003* (London: DFID Health Systems Resource Center, November 2003), pp. 7, 45.

[20] WHO, *Treating 3 Million by 2005*, p. 10.

[21] Sereen Thaddeus and Deborah Maine, "Too Far to Walk: Maternal Mortality in Context," *Social Science and Medicine* 38 (8) (1994): 1091–1110.

transportation costs, which are especially relevant for poor, rural women. The stigma and shame associated with sexually transmitted infections, compounded by attitudes of health care providers, contribute to delays in seeking treatment.[22] Girls, in particular, often face greater stigma in seeking information and services related to STIs, which takes on greater urgency given that the presence of STIs increases the risk of HIV transmission.

Power relations within the family often preclude women from making their own decisions to seek health care, since they often must seek approval from their spouse or another senior family member. This circumscribes women's ability to travel and determines whether the family will pay the cost of treatment. These considerations frequently apply unequally to women and men, and girls and boys, with the preference for treating the males. "Social dynamics are an obstacle to treatment for women," noted Sophia Mukasa Monico of the Global Health Council and formerly with the AIDS Support Organization (TASO) in Uganda. "If a boy and a girl are infected, the boy will be treated first."[23]

Violence against Women

Violence against women and the threat of violence affect multiple aspects of HIV prevention and care. To begin with, the threat of violence undercuts women's ability to negotiate safer sex, including condom use. Violence contributes to women's vulnerability to HIV infection and includes: physical assaults; sexual violence and other sexual abuse, including rape within and outside marriage, sexual abuse and exploitation of girls, and sexual violence as a weapon of war; domestic violence; intimate partner violence; and abuse of sex workers. The risk of HIV transmission increases with the physical trauma of coercive sexual intercourse.

Women also risk being subjected to violence and abuse upon disclosing their HIV status, especially when they are the first to be diagnosed and are blamed for bringing the virus into the household. "When women are infected with HIV they often face physical and emotional violence," said Ludfine Anyango, a woman living with HIV and the national HIV/AIDS coordinator of ActionAid Kenya. "As a result, they can be abandoned by their families and ostracized by their communities."[24] These factors increase the likelihood that a woman would engage in high-risk behavior, such as transactional or commercial sex, in order to fend for herself and her family, thus increasing the risk of infection.

Studies have linked intimate partner violence and HIV/AIDS. A report by Horizons found that "a serious barrier to disclosure for women is fear of a violent reaction by male partners and that HIV-infected women are at increased risk for

[22] Ibid., pp. 1097–1098.
[23] Interview with Sophia Mukasa Monico, Global Health Council, Washington D.C., October 29, 2003.
[24] UNAIDS, "Studies find women, girls more vulnerable to infection" (press release), February 5, 2004, http://allafrica.com/stories/200402060020.html.

partner violence."[25] The report found that many women lack autonomy in decisions about HIV testing and are compelled to seek permission from their partners. Partner violence is a serious problem for many female clients at VCT centers, with 38.5 percent reporting that they had had at least one partner who had physically abused them and 16.7 percent reporting at least one partner who had sexually abused them. Regardless of their HIV status, few said that their male partners would agree to be tested.[26] The study concludes, "HIV-infected women were significantly more likely to have had a physically violent partner in their lifetime and to have experienced an episode of physical and sexual violence with their current partner…the likelihood of reporting violence among younger (<30 years) HIV-positive women was ten times higher than among younger HIV-negative women."[27]

A short course of ARVs, known as post-exposure prophylaxis (PEP), has been shown to be an affordable and feasible intervention to reduce the risk of HIV transmission in cases of rape where the perpetrator is or could be HIV positive (and is also used for occupational exposures to HIV, such as needle-stick injuries to health care workers). However, widespread lack of information about, and availability of, PEP in most severely affected countries means that rape continues to pose the threat of HIV infection and ultimately death.[28]

ARV Programs in Botswana and South Africa

There are few examples of developing countries making the financial and political investment to extend ARV treatment beyond the privileged few, with Brazil being the first—and until 2002 the only—developing country to guarantee universal access to treatment.[29] Botswana—a country with 38.8 percent prevalence,[30] the highest in the world, but also a middle-income country benefiting from mineral wealth and good governance—was the first country in Africa to offer ARVs through the public health system. This program has been made possible through a joint initiative of the government of Botswana, the Bill and Melinda Gates Foundation, and the Merck Company Foundation, known as the African Comprehensive HIV/AIDS Partnerships (ACHAP). Other partnerships include a collaborative research partnership between the Botswana Ministry of Health and

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[25] Suzanne Maman et al., *HIV and Partner Violence: Implications for HIV Voluntary Counseling and Testing Programs in Dar es Salaam, Tanzania* (New York: Horizons and the Population Council: February 2001), p. 1.
[26] Ibid., p. 4.
[27] Ibid., p. 30.
[28] Human Rights Watch, *Policy Paralysis*, p. 27.
[29] Brazil guaranteed universal and free access to ARVs by presidential decree in November 1996.
[30] UNAIDS, UNICEF, and WHO, *Botswana: Epidemiological Fact Sheets on HIV/AIDS and Sexually Transmitted Infections, 2002 Update* (New York: UNAIDS, 2002).

the Harvard AIDS Institute, and one between the government and the Centers for Disease Control and Prevention to set up VCT sites across the country.[31]

Despite the realities of stigma and discrimination, data from Botswana indicate some promising developments that may help address obstacles to treatment. Although the uptake in testing and treatment has been slower than expected, more women than men are accessing VCT and treatment services. Approximately 11,000 patients are on ARVs, with 6,000 in Gaborone, of whom 57 percent are female. In the other nine sites, 70 percent are female.[32] The fact that more women than men are being tested seems to be linked to referrals from MTCT programs or antenatal clinics, to more women practicing health seeking behavior, and generally to being more accustomed to public health services. In addition, women are increasingly organizing to provide care and support services in nongovernmental and community-based organizations.

However, the subordinate status of women,[33] combined with the ongoing stigma surrounding HIV, continues to be a driver of the AIDS epidemic in Botswana. Joy Phumaphi, the former minister of health of Botswana and currently assistant director general for family and community health of WHO, described the uptake in VCT services by women as "a positive effect driven by a negative catalyst,"[34] referring to the higher infection rates among women and girls.

Some analysts see the slow uptake in testing and treatment in Botswana, especially among men, as linked to a lack of entry points for men in the health care system. Ernest Darkoh, operations manager for the ARV Project of Botswana's Ministry of Health, reflected on the gender dynamics in Botswana, especially relating to men and boys: "There are more interfaces with the health care system for women—birth, reproductive health, children—there are more entry points. There is basically nothing for men. We need a men's health movement."[35] This raises additional concerns about backlash among men against HIV testing and treatment programs that they perceive as being overly focused on women.

The program being run by MSF in Khayelitsha, South Africa, provides another example of women accessing treatment in greater numbers than men. MSF reports that 650 patients are on treatment, and the majority (70 percent) are women, mainly because the program is connected to an MTCT site.[36] Some analysts note that the selection criteria set up in Khayelitsha favored women, since clients had to show that they were stable, lived in a family setting, arrived

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[31] J. Stephen Morrison and Heather Hurlburt, *Botswana's Strategy to Combat HIV/AIDS: Lessons for Africa and President Bush's Emergency Plan for AIDS Relief*, a conference report of the CSIS Task Force on HIV/AIDS (Washington, D.C.: CSIS, January 2004).
[32] Information supplied by ACHAP, e-mail correspondence, January 21, 2004.
[33] Morrison and Hurlburt, *Botswana's Strategy to Combat HIV/AIDS.*
[34] Telephone interview with Joy Phumaphi in Geneva, Switzerland, October 8, 2003.
[35] Telephone interview with Ernest Darkoh in Gabarone, Botswana, November 6, 2003.
[36] Rachel Cohen, "Positive Replication: The MSF Experience Providing HAART in Developing Countries," ICRW/GAAN meeting on U.S. Strategy for Rapid Scale-up of ARV Treatment, Washington D.C., December 12, 2003.

for medical appointments, and were willing to disclose their status to someone, even if not to their partner. In general, women had an easier time fitting these criteria than men. It is important to note that data on the total number of women versus men receiving treatment are incomplete: as a study from the University of Cape Town points out, men are more likely than women to have access to private, rather than public, health care services.[37]

In September 2003, MSF opened a rape clinic linked to its HIV program. It provides follow-up services for rape survivors, including PEP, pregnancy tests, and HIV tests, as well as referrals to specially assigned police investigators.[38] The clinic has begun to receive both children and adults referred from the acute rape center.[39] As of February 2004, the clinic had received 105 cases: 75 were girls under 14 years old; 76 were tested for HIV; 37 received PEP. Speaking at a CSIS panel on gender and treatment, Rachel Cohen, U.S. director of MSF's Campaign for Access to Essential Medicines, said that MSF is working to ensure that responding to sexual violence and HIV/AIDS becomes an increasingly important part of their programs, stating that "the alarming rate of sexual violence demands a radical reaction from care and treatment providers in addition to local authorities and others."[40] This initiative to integrate broader services for women as a component of treatment is an interesting development that could serve as a model for other programs.

The treatment programs in Botswana and South Africa demonstrate that women can indeed be reached with treatment regimens, provided they have opportunities to access the public health care system and provided that adequate referral systems are in place. Further, in an enabling environment, women are willing to proactively organize around systems of support and care at the community level. A critical challenge, then, is to expand opportunities for interaction with the health care system and use available entry points and referral mechanisms to provide more comprehensive services for HIV-positive women, including counseling, social and economic support services, and safe shelters for women. These experiences underscore that outreach should be expanded beyond pregnant women to include nonpregnant women, adolescent girls, women visiting family planning and reproductive health centers, youth clinics, and sex workers.

It is still unclear whether the experience of treatment programs in Botswana and South Africa can be replicated in other acutely affected countries, especially those where women face greater obstacles in accessing health care, where public health infrastructure is less developed, and where cost-sharing issues may be more

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[37] Helen de Pinho, *Report on a Workshop on Gendered Experience of People Who Are HIV Positive, 26-27 May 2003* (Cape Town: Women's Research Unit, School of Public Health and Family Medicine, University of Cape Town, 2003), pp. 4–5.
[38] Telephone interview with Bettina Schunter, deputy head of mission, MSF South Africa, October 21, 2003.
[39] E-mail correspondence from Bettina Schunter, MSF South Africa, February 6, 2004.
[40] Rachel Cohen, presentation at CSIS HIV/AIDS Task Force panel on gender and treatment, Washington, D.C., February 12, 2004.

pronounced. Accordingly, equal access by women and girls should be factored into the development of appropriate eligibility criteria for treatment.

MTCT Programs

One of the earliest effective medical interventions focused on the prevention of mother-to-child transmission to stop the transmission of the virus from an HIV-positive mother to her child during pregnancy, labor and delivery, and breastfeeding. The risk of vertical transmission is about 15 to 30 percent during labor and delivery, and an additional 5 to 15 percent if the child is exclusively breastfed, with the percentage rising if breastfeeding is mixed with other feeding liquids or solids.[41] An estimated 700,000 infants and children became infected with HIV in 2003, the overwhelming majority infected through MTCT.[42]

In the last few years, great progress has been made in the prevention of mother-to-child transmission. Low-cost and effective ARV treatment procedures are now available, including single doses of nevirapine that can cut the risk of transmission to the child in half.[43] Still, many challenges remain in implementing the package of specific interventions to prevent MTCT in developing countries. Many women do not have access to adequate antenatal care or to information and counseling about HIV, and important issues remain related to securing their consent. These issues were raised in a WHO consultation on integrating gender into HIV/AIDS programs: "In some cases, the priority is placed on preventing transmission to the unborn child without regard for the rights of the mother to be informed and choose appropriately what is best for her and her child. This may include loss of choice over whether to be tested for HIV, whether to accept a MTCT intervention and to prevent MTCT if it is available, or whether to freely choose pregnancy termination."[44]

A study of MTCT programs in six African countries found that fear of ostracism and domestic violence were among the reasons that women refused to be tested or did not return for their results. Similarly, the social constraints against avoiding breastfeeding are strong, since breastfeeding is seen as an integral part of motherhood, and artificial feeding as opposed to breastfeeding has become associated with being HIV positive.[45]

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[41] International Center for Research on Women, *Community Involvement and the Prevention of Mother-to-Child Transmission of HIV/AIDS* (Washington, D.C.: ICRW, 2002).
[42] WHO, *Antiretroviral Drugs and the Prevention of Mother-to-child Transmission of HIV Infection in Resource-constrained Settings*, recommendations for use, draft version for public consultation (Geneva: WHO, January 2004), p. 1.
[43] Allan Rosenfield, M.D., Dean, Mailman School of Public Health, Columbia University, "Testimony before the Committee on Health, Education, Labor and Pensions, U.S. Senate," April 11, 2002.
[44] Geeta Rao Gupta, Daniel Whelan, and Keera Allendorf for the International Center for Research on Women on behalf of the World Health Organization, *Integrating Gender into HIV/AIDS Programmes: Review Paper for Expert Consultation, 3-5 June 2002* (Geneva: WHO, 2002), p. 11.
[45] Ibid., pp. 11–12.

A benefit of MTCT programs is that they provide an opportunity to identify HIV-infected women who need access to broader care, treatment, and support.[46] It is clear that care, treatment, and support of the mother contributes to the protection and well being of the child, and that the survival of the child is compromised if the mother dies.[47] The importance of integrating services is evident from the MTCT experience, since women identified in MTCT clinics should also receive infant feeding counseling and support, especially for those who breastfeed, and these counseling sessions can also be used to provide information about family planning and maternal and child health, as well as other social and legal referral services. Unfortunately, counseling has been the weak link in many of these programs, and the rapid scale up of training of counselors that was promised in the early years of VCT have yet to materialize.[48]

The opportunity to extend care and treatment to the HIV-positive mothers identified through MTCT programs has led to various pilot projects to treat the mothers. One such program is the MTCT-Plus Initiative,[49] which adds treatment and care to HIV-infected mothers and families. MTCT-Plus aims to get to women early, hopefully slowing their progression to AIDS and extending their lives, and thereby reducing the suffering of their children. The program is expected to be multidisciplinary, with referrals to community organizations, income-generating activities, family planning, and support groups.[50] The MTCT-Plus Initiative rolled out its first programs in February 2003, so data are still limited, but over 2,000 individuals were enrolled as of early 2004: 75 percent were women who had been enrolled in MTCT and were subsequently enrolled in MTCT-Plus; 24 percent were their partners; 1 percent were others in the household. About 35 percent were eligible for ARVs, indicating that women tend to be younger and healthier in antenatal care but that higher rates of infection are expected in the general population.[51]

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[46] A study from Thailand released on February 9, 2004, at the 11th Annual Conference on Retrovirus and Opportunistic Infections indicates that women who take a single dose of nevirapine as part of the MTCT intervention may develop resistance to that important antiretroviral medicine. This finding could have serious implications for ARV treatment in developing countries, since nevirapine is one of the three first-line therapies recommended by WHO, and especially for women participating in MTCT programs. WHO said that it has no plans to change its recommended drug therapy and called the findings of the study inconclusive. See Lawrence K. Altman, “Infant Drugs for H.I.V. Put Mothers at Risk,” *New York Times*, February 10, 2004.

[47] WHO, *Strategic Approaches to the Prevention of HIV Infection in Infants: Report of a WHO Meeting, Morges, Switzerland, 20-22 March, 2002* (Geneva: WHO, 2003) p. 13.

[48] E-mail correspondence with Joanne Csete, director of HIV/AIDS and human rights project, Human Rights Watch, January 22, 2004.

[49] The MTCT-Plus Initiative is a new HIV/AIDS treatment program coordinated by the Mailman School of Public Health at Columbia University. See http://www.mtctplus.org/.

[50] Interview with Wafaa El-Sadr, director, MTCT-Plus Initiative, Mailman School of Public Health, Columbia University, December 16, 2003.

[51] Presentation by Thomas W. Hardy, associate director, MTCT-Plus Initiative, Mailman School of Public Health, Columbia University, at ICRW/GAAN meeting on U.S. Strategy for Rapid Scale-up of ARV Treatment, Washington D.C., December 12, 2003; presentation at CSIS HIV/AIDS Task Force panel on gender and treatment, Washington, D.C., February 12, 2004.

Need for Community Mobilization and Support for Civil Society Organizations

Community involvement and mobilization, including that of people living with HIV/AIDS has proven to be an essential element in an effective and sustainable response to HIV/AIDS. This means involving civil society organizations from the outset in designing and implementing HIV/AIDS programs focusing on prevention, treatment preparedness and literacy, gender, orphans and vulnerable children, and adherence support. In programs around the world, community mobilization has been shown to reduce stigma and discrimination, to relieve the burdens on the health care system, and to help provide better treatment, care, and prevention services. Indeed, one of the challenges to scaling up treatment programs is responding to the broader needs of the affected communities, including management of opportunistic infections and psychosocial support.

Ample evidence supports this strategy. For example, a key element of the MSF program in Khayelitsha focused on community involvement in treatment literacy and advocacy. MSF found that the mobilization of the community served to increase prevention, reduce stigma and discrimination, increase adherence, and pressure the government to increase access to treatment.[52] Similarly, the International HIV/AIDS Alliance found that community engagement was critical for the effective delivery and support for ARV treatment and that such engagement has been an indispensable element in reducing stigma, relieving the burden on the public health system, supporting good treatment and prevention outcomes, and building social capital in communities. The alliance uses community-based delivery models and seeks to involve the community in the planning and implementation of treatment programs.[53] In Haiti, Partners in Health and its Haitian partner organization, Zamni Lasante, developed the country's first community-based HIV-treatment program.[54] Its TB project pioneered the use of community health workers, largely peasant farmers, to provide assistance to patients to pay for food, childcare, and transportation to medical appointments.[55]

In resource-poor settings, wider public debate will be critical to focus on treatment access and equity issues, such as gender; rural versus urban; children, including orphans and other vulnerable children and street kids; sex workers; and other populations at risk. Community engagement, and the accompanying support for civil society groups, will be an essential element in addressing these issues.

At this time of increased national and international engagement on HIV/AIDS, there is reason to hope that the new resources will also strengthen the

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[52] Cohen, "Positive Replication."

[53] Presentation by Mandeep Dhaliwal, International HIV/AIDS Alliance, "Community Engagement and Support for Effective Delivery of ARV Treatment," at ICRW/GAAN meeting on U.S. Strategy for Rapid Scale-up of ARV Treatment, Washington D.C., December 12, 2003.

[54] International HIV Treatment Access Coalition, *A Commitment to Action for Expanded Access to HIV/AIDS Treatment*, (Geneva: WHO, 2002).

[55] Tracy Kidder, *Mountains Beyond Mountains: Healing the World: The Quest of Dr. Paul Farmer*, (New York: Random House, 2003), p. 35.

structures of societies and communities that have been devastated by the epidemic. From building public health infrastructure and reaching development goals, to addressing the root causes and not just the symptoms of women's subordinate status, to ensuring accountability in political leadership, an effective response to the AIDS crisis will depend on progress in meeting these challenges.