



## *Gender, AIDS, and ARV Therapies: Ensuring that Women Gain Equitable Access to Drugs within U.S. Funded Treatment Initiatives*

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### **Submitted to the Office of the Global AIDS Coordinator**

On February 20<sup>th</sup>, 2004, the Office of the Global AIDS Coordinator at the U.S. Department of State will make public the draft strategy guiding implementation of U.S. global AIDS policies authorized by the United States Leadership Against AIDS, TB, and Malaria Act of 2003 (“AIDS Act,” P.L. 108-25). The law tasks the Global Coordinator with developing programs to provide antiretroviral (ARV) treatment to at least 2 million individuals by the end of 2006 (with a goal of reaching 500,000 people with ARV treatment by the end of 2004) (AIDS Act §402 (a)). In support of the Coordinator’s strategy, Congress has provided \$2.4 billion for global AIDS initiatives in 2004 (Consolidated Appropriations Act, 2004, P.L. 108-199) and directs that 55% of these monies be used for the treatment of individuals with HIV/AIDS (AIDS Act §402(b)(1)).

Even with increased commitment, funding, and coordination, U.S. AIDS treatment efforts will fall far short of what is needed to provide ARV treatment even to a significant minority of suffering from AIDS today. Currently, there are an estimated 40 million people living with HIV worldwide. In sub-Saharan Africa, where an estimated 4.1 million people are infected with HIV, only 50,000 currently have access to treatment (Attawall and Mundy 2003). The U.S. initiative therefore represents only a modest beginning to what must be an international commitment to prevent and treat HIV and AIDS.

Given limited resources, choices will inevitably be made about who will be treated and when, raising the issues of equity in access to treatment for sub-groups of those infected. In turn, these considerations dramatically underscore the need for specific efforts to ensure that treatment programs reach those groups – namely women and girls and other vulnerable populations, such as sex workers and men who have sex with men – which, due to social, economic, and cultural discrimination and lack of access to health care, already face a disproportionately higher risk of infection. Today, for example, women represent more than half of those infected with HIV worldwide, and more than 60 percent of those infected in sub-Saharan Africa (UNAIDS 2003). In many countries, the rate of new infections is highest among married women and adolescent girls. The failure to understand and address the barriers to treatment access faced by women and girls will undermine investments made by the United States to seek long-term and sustainable solutions to the global HIV/AIDS epidemic.

To ensure that U.S. global AIDS strategies promote justice and equity and reflect international consensus on the ethical principles guiding access to health care, the United States must take proactive steps to address the barriers to access faced by women. There is no consistent formula for ensuring equity in access to treatment given scarce resources. At the same time, a set of standard considerations, guidelines or questions can and must be formulated and applied within each setting to ensure that concerns for gender equity and social justice are incorporated into treatment access schemes. Such guidelines can be used to ensure consistent application of ethical principles to treatment access, while reflecting specific circumstances, and should be carefully reviewed on a regular basis in response to changes in the dynamics of the epidemic or as treatment access expands. Through literature review and field research, we have identified the following essential elements of a gender-sensitive approach to treatment access.

## 1. Expand Eligibility Criteria

### **Ensure that eligibility criteria reflect both biomedical and socio-economic vulnerabilities:**

The current eligibility criteria suggested by the World Health Organization (WHO) indicates that priority for access to treatment should be given to those who meet certain biomedical markers, i.e. those with a CD4 cell count below 200, or, where facilities for monitoring CD4 cell counts are lacking, those whose symptoms reflect accepted clinical diagnoses. In most countries, the tests needed to ensure accurate and consistent readings of CD4 cell counts are not widely available. Moreover, given limited access to ARVs overall, only a small share of those in resource-poor settings who have access to such diagnostics and meet established criteria will actually gain access to treatment (Attawall and Mundy 2003). In sub-Saharan Africa today, for example, only 50,000 out of an estimated 4.1 million people in need of ARV treatment actually have access to drugs (Attawall and Mundy 2003).

While efforts to expand access to treatment overall are therefore obviously critical, using only standard criteria will not address barriers to access faced by women and other vulnerable groups. Specific steps must be taken to consider the non-medical barriers faced by those most vulnerable to HIV infection and to AIDS. For example, evidence shows that women are less likely than men to have access to or control over income within families, and as a result, are less likely to be able to pay for primary, secondary, or tertiary care (Nanda 2002). In some settings, women cannot seek care without the permission of their husbands. Moreover, in many countries, scarce health resources are preferentially invested in some members of a family over others (i.e. in men over women and boys over girls), simply because of their sex and lower social status. As a result, women have less access to diagnostic and testing services overall, and so the disease burden they carry may not be as readily apparent even when accepted criteria for determining priority access are applied across a community.

Overwhelming evidence on access to care drawn from nearly four decades of research in developing countries shows how profoundly socioeconomic and health systems barriers can affect women and other vulnerable groups. The many barriers to care are systemic within resource-poor health care systems and can affect real demand for treatment. Bias and discrimination perpetuated by health workers against

specific groups or individuals, for example, reduces the willingness of individuals to seek care. Treatment and care-seeking is also affected by lack of adequate staff or facilities to ensure real access; poor logistics for distribution of drugs and shortages of supplies in clinical settings; long distances to facilities and lack of access to transportation to appropriate health facilities; stigma, denial, and misinformation; high costs of drugs and imposition of user fees; and lack of medical insurance schemes (Nanda 2002). All of these barriers affect women disproportionately, and unless addressed effectively, will reflect on both apparent demand for drugs and access to treatment. Distortions in women's treatment and care-seeking will exist even when ARV treatment is made more widely available and when eligibility criteria indicate treatment for large numbers of people.

Women's lack of access to preventive and curative health care undermines their critical role in sustaining healthy families and communities. In Africa, for example, mothers are key actors in ensuring child health and survival and in providing food and other needed goods for domestic consumption. Women today also bear the major burden of providing care to those afflicted with AIDS. Without a specific focus on removing barriers to access, and despite best intentions, gender disparities will keep women at a disadvantage from gaining access to treatment.

The eligibility criteria developed by the United States for expanding access to treatment must go beyond the purely biomedical to recognize the effect of gender inequities at the household and community level on women's access to treatment. Broader criteria must be developed for use at the country level to reflect and address existing disparities and ensure that women get equal or proportional representation among the selected eligible participants in ARV programs. Any and all criteria should be consistently reviewed at the country and regional level to ensure that they reflect the changing dynamics of the epidemic in any given setting.

### **Ensure that eligibility criteria do not discriminate against women depending on their pregnancy status nor focus on women only in relation to their pregnancy:**

Increasing women's access to ARVs overall is critical and should not be based solely on pregnancy status. In some settings, including Botswana, Kenya, and Zambia, ARVs are being introduced through a multiple entry approach, which increases access through parental/maternal to

child treatment (PMTCT) as well as through regional or district hospitals (Attawall and Mundy 2003). Increasing families' access to treatment through provision of care to pregnant women does not ensure that barriers to access faced by non-pregnant women in the broader population are being addressed. For example, efforts to expand access to treatment may accord high priority to pregnant women through PMTCT programs, but may simultaneously neglect a large pool of infected non-pregnant women, who are unable (for reasons articulated elsewhere in this paper) to gain access to treatment at other entry points (Attawall and Mundy 2003). Additionally, increased access for pregnant women for PMTCT *must* be coupled with sustained treatment for the individual women themselves, and not solely to prevent transmission to an infant.

Special efforts must be made to remove barriers to access for adolescents girls—whether or not they are pregnant or married. In many countries, adolescent girls are at highest risk of infection and yet have the lowest levels of social and economic status, and the least power to demand access to therapy. Legal barriers, such as age of consent laws and other means of “protecting” adolescents, may actually further undermine girls' access to life-saving information, services, and therapies.

***Ensure that criteria and processes for expanding access to treatment are transparent and accountable to communities in question:***

The criteria for deciding who gets access to treatment and when must be transparent to and easily understood by the communities involved. HIV/AIDS programs must make clear that not everyone will benefit immediately from ARV treatment. The rationale used to make decisions regarding the allocation of scarce resources must be widely accepted. When a program for ARVs is implemented at the community level, decisions and criteria for treatment must involve people affected by HIV/AIDS and likely to be participating in treatment access programs.

***Develop equitable pricing for drugs:*** Dual pricing, i.e. fee-based and/or subsidized health care, and partial pay systems, are often employed by governments to promote increased access to drugs in a sustainable and affordable manner. Careful attention must be paid to implementation of these pricing structures and related regulations. Specific questions that must be addressed include which groups will receive free therapy, which will receive therapy at subsidized prices, which will self-

pay, and how pricing structures will be applied throughout the health sector. Given their limited access to income and other productive resources, women are less likely to be able to participate in self-pay schemes, even with subsidized prices. Evidence indicates that without clear and careful application, subsidies for drugs and other health care services often do not fully benefit their intended target groups and, as a result, can become unsustainable over time (Nanda 2002). Both the levels of subsidies and the eligibility criteria for subsidized ARVs should be clear and targeted to those most in need, with established measures for ensuring accountability of pricing at the source of drug disbursement.

***Ensure drug adherence programs are gender-sensitive:***

Evidence shows that within the home and community, stigma, fear, and misinformation can affect adherence to drug regimens. In Botswana, Kenya, and Zambia, for example, women report returning drugs provided to them for treatment because of opposition to their use from husbands, or, in the case of pregnant women, misconceptions that drugs can harm the fetus (Attawall and Mundy 2003). Programs to scale up ART will need to address these and other barriers women face. Assessments of adherence for treatment should also recognize that time constraints related to domestic and family responsibilities are a major limiting factor in women's ability to sustain access to and maintain treatment for illness. Studies in many settings show that women have been unable to make effective use of existing primary and secondary health care services because these services' hours of operation and staffing patterns do not account for women's work and domestic schedules or responsibilities, or lack of access to reliable transportation (Kumar et al 2003). Other obstacles to access, such as the need for privacy and confidentiality in accessing care, are similarly not addressed (Kumar et al 2003). Not surprisingly, the best results for adherence rates are evident in pilot programs, such as those in South Africa and Kenya, where all groups within a community have a voice in selection of beneficiaries and in supporting sustained access to therapies (Attawall and Mundy 2003).

***2. Ensure that ART Programs Enhance the Capacity of Health Systems***

***Ensure that capacity and infrastructure of primary health systems is developed and improved:***

Today, HIV/AIDS is having a profound negative impact on health systems that are underfunded and under-staffed. The HIV epidemic is

increasing demand for diagnosis, testing, treatment and care and increasing the burdens on health staff at a time when there is increased flight of health professionals from the public sectors in many countries (due to poor salaries, absenteeism, and government freezes on employment due to budget constraints). With adequate investment in infrastructure, human resources, and logistics systems, expanded ART programs may help strengthen health systems overall, thereby improving the picture for health over the long term. Such an effort would enhance the commitment and morale of health workers, improve the referral system and improve outcomes for non-HIV related care and treatment (Attawall and Mundy 2003). Conversely, ART programs could further undermine health systems by drawing funding away from primary health care, and further accelerating the broader decline in the health care system, especially if resources for ART programs are deployed selectively and vertically through tertiary health care units. Erosion in the health care system further exacerbates the barriers to access already faced by women and other vulnerable groups.

**Invest in quality of care and efforts to eliminate bias within the health care system:** Improved quality of care is a critical aspect of ensuring long-term success of ART programs. Recent research suggests that at the current rate of attrition, over the next ten years there will be a shortage of 20,000 nurses in South Africa (Attawall and Mundy 2003). Many facilities already lack trained staff, equipment, drugs and supplies, and back-up systems. These factors signal a danger for a potential rise in the spread of incomplete ARV therapy, increasing the risk of toxicity and drug resistance.

Quality of care also affects women's access in direct ways. For example, given that women often face high levels of stigma, discrimination, and even violence in revealing their HIV status (UNICEF and Panos 2001), concerns about privacy and confidentiality in access to and delivery of health services are critical determinants both of the quality of and access to care. Likewise, discrimination against those infected is often perpetuated by the very health care providers that are the gatekeepers for access to care. In India, several studies show that those infected with HIV, especially HIV positive women, face stigma and discrimination in health care settings in various ways (UNICEF and Panos 2001). Among other things, these included mandatory testing without informed consent of those undergoing surgery and of pregnant women, refusal to admit HIV-infected persons to hospitals or to treat HIV-positive persons, physical isolation of HIV-positive persons, early

discharge from the hospital, and refusal to assist or operate for clinical procedures (Bharat, Aggleton and Tyrer 2001; UNICEF and Panos Institute 2001).

To ensure the levels of quality of care essential to success of ART programs, plans to scale-up ART should include specific and sustained investments in providing adequate physical infrastructure; expanding identification and management of HIV-related illnesses; addressing problems with side effects of drugs; expanding accessibility of safe counseling services; increasing availability of laboratory services; investing in staff training and sensitization; improving quality assurance for drugs; incorporating community involvement in monitoring and evaluation of these efforts; and addressing stigma and discrimination perpetuated by health care providers.

**Expand safe and gender-sensitive counseling services as a part of treatment and prevention programs:** Gender power inequities, low decision-making power, and limited mobility within the household affect women's ability to seek health services. As ART programs are expanded, investments must be made to simultaneously expand intensive and interactive counseling models that address risks, such as the heightened exposure to partner violence, related to disclosure of HIV status. Effective counseling is also critical to help maintain adherence, face stigma, identify and link people to referral and support services as well as to build overall community support. Recent studies show that uptake and adherence levels are lower in communities where these issues were not proactively addressed (Attawall and Mundy 2003). Treatment uptake and adherence are higher in those settings, such as in Brazil and Khayelishta, South Africa, where intensive counseling and the involvement of people living with AIDS in community mobilization have helped overcome barriers to uptake and adherence to treatment (Attawall and Mundy 2003). Given existing constraints in public health infrastructure – staff vacancies, high workload, inadequate supervision and support of counselors and inadequate training – resources must be invested in these areas.

**Ensure equity in access to ARV therapy through more sensitive health-financing mechanisms:** User fees are the most common health financing strategy used in most developing countries. But there is now ample evidence that user fees are regressive because they hurt the poor disproportionately (Nanda 2002). Even where the poor are technically or officially exempt from fees, such exemptions are, in reality, often not made in

practice at the clinic or individual level. Health care providers, often working with very minimal resources, sometimes lack accurate information about who is exempt from fees, and sometimes charge fees informally as a way of supplementing clinic or personal income. In such resource-constrained environments, staff often receive low salaries and sometimes go for months without being paid, such as has been documented in Zambia (Nanda 2000). In these cases, even if ARV therapy is provided freely, fees may still be levied on those individuals selected for ARV.

Evidence shows that such fees will in turn affect uptake of and adherence to drug regimens, in part because they force the poor to make trade offs in paying for food and shelter as opposed to medicines (Attawall and Mundy 2003; Nanda 2002). Efforts must be made to rationalize or completely eliminate user fees, to ensure accountability in application of such fees, and to strengthen drug supplies and logistics to reduce or eliminate de facto payment for “free” drugs at the clinic level.

**Address gender inequities in health staffing and personnel policies:** Health systems and the hierarchy of health personnel mirror the same gender inequities that exist in society at large. For example, research conducted by the Center for Health and Gender Equity (CHANGE) in India indicates that female VCT counselors were co-opted by senior doctors into fulfilling the duties of other staff, including filling registers, maintaining records, and filling prescriptions. As a result, female counselors were often unavailable to offer counseling to women attending the VCT service (Amin 2004). The expansion of ART should include a focus on reforming legislation, regulations, and personnel policies that exacerbate inequities within the health sector itself. In addition, the flight of nurses from developing to developed countries needs to be addressed within the context of these inequities and vulnerabilities.

### **3. Make ART Part of a Continuum of Prevention, Treatment, and Care**

**Ensure ART services are provided within the context of integrated comprehensive health care:** ARV therapy needs to be part of a comprehensive approach to prevention and care services, including voluntary testing and counseling (VCT), PMTCT, diagnosis and treatment of opportunistic infections, and other prevention and social support services (Population Council 2002). Although there are examples of programs that have integrated ARV therapy into a

continuum of prevention and care, ARV programs must be included as part of a gender-sensitive multiple entry approach.

Ideally, the availability of ART will affect the HIV epidemic overall by providing incentives for people to seek HIV testing while simultaneously providing opportunities to reach a far greater number with prevention information. The referral, linkage and community outreach systems of public health systems in resource-poor countries, however, remain very weak. In many cases PMTCT, VCT and sexually transmitted infection services are operating as vertical and unlinked services, even within the same hospital or clinic setting (van Dam and Hutchinson 2001). Lack of effective linkages between these points of service leads to missed opportunities in referring clients to counseling or referring pregnant women for PMTCT services. Effective integration will especially benefit women who may be using only antenatal services or PMTCT care. Because women are more vulnerable to cultural and physical constraints in identifying and accessing health care (lack of cash, autonomy, mobility, stigma) there is a greater need to link services they use with prevention, counseling, treatment and other care. There is also an urgent need to increase investment in improving the capacity of health systems to absorb ARV therapy along the prevention and care continuum.

**Ensure all women and adolescent girls and boys have access to comprehensive reproductive and sexual services and education, including efforts to address gender-based violence:** Linking ARV therapy with prevention and care is both critical from a health perspective and represents an ethical and moral obligation. Reducing the rate of infection among women and girls will require linked prevention strategies that increase their ability to negotiate safe sex and increase their access to male and female condoms. Such efforts must also address gender-based violence, which data from throughout the world now confirm is a leading risk factor for HIV infection and is also a factor in access and adherence to drug therapies (UNAIDS 2003).

Expanded investments in family planning, maternal and child health and other related services are critical to the success of prevention and to treatment over the long run. Women need access both to HIV prevention information and technology as well as to other forms of information in order to make informed decisions about their health. CHANGE’s research in India indicates that majority of pregnant women clients are not diagnosed as HIV positive until after their fifth month of the gestation. In

some instances, women might have opted for safe abortion services but did not know their HIV status until too late in the pregnancy (Amin 2004). Other studies also conducted in India also document that in other cases, HIV-positive women experience coercion by health care staff to undergo abortion (UNICEF and the Panos Institute 2001). Lack of information and agency constrain women's ability to control the outcomes of their pregnancy in both directions. Women's basic human right to decide whether and when to bear children must be safeguarded.

**Ensure access to female controlled prevention technology:** Social and economic inequality and fear of physical and sexual violence leave millions of women unable to control the "if and when" of sex. For these same reasons, women cannot rely on husbands and partners to consistently use male condoms to prevent transmission of HIV and other diseases. Therefore, there is an immense need for female-controlled prevention technology for HIV. The resources invested in prevention, including strategies to address women's ability to control their own sexuality, will lessen the need for treatment programs in the future.

Consistent and correct use of the female condom is estimated to reduce the risk of sexually transmitted infection (including HIV) by between 94% and 97% per act of intercourse. Today, however, the high cost per unit of the female condom is a critical impediment to its increased access worldwide. The United States government is in a position to dramatically reduce the cost and simultaneously increase access to the female condom worldwide by making the female condom a core component of prevention strategies developed through USAID and other agencies—and by investing directly in access to the female condom and other female controlled mechanisms through bilateral and multilateral funding mechanisms.

Microbicides are currently under development. The AIDS Act authorizes a significant investment in microbicide research and development. The law requires that microbicides then be quickly disseminated to those who need them. Programmatic investment consistent with the Act will profoundly change the landscape of HIV prevention efforts, and, in the long run, dramatically reduce the costs of ARV treatment.

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