

Women and HIV/AIDS: Confronting the Crisis



A Joint Report by
UNAIDS / UNFPA / UNIFEM

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UNAIDS is the main advocate for global action on the epidemic. It leads, strengthens and supports an expanded response aimed at preventing HIV transmission, providing care and support, reducing the vulnerability of individuals and communities to HIV, and alleviating the impact of the epidemic.

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FRONT COVER: An AIDS awareness activist at a World AIDS Day march in Calcutta.

Photo by Deshakalyan Chowdhury—AFP/Getty

BACK COVER: A Brazilian student prepares a poster for World AIDS Day. *Photo by Evaristo Sa—AFP/Getty*

WOMEN AND HIV/AIDS: CONFRONTING THE CRISIS

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Women and
HIV/AIDS:

**Confronting
the Crisis**

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Acronyms

ART	antiretroviral therapy
CEDAW	Convention on the Elimination of All Forms of Discrimination against Women
CEE/CIS	countries of Central and Eastern Europe and the Commonwealth of Independent States
DOTS	directly observed therapy, short-course
FGC	female genital cutting
HEI	HIV Equity Initiative, Haiti
IAVI	International AIDS Vaccine Initiative
ICW	International Community of Women Living with HIV/AIDS
IPPF	International Planned Parenthood Federation
MaP	Men as Partners, a Southern Africa NGO
MDGs	Millennium Development Goals
MSF	Médecins Sans Frontières
MTCT	mother-to-child transmission
NGO	non-governmental organization
PAHO	Pan-American Health Organization
PEP	post-exposure prophylaxis
PMTCT	preventing mother-to-child transmission
SHAZ	Shaping the Health of Adolescents in Zimbabwe
STI	sexually transmitted infection
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNFPA	United Nations Population Fund
UNGASS	UN General Assembly Special Session (on HIV/AIDS)
UNICEF	United Nations Children's Fund
UNIFEM	United Nations Development Fund for Women
VCT	Voluntary counselling and testing
VSO	Voluntary Services Overseas, UK
WAR	Women against Rape, Botswana
WHO	World Health Organization

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Preface

HIV/AIDS is no longer striking primarily men. Today, more than 20 years into the epidemic, women account for nearly half the 40 million people living with HIV worldwide. In sub-Saharan Africa, 57 per cent of adults with HIV are women, and young women aged 15 to 24 are more than three times as likely to be infected as young men. Despite this alarming trend, women know less than men about how HIV/AIDS is transmitted and how to prevent infection, and what little they do know is often rendered useless by the discrimination and violence they face.

This report is an urgent call to action to address the triple threat of gender inequality, poverty and HIV/AIDS. By tackling these forces simultaneously, we can reduce the spread of the epidemic and its devastating consequences.

Women must not be regarded as victims. They are, in many places, leading the way forward. In communities scattered around the globe, women and men are taking action to increase knowledge about the disease, expand access to sexual and reproductive health and educational services, increase women's ability to negotiate safer sexual relations, combat gender discrimination and violence and increase access to female-controlled prevention methods such as the female condom.

All of these efforts, outlined in this report, are critical. As long as women and adolescent girls are unable to earn an income and exercise their rights to education, health and property, or are threatened with violence, progress on the AIDS front will pass them by. As the stories in this report attest, there is no limit to innovative practices. Strategies for survival are pioneered every day on the ground by women living with HIV/AIDS. The limitations lie elsewhere: in the painful shortage of resources—especially for women and women's issues—and in the shameful lack of political will to meet international commitments. For too many years, the voices and demands of women, particularly women living with HIV, have fallen on deaf ears. The world can no longer afford to ignore them. We must find the money needed for care and treatment for all. We must put an end to the stigma and discrimination

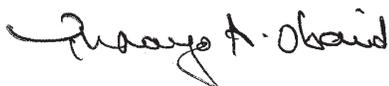
that limit women's access to treatment and leave them responsible for taking care of the ill and dying. We must make it possible for them to envision a future.

This report grows out of our shared belief that the world must respond to the HIV crisis confronting women. It highlights the work of the Global Coalition on Women and AIDS—a UNAIDS initiative that supports and energizes programmes that mitigate the impact of AIDS on girls and women worldwide. Through its advocacy and networking, the Coalition is drawing greater attention to the effects of HIV on women and stimulating concrete, effective action by an ever-increasing range of partners.

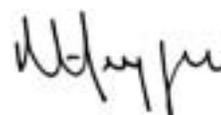
We believe this report, with its straightforward analysis and practical responses, can be a valuable advocacy and policy tool for addressing this complex challenge. The call to empower women has never been more urgent. We must act now to strengthen their capacity, resilience and leadership.



Dr. Peter Piot
Executive Director, UNAIDS

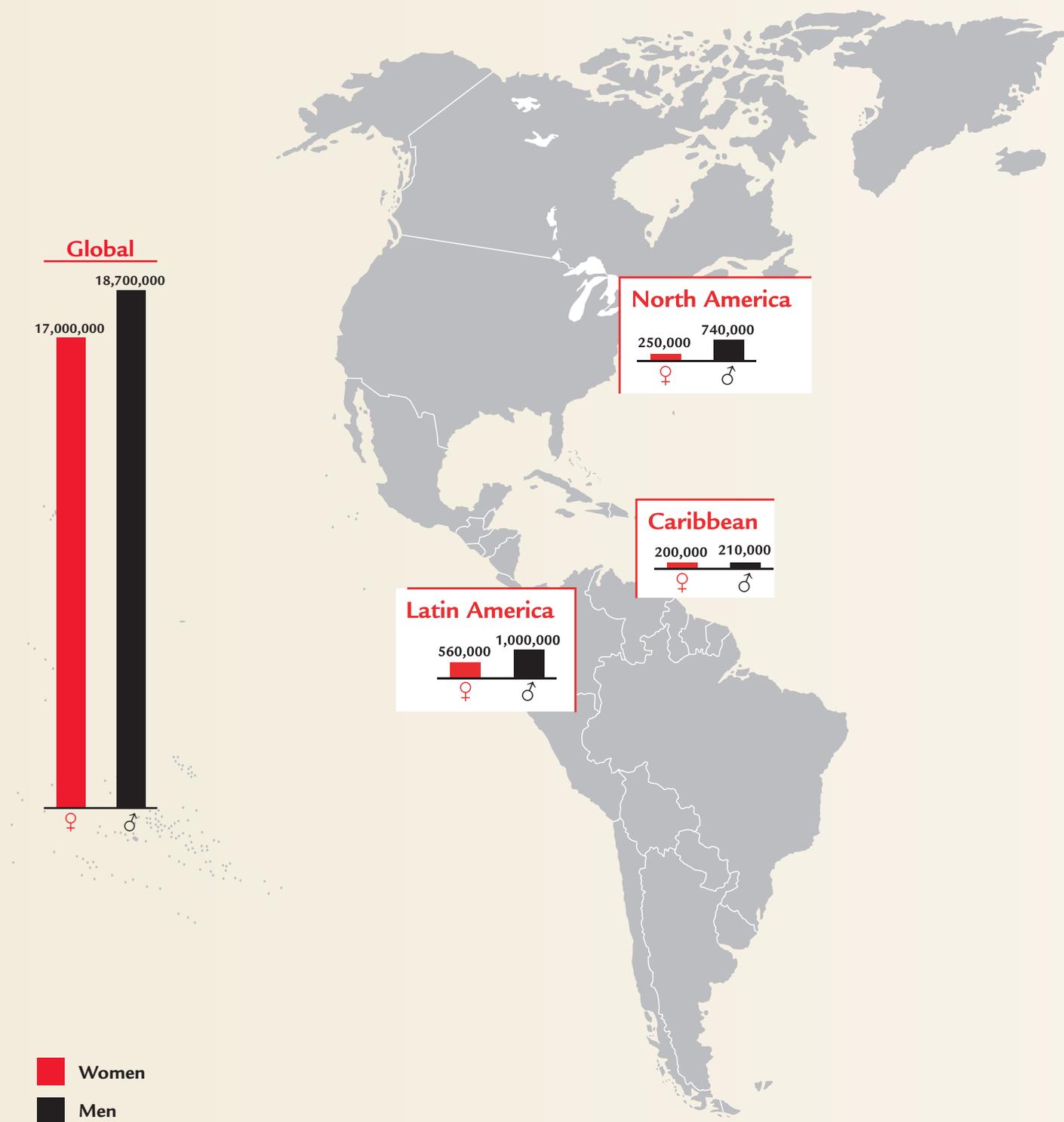


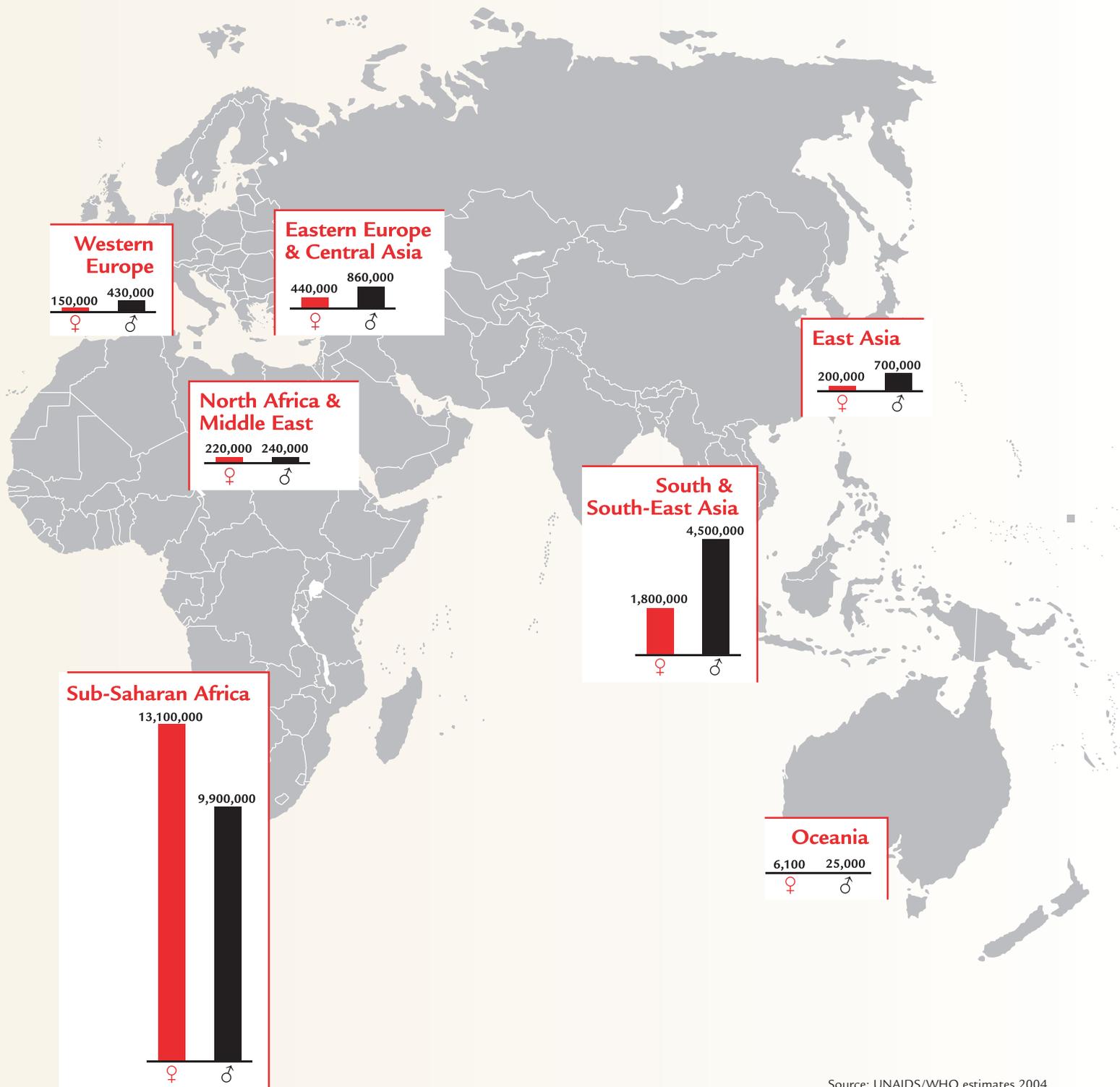
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Executive Director, UNIFEM

Estimated number of women and men (15-49) living with HIV/AIDS by region for 2003 (as of 21 June 2004)





Source: UNAIDS/WHO estimates 2004

Chapter 1

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CONFRONTING THE CRISIS

To reverse the global spread of HIV/AIDS, we must break the chains of poverty and gender inequality that help the disease to spread. All over the world, greater efforts are required to address the concrete needs of women and girls and to increase the roles and responsibilities of boys and men. It is critical at this point in the global pandemic that efforts focus simultaneously on individual behaviour change and on wider social, cultural and economic change. Realistic strategies must be found that address the triple challenge of poverty, gender inequality and HIV/AIDS.

Globally there are now 17 million women and 18.7 million men between the ages of 15 and 49 living with HIV/AIDS (see Map, p. vi-vii). Since 1985, the percentage of women among adults living with HIV/AIDS has risen from 35 per cent to 48 per cent. Of particular concern are the dramatic increases in HIV infection among young women, who now make up over 60 per cent of 15- to 24-year-olds living with HIV/AIDS. Globally, young women are 1.6 times more likely to be living with HIV/AIDS than young men.

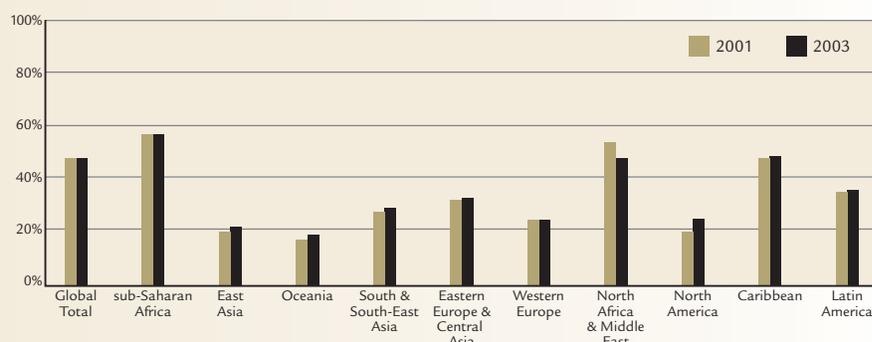
Gender and Regional Differences¹

The overwhelming majority of people with HIV/AIDS—98 per cent of women and 94 per cent of men—live in developing countries (see Map). Of all regions, sub-Saharan Africa is the most devastated. No other region in the world approaches its HIV prevalence rates or displays such a disproportionate impact on women and girls: 77 per cent of all HIV-positive women live in sub-Saharan Africa. However, some regions, such as the Caribbean and parts of Asia, are experiencing epidemics in several countries that are spreading

An 18-year-old Mozambican girl with her brothers. She has become the head of her family since both parents died from AIDS. In her local school, there are 200 orphans out of a thousand students.

CHART 1

Estimate of per cent of adults (15-49) living with HIV/AIDS who were female in 2001 and 2003



Source: UNAIDS/WHO estimates 2004

from particular population groups—such as sex workers or injecting drug users—into the general population, with women and girls increasingly affected. The distinct differences in regional trends in terms of modes of transmission and burden of disease—and the cultural, social and economic environments in which these exist—must be taken into account in helping regions, nations and local communities design effective interventions.

Sub-Saharan Africa

In sub-Saharan Africa, about 23 million adults aged 15 to 49 are infected, with 57 per cent—13.1 million—of them women (see Map). Since 1985, there has been an increasingly disproportionate impact on women

in this region (see Chart 2). In 1985, roughly half a million women and half a million men were living with HIV/AIDS in sub-Saharan Africa. Since then, the number of women living with HIV/AIDS relative to men has increased every year, particularly affecting young women aged 15 to 24, who are now more than three times more likely to be infected than young men.

HIV is spreading predominantly through heterosexual contact, which has increased the impact on women. This is seen most clearly in Southern Africa, where more than 20 per cent of pregnant women tested were infected with HIV in most countries in the region, with prevalence rates among

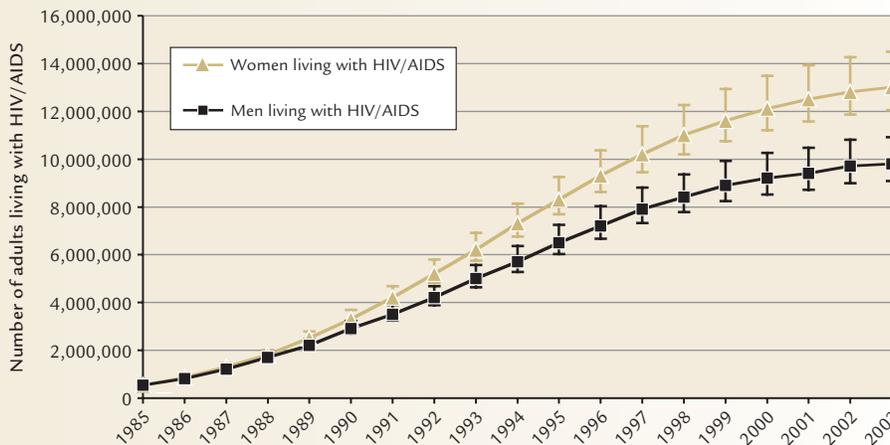
pregnant women in Botswana and Swaziland of almost 40 per cent. An analysis of data from antenatal clinics in eight countries shows that HIV prevalence may now be levelling off, although the numbers remain very high.

The United Nations Secretary-General’s Task Force on Women, Girls and HIV/AIDS in Southern Africa has identified three key factors that contribute to the greater vulnerability of the sub-region’s women and girls to HIV infection, each of which must be addressed:

- The culture of silence surrounding sexuality;
- Exploitative transactional and intergenerational sex; and
- Violence against women within relationships.

CHART 2

Estimated number of adult (15-49) women and men living with HIV/AIDS in sub-Saharan Africa over time (1985-2003)



Source: UNAIDS/WHO estimates 2004

All three factors must also be understood in the context of the poverty and inequalities that define the daily lives of both women and men in the region.

Asia and the Pacific

According to the United Nations, the Asia Pacific region, where more than 7 million people are living with HIV/AIDS (see Map), could become the epicentre of the global AIDS pandemic in the next decade, with China and India—the world's two most populous nations—facing a potential AIDS catastrophe.

In East Asia 22 per cent of adults living with HIV/AIDS are women, as are 28 per cent of young people aged 15 to 24.

In South and South-East Asia more than a quarter of adults and 40 per cent of young people living with HIV/AIDS are women. According to India's National AIDS Control Organization (NACO), HIV/AIDS is no longer confined to specific groups or urban areas but is steadily spreading into the wider population and rural areas. The number of adults living with HIV/AIDS in India is estimated at nearly 4 million.

In China, where the epidemic is spreading, the gap between the rates of HIV infections among men compared to those of women is narrowing.

Until now the mode of transmission in Asia has been mainly through injecting drug use and sex work. As a result, the prevalence of HIV/AIDS in most countries of the region has been restricted to groups with high-risk behaviour and has not spread to the general population. However this could change quickly. For example, injecting drug use and sex work are so pervasive in some areas of China that the epidemic could rapidly spread outside these groups to the wider population. Three Asian countries—Cambodia, Myanmar and Thailand—are already dealing with serious epidemics. All three have made efforts to prevent the spread of HIV by targeting high-risk groups, and to some degree they have succeeded. However there is also evidence that HIV transmission between spouses has become a more prominent cause of new infections.

Factors affecting the spread of HIV/AIDS among women and girls in the region are poverty, early marriage, trafficking, sex work, migration, a lack of education, and gender discrimination and violence. Breaking the culture of silence is critical. As in many regions, both industrialized and developing, complex social and cultural barriers have made talking about sexuality or insisting on protection from HIV so difficult that even educated middle class women say they are unable to protect themselves, while poor women have even less power to do so.

Eastern Europe and Central Asia

HIV prevalence has grown rapidly in this region. In 1995 relatively few cases were recorded but, by the end of 2003, about 1.3 million people were living with HIV/AIDS in the region (see Map). Over a quarter of a million people became infected in 2003 alone. The worst affected countries were the Baltic States (Estonia, Latvia and Lithuania), the Russian Federation and Ukraine, with serious outbreaks in Belarus, Kazakhstan and Moldova as well. Overall, women account for 33 per cent of people with HIV/AIDS in the region, and young women account for 28 per cent. Evidence suggests that their rates are increasing compared to men's. For example, in 2002 in the Russian Federation, 33 per

cent of newly diagnosed infections were among women, compared to 24 per cent a year earlier.

The social and economic upheaval that took place in the former Soviet Union in the 1990s has brought declining socio-economic conditions and increasing inequity throughout the region. The resulting sense of hopelessness among those left out of new market economies is fuelling HIV transmission through injecting drug use and unsafe sex. Because most drug users are young and sexually active, sexual transmission is also becoming a significant mode of HIV transmission.

Latin America and the Caribbean

Some 2 million people between the ages of 15 and 49 are living with HIV/AIDS in Latin America and the Caribbean, with 36 per cent women in Latin America, and virtually half (49 per cent) in the Caribbean. Young women are 2.5 times more likely to be infected than young men in the Caribbean. HIV prevalence has reached rates of 1 per cent or higher in the general population in at least 12 Caribbean and Central American countries (the Bahamas, Barbados, Belize, the Dominican Republic, Guatemala, Guyana, Haiti, Honduras, Jamaica, Panama, Suriname and Trinidad and Tobago).

In the Caribbean, the main mode of transmission is heterosexual; however in Puerto Rico, injecting drug use appears to be the main source of the epidemic. In South America, HIV is transmitted mainly through injecting drug use and from relations between men, with subsequent heterosex-

THE UN TASK FORCE ON WOMEN, GIRLS AND HIV/AIDS IN SOUTHERN AFRICA

In 2003, United Nations Secretary-General Kofi Annan convened a Task Force on Women, Girls and HIV/AIDS in Southern Africa, which identified key actions to reduce girls' and women's prevalence rates:

- 1** Collapse the bridge of infection between older men and younger women and girls;
- 2** Protect female enrolment figures—AIDS may be taking girls out of school;
- 3** Protect girls and women from the direct and long-term risks of HIV infection as a result of violence;
- 4** Protect the rights of women and girls to own and inherit land;
- 5** Put in place a Volunteer Charter articulating the rights and responsibilities of women and men who provide care and support to the sick and orphaned; and
- 6** Address gender norms, violence, stigma and discrimination as potential barriers to women's access to care and treatment.

STRATEGIES THAT WORK

The Task Force highlighted the following strategies:

- **Challenging the social norms and values that contribute to the lower social status of women and girls and condone violence against them**, e.g. through the use of drama and community-based educational initiatives;
- **Increasing the self-confidence and self-esteem of girls**, e.g. through life-skills training and other school-based programmes in which they are full participants;
- **Strengthening the legal and policy frameworks that support women's rights to economic independence** (including the right to own and

ual transmission to other partners. In Central America infection appears to be occurring through sexual transmission, both heterosexually and among men involved with men. Among the factors helping to drive the spread of HIV in the region overall is the combination of unequal socio-economic development and high population mobility.

Middle East and North Africa

HIV prevalence in the Middle East and North Africa is still very low. The exception is southern Sudan. In addition, HIV infections are increasing among injecting drug users in Bahrain, Iran and Libya, and to a lesser degree in Algeria, Egypt, Kuwait, Morocco, Oman and Tunisia. However, infections among this group could spread quickly to the general population. For example, a study in Iran showed that half of injecting drug users were married and a third had reported having extra-marital affairs. Already, young women aged 15 to 24 are more than twice as likely to be living with HIV/AIDS as young men, although this figure is somewhat skewed due to the high levels of infection in young women in southern Sudan.

In countries of this region, social and cultural norms limit the discussion of sexuality and reproductive and sexual health issues, and many countries have not developed prevention programmes. Part of the challenge facing the region is the need to defuse the stigma and blame that are so often attached to vulnerable groups, and to widen the general public's knowledge and understanding of the epidemic.

inherit land and property), e.g. by restructuring justice systems, enacting laws and training NGOs to popularize these laws;

- **Ensuring access to health services and education, in particular life-skills and sexuality education for both boys and girls**, e.g. by training health workers and teachers to be gender sensitive and re-orienting health and education systems so that they are participatory and community-centred rather than bureaucratic and hierarchical; and
- **Empowering women and girls economically**, e.g. by providing them with access to credit and with business, entrepreneurship and marketing skills.

STRENGTHENING THE RESPONSE

To expand the capacities of communities and of those working on HIV/AIDS programmes to ensure the fulfilment of the rights of women and girls, the Task Force recommended the following:

- **Expand the pool of gender experts** who know how to conduct a thorough gender analysis and design a response to meet the different requirements of men, women, boys and girls;
- **Address the fears and resistance that surround gender** in order to prioritize initiatives that seek to challenge the status quo;
- **Support and strengthen local women's movements and organizations,**

and partnerships between governments, women's organizations and community-based organizations;

- **Increase public awareness and debate** about the relationship between gender inequality and HIV/AIDS; and
- **Address the causes of gender inequality**, not only the consequences.

Source: United Nations Secretary-General's Task Force on Women, Girls and HIV/AIDS in Southern Africa, 2004, *Facing the Future Together*

High-Income Countries

In both Western Europe and North America, the percentage of women among adults living with HIV/AIDS is rising. There is mounting evidence that prevention activities in several high-income countries are not keeping pace with the changes occurring in the spread of HIV. Such shortcomings are most evident where HIV is lodged among marginalized sections of populations, including minorities, immigrants and refugees.

Western Europe

In Western European countries that report HIV cases, heterosexual intercourse may now be the most common mode of transmission, with the role of injecting drug use varying between countries. A large share of the increase in new infections is among people who had acquired HIV while

Helping Positive Women Cope: In 1992, when Helen Ditsebe-Mhone found out she was HIV-positive, there were no drug cocktails to treat AIDS and there was hardly any place in Botswana to turn to for help or consolation. With little to offer but her own honesty about her HIV status, and no idea how long she might live, Ditsebe-Mhone became a volunteer counsellor at the centre where she had been tested. She also began giving speeches in which she publicly discussed her HIV status. Since she was one of the few women business leaders in Botswana, people listened. They turned to her for advice, counselling, a shoulder to lean on. At group meetings, they shared experiences with each other and planned a response to the growing stigma surrounding HIV. Then the centre closed. Unwilling to disperse, people began to gather where they could—most frequently at Ditsebe-Mhone’s home. It took several years, but in 1999 she created an NGO out of those informal meetings—the Coping Centre for People Living with HIV/AIDS (COCEPWA), run by and for HIV-positive people. The centre has meeting sites in four towns in Botswana, providing education and support. It is not a treatment centre—the government does that—but people living with HIV need much more than medication.

COCEPWA works with anyone who walks through their door, but it has put a spotlight on the needs of Botswana’s women. Women make up 56 per cent of the nation’s HIV-positive population and although antiretrovirals are free, stigma, fear and poverty keep many of them from seeking help. One of COCEPWA’s most innovative projects is its ‘Buddy’ network, in which an HIV-positive woman volunteers to be a friend and sounding board for women who are newly diagnosed or who are not responding to therapy.

In 2003 Ditsebe-Mhone was awarded the 2003 Poverty Eradication prize by the United Nations Development Programme (UNDP) for creating “an international model of how to support those living with HIV/AIDS and their communities”.

Source: www.achap.org/COCEPWA.htm

living in countries with generalized epidemics. The percentage of women among adults living with HIV/AIDS remained stable at 25 per cent from 2001 to 2003.

North America

In North America, where the epidemic was thought to be under control due to the general availability of antiretroviral therapy (ART), women's prevalence rates jumped 5 per cent between 2001 and 2003, the largest increase among women in any region of the world. Twenty-five per cent of all North Americans living with HIV/AIDS are women. Among young people, 28 per cent of those living with HIV are female.

According to the US Centers for Disease Control, the proportion of AIDS cases among adult and adolescent women in the United States has more than tripled since 1985. The epidemic has increased most dramatically among African American and Hispanic women. Together they represent less than one fourth of all women in the US, yet they accounted for 80 per cent of AIDS cases reported among women in 2000. Heterosexual contact is the greatest risk for women followed by injecting drug use. A significant proportion of women infected heterosexually were infected through sex with an injecting drug user.²

Australia and New Zealand

In Australia and New Zealand, the percentage of women among adults living with HIV/AIDS is 8 per cent, one of the lowest in the world.

The Impact of HIV/AIDS on Women

The rates of HIV infection among women and girls are a cause for deep concern, but when combined with the workload that women take on as well—in caring for AIDS patients, AIDS orphans and their own families—the situation becomes untenable, as it already is in Southern Africa. Similar conditions are developing quickly in the Caribbean, and possibly in Eastern Europe and parts of Asia due to rapidly rising rates in those regions.

At its heart, this is a crisis of gender inequality, with women less able than men to exercise control over their bodies and lives. Nearly universally, cultural expectations have encouraged men to have multiple partners, while women are expected to abstain or be faithful. There is also a culture of silence around sexual and reproductive health. Simply by fulfilling their expected gender roles, men and women are likely to increase their risk of HIV infection.

But the gender disparities go far deeper than sexual relations. Women in many regions do not own property or have access to financial resources and are dependent on men—husbands, fathers, brothers and sons—for support. Without resources, women are susceptible to abuses of power.

Violence and the threat of it also limit women's ability to protect themselves from HIV/AIDS. They risk violence if they insist on protection. They may stay in violent relationships because they have nowhere else to go. They may give in to male demands for unprotected sexual relations, even when they know the danger. Whether in conflict areas or in the

home, rape and sexual abuse make a mockery of the notion of safer sexual relations.

In addition, poverty pushes some women into risky behaviour or dangerous situations. With no other options in sight, they may resort to sex work to feed their families. Women and girls are susceptible to the growing trade of trafficking. In Southern Africa, many older men seek out young women and adolescent girls for sexual favours while providing them with school fees, food and highly sought after consumer goods.

In countries that are hard-hit by the epidemic, particularly in sub-Saharan Africa, women have taken on the care of HIV/AIDS patients. They provide home-based care, take in orphans, cultivate crops or find paid employment to keep families going. They clean, cook and nurse, often without access to clean water and sanitary supplies. Because of the additional work involved in caring for the sick, fields are lying fallow, children (usually girls) are being taken out of school to help and households are not being maintained.

Girls and women know that if they do not do this work, no one else will, and so they take it on at enormous cost to themselves. But women

Young Chinese women brave the rain to visit an exhibition on AIDS in Guangzhou.



and girls cannot continue to bear this burden alone. And the world can no longer allow them to carry such a heavy load.

Violence, poverty, inequality and the lack of basic rights all need to be addressed if HIV/AIDS is to be brought under control.

Women living with HIV/AIDS have identified actions that would improve their situations. They have called for recognition of their fundamental human rights, and for decision-making power and consultation at all levels of policy and programmes affecting them. They have urged economic support for women living with HIV/AIDS in developing countries, support for self-help groups and networks, realistic portrayals of people living with HIV/AIDS by the media and accessible and affordable health care. They also want their reproductive rights to be respected, including the right to choose whether or not to have children.³

Building the Commitment

The UN General Assembly Special Session (UNGASS) on HIV/AIDS in June 2001 made the gender dimensions of the epidemic explicit. Delegates from over 180 countries stressed that gender equality and the empowerment of women are fundamental elements in reducing women's and girls' vulnerability to HIV/AIDS. They committed themselves to "intensify efforts to...challenge gender stereotypes and attitudes, and gender inequality in relation to HIV/AIDS, encouraging the active involvement of men and boys." (para 47)⁴ With this statement, the world recognized that all would benefit from a gender-based approach to fighting the disease, reducing the risk to both men and women.

The UNGASS Declaration broadens the Millennium Declaration, adopted by world leaders in 2000, in which leaders pledged to promote gender equality and the empowerment of women as effective ways to combat poverty, hunger and disease. Millennium Development Goal 3 focuses on gender equality and women's and girls' empowerment while Goal 6 aims at reducing the impact of HIV/AIDS, malaria and other diseases.⁵ All the goals are mutually reinforcing.

This report, which focuses on women and HIV/AIDS in the developing world, features many stories of HIV-positive women who have provided leadership in responding to the challenges of the epidemic. It uses examples primarily from sub-Saharan Africa because this region is the hardest-hit and has the most experience in responding to the epidemic. Despite poverty and lack of public services, the women and men in the region have shown courage, determination and strength. It is this strength and local wisdom that must be supported in every region and community that is affected by HIV/AIDS in order to move forward.

This report builds on the work of the Global Coalition on Women and AIDS, a new initiative launched by UNAIDS involving activists, UN system organizations, NGOs, government representatives, the private sector, community workers and celebrities who seek to stimulate concrete action on the ground to improve the daily lives of women and girls. The Coalition's focus includes:

- Preventing HIV infection among adolescent girls, focusing particularly on improved access to reproductive health;
- Reducing violence against women;
- Protecting the property and inheritance rights of women and girls;
- Ensuring equal access to care, treatment and support for women and girls;
- Improving community-based care with a special focus on women and girls;
- Improving access to female-controlled prevention technologies including the female condom and microbicides; and
- Supporting ongoing efforts towards universal education for girls.

Chapter 2



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AIDS education for community health volunteers in Calcutta.

PREVENTION

Recommendation: Ensure that adolescent girls and women have the knowledge and means to prevent HIV infection

The need for prevention strategies that reach girls and women is urgent. This is especially the case for adolescent girls, who face infection rates in some countries that are five to six times higher than those of boys the same age. Even though girls and women are highly vulnerable to HIV infection, they know less than males about HIV/AIDS and how it is transmitted.¹

The rising rates of HIV infection among girls and women require approaches to prevention that address their specific needs and realities and that are linked with other reinforcing elements along a broad continuum of prevention, treatment and care. Effective prevention is composed of many facets—including education, health services, media campaigns, behaviour change, life skills-building and job training. All these components must address the critical role that gender plays in sexual and reproductive life, and how it affects HIV prevention.

Knowledge

Many girls and women know very little about their bodies, their sexual and reproductive health or HIV/AIDS.

In many societies both the discussion of and education about sexual matters is frowned upon. As a result, millions of people, especially girls and women, remain ignorant about HIV/AIDS, with potentially deadly consequences.

Although many adults in both the industrialized and developing world disapprove of sexual and reproductive health education for young people because they believe it encourages promiscuity, research and long experience show that just the opposite is true. A review of 50 sexual health education programmes in different parts of the world found that young people were more likely to delay sexual activity when they had the correct information to make informed decisions.²

Although HIV prevention programmes are expanding, they are not keeping pace

A 1999 nationwide reproductive health survey among 30,556 Chinese women of childbearing age in 32 counties found that 72 per cent overall had heard about HIV/AIDS but half the illiterate or semi-literate women in the study had not. The most common sources of information were radio, TV and friends. Very few had received information about HIV/AIDS in a health-care setting. When asked, “Is it possible for you to become HIV infected?” most women (86 to 92 per cent) of all ages, both rural and urban, and of different levels of education answered, “impossible”.

Source: UNAIDS 2001, *HIV/AIDS: China's Titanic Peril*, 2001 Update of the AIDS Situation and Needs Assessment Report, The UN Theme Group on HIV/AIDS in China

PREVENTION: THE MILLENNIUM DEVELOPMENT GOAL (MDG) INDICATORS ON KNOWLEDGE AND BEHAVIOUR

One of the eight goals of the United Nations Millennium Declaration is to combat HIV/AIDS, malaria and other diseases. To monitor the success of national programmes to prevent the spread of HIV/AIDS, data are now being collected by a number of developing countries and compiled by UNICEF on knowledge about HIV/AIDS and the use of condoms among young people. The data reported below refer to young women and young men aged 15 to 24 and were collected between 1998 and 2003.

According to data from the surveys, globally, more than 80 per cent of the young women did not have 'sufficient' knowledge about HIV/AIDS. Many had no idea how HIV/AIDS is transmitted and little or no information on protection methods.

In South-East Asia only 13 per cent of young women were able to correctly identify two prevention methods (using condoms and limiting sex to one faithful, uninfected partner) and three common misconceptions about HIV/AIDS.

- In Viet Nam almost half of all young women believed they could get HIV from a mosquito bite.
- In Cambodia and Viet Nam 30 per cent of young women believed that HIV could be contracted by supernatural means and nearly 35 per cent believed a healthy-looking person could not be infected.

In sub-Saharan Africa only 20 per cent of women aged 15 to 24 were able to identify the two prevention methods and the common misconceptions about HIV.

- In Somalia only 26 per cent of young women had heard of AIDS and only 2 per cent knew how to avoid infection.

Many young women did not know that a healthy-looking person can be infected with HIV and that a condom can prevent HIV transmission. The percentages of young women who did not know these facts:

- 50 per cent in South-East Asia;
- 50 per cent in sub-Saharan Africa;
- 43 per cent in the CEE/CIS countries and the Baltic States; and
- 25 per cent in Latin America and the Caribbean.

Young women's more limited knowledge is evident in nearly every country surveyed with sex-disaggregated data for both sexes. In some regions and countries, the gap is substantial.

In sub-Saharan Africa 53 per cent of young women know that a healthy-looking person can be infected, compared to 64 per cent of young men.

- In Burkina Faso the differences are 42 per cent of young women, compared to 64 per cent of young men.
- In Ethiopia 39 per cent of young women know that a healthy person may have HIV, compared to 54 per cent of young men.

Too few young people report condom use at last sexual encounter with a non-cohabiting partner, with young women reporting condom use less than young men.*

- In sub-Saharan Africa 23 per cent of young women reported using a condom at last sexual encounter with a non-cohabiting partner, in contrast to 41 per cent of young men.
- In India 51 per cent of young women used a condom at last sexual encounter with a non-cohabiting partner, compared to 59 per cent of young men.

**Relatively few countries collect data on condom use at last sexual encounter with a non-cohabiting partner, although this is used as an indicator for the MDG. From a gender perspective, there are problems with an indicator that is based only on 'high-risk' sex, since many women are infected by a husband or other stable partner who has had multiple partners, and these women do not know they are in a high-risk relationship.*

Source: Data prepared by UNICEF for the United Nations Statistics Division; Millennium Indicators Database accessed at <http://millenniumindicators.un.org/>; UNFEM/UNAIDS, March 2004, *Women in Mekong Region Faced with Higher Rates of HIV Infection Than Men*, Mekong Leaders Consultative Meeting on Women and AIDS

with the epidemic. Greater efforts are needed to ensure that initiatives promote female empowerment, gender equality and male responsibility. Breaking the silence on these sensitive issues builds awareness and effective action. Greater dialogue and partnerships are needed that can result in gender-responsive policies and programmes.

In Eastern Europe, a public service campaign, ‘What’s Your Excuse?’ uses posters, T-shirts, condom packaging and print, TV and radio advertisements to confront sexually active teens on their failure to use condoms. Reasons range from a tough-looking hipster who admits, “I’m embarrassed,” to young lovers who insist, “We trust one another.” The answer to all of them: “There is no excuse. Wear condoms.”

In Nicaragua, *Puntos de Encuentro*, a youth-oriented NGO, offers a weekly TV soap opera on topics such as AIDS and domestic violence that had not been discussed in the popular media before. The programme—which has become one of the most popular series on Nicaraguan TV—is followed up with local discussion groups, sometimes with actors from the programme on hand.

These programmes make several critical points:

- Talking about sexuality and health is important;
- Coercion, force and sexual violence are not acceptable;
- Protecting oneself from HIV is a necessity and the means to do so are available.

With young women facing some of the highest risks, the message needs to be emphasized in as many ways as possible. For adolescent girls, it is important that programmes reflect their realities and build self-confidence and life skills, including decision-making and negotiation skills. For girls who are not yet sexually active, abstaining from or delaying their first sexual experience are important options. Experience shows that young people themselves, including those who are HIV-positive, are effective communicators, advocates and educators and need to be involved in prevention campaigns. It is also important for policy makers to consider the context in which decisions about sexuality take place. Above all, young women need alternatives, including economic opportunities. They stand a better chance of living healthy and satisfying lives in societies that value their productive as well as reproductive roles.

The Power to Use Knowledge

For many girls and women, knowledge is not enough. They need to learn not only how HIV is transmitted but also how to negotiate abstinence,

GIRL POWER

In Nigeria, Girls’ Power Initiative, a non-governmental organization (NGO), equips adolescent girls between the ages of 10 and 18 with information on sexuality, human rights and reproductive health. Meeting once a week, girls learn new skills in leadership and economic management to help them cope with growing up. Parents, teachers and health workers meet with the girls to improve communication and increase understanding and support. The programme also offers counselling and health service referrals. To bring about wider change throughout society, Girls’ Power Initiative has started a Gender Development Institute to conduct research and foster greater awareness and policy changes for social equality.

Source: International Women’s Health Coalition, www.iwhc.org

“If you want me to have sex with a condom, I won’t give you any money for food.”

The response a South African woman received when she asked her husband to use a condom.³

unwanted sex or safer sexual relations. And they need to find safe ways to financially support themselves. Because women have unequal access to resources, they are more vulnerable to coercion, more likely to be economically dependent on men and less likely to be able to negotiate methods of protection.

In Zimbabwe, one project works with 200 women to reduce poverty and economic dependence on men, increasing their bargaining power for safer sexual relations. The women have received grants and training to start income-generating projects such as grinding mills, horticulture, poultry farming, soap making, juice making, butchery and tailoring. The interest repaid on the loans goes into a revolving fund that is used to make

Living For Tomorrow: In 1997, few people would have identified Estonia as a nation on the verge of a serious HIV/AIDS problem. But increasing poverty, a collapsed social infrastructure, a fragile economy and soaring drug use created a conducive environment for new infections. That year, Jill Lewis, a professor of literature and gender studies at Hampshire College in the United States, began an educational project on gender and HIV awareness for young people, sponsored by the Nordic Institute for Women's Studies and Gender Research.

Lewis hoped that sexual safety would be more compelling if it was attached to a series of discussions about gender and personal relations. She wanted to push participants to question the 'naturalness' of existing gender relations and help them feel more comfortable practicing safer sex. "These gender beliefs are central to the HIV risk behaviours young people engage in, yet they are rarely discussed in HIV prevention education," wrote Lewis.

As part of the project, questionnaires were distributed to young people in the capital, Tallinn. The results were predictable in many ways—both young women and men considered submissiveness a trait that women were valued for—with one exception. Young women were three times more likely than young men to say a condom ruined men's pleasure.

"There were a lot of arguments and hot discussions," said Anna Bykova, who was 15 when she joined the programme. "We would talk about stereotypes, sexual issues, intercultural relations." At the end of the programme, Bykova was eager to share her knowledge with others but was shocked by how little other students knew about HIV/AIDS. "When we went to a local school to conduct a workshop, they asked us incredible questions: 'Can you get it from a handshake?' How could they not know?"

Participants of the original workshop have created their own group, Living for Tomorrow, which continues to work with young people in Estonia to confront gender norms, encourage safer behaviour and reduce HIV transmission.

Source: Jill Lewis and Stephen Clift, 2001, *Challenging Gender Issues: Report on findings from the Living for Tomorrow project about young people's attitudes to men, women and sex*, The Nordic Institute for Women's Studies and Gender Research (NIKK), www.nikk.vio.no

loans to other women. During the entire process, women also receive technical support and education on their human rights, reproductive and sexual health and on how to deal with domestic violence. They are given personal empowerment lessons on assertiveness, communications and negotiation. The project also involves men and the community at large, including traditional leaders, to encourage sensitivity to women's concerns and responsibility for preventing both domestic violence and HIV/AIDS. The campaign is led by women and other trained community resource persons.⁴

Poverty and economic dependence are not the only reasons it is difficult for many girls and women to insist on using protection. In some cases, they are not comfortable speaking about sexual issues. In other cases, women—especially girls—may acquiesce to unsafe sexual practices in order to preserve a relationship. In Brazil, nearly half the respondents in a study of adolescent sexuality admitted they did not use condoms regularly. “Besides having less bargaining power to convince their partners to use condoms, girls tend to stop insisting on condom use once the relationship evolves into a more stable one based on ties of affection,” said Alexandre Granjeiro, the head of the Brazilian Health Ministry's division on Sexually Transmitted Diseases and AIDS. The failure to use condoms has had devastating consequences for Brazilian girls, many of whom have older men as partners. HIV prevalence rates for girls in the 13- to 19-year-old range are now six times that of boys in the same age group, with teenage girls' rates rising rapidly while boys' are going down.⁵

Ultimately, much of the discrepancy between what girls and women know they should do and what they actually have the power to do is rooted in gender inequality. As one recent study noted, “deeply entrenched beliefs about female and male sexuality mean that women generally have less power than men to decide with whom, how and when they have sex. These beliefs are reinforced by a number of factors, including poverty, age or disability, but may still affect women who are financially independent, or middle or upper class.”⁶

It's Not as Simple as 'ABC'

With less ability to control sexual encounters, and increased physiological susceptibility to HIV, many women are finding that commonly accepted methods of prevention are insufficient. While the ABCs—Abstain, Be faithful and use Condoms—have been successful in some countries, such

DEALING WITH 'SUGAR DADDIES'

She is an AIDS orphan trying to support her family. In one case, she becomes involved with a rich older man to pay for her expenses, but soon finds herself pregnant and gives birth to a child who is HIV-positive. In another instance, she joins a local support group that offers sex education, access to condoms and job training. She finds a job and is able to help support her family.

The two stories are alternative endings to a play produced for a new programme, Shaping the Health of Adolescents in Zimbabwe (SHAZ). It is one among many projects that are trying to empower girls and women to protect themselves. It offers young women, many orphaned by AIDS and now heads of household, what project directors call a 'financial prophylactic'.

Researchers from the University of California in San Francisco are focusing on young girls who are involved with older men known as 'sugar daddies', or 'dharas' in the Shona language. Although up to a third of dharas in Zimbabwe may already carry HIV, many of the girls involved with them say they do not use condoms.

SHAZ offers reproductive health services and classes on HIV prevention and how to use condoms. In a departure from traditional prevention programmes, SHAZ is attempting to strike at the root cause of these girls' dependence on sugar daddies by offering vocational training, classes in entrepreneurship and help in developing a business plan. Each girl is mentored by a local businesswoman.

Source: Marilyn Chase, 25 February 2004, "Saying No to 'Sugar Daddies': Can a Financial Prophylactic Shield Girls From Liaisons That Spread AIDS in Africa?" *Wall Street Journal*

In one study in Zambia, fewer than 25 per cent of the women surveyed believed a wife could refuse sex with her husband (even if she knew he had had multiple partners) and only 11 per cent believed she had a right to ask him to use a condom.

as Uganda,⁷ there is mounting evidence that the approach needs to be expanded to meet the needs of women and girls. According to Noerine Kaleeba, founder of The AIDS Support Organization (TASO) in Uganda and now with UNAIDS, the approach “simply misses the point for the majority of women and girls in many cultures and situations”.⁸

For example, abstinence is meaningless to girls and women who are coerced or forced into sexual activity. Faithfulness offers little protection to wives whose husbands have several partners or were infected before they were married. Condoms require the cooperation of men, who may refuse to use them. Furthermore, married couples frequently do not use condoms either because they want to have children or because condoms would indicate a lack of trust.

In many countries, including several with high rates of HIV infection, girls are married in their teens as a poverty reduction strategy. However, recent studies in Africa indicate that young married women are at higher risk of HIV infection than their unmarried counterparts. A study in Kisumu, Kenya, found that 33 per cent of married girls were HIV-positive, compared to 22 per cent of sexually-active unmarried girls of the same age. In Ndola, Zambia, 27 per cent of married girls were HIV-positive, compared to 16 per cent of unmarried girls. The Kisumu study also found that adolescent girls who were married to much older men—a common occurrence—were more likely to be HIV-positive. Half of the married women whose husbands were 10 or more years older were infected with HIV, compared to none of the women whose husbands were up to three years older. Researchers have posited that the increased risk is linked to older men’s increased sexual experience and exposure to HIV, young wives’ inability to make demands on older husbands, increased sexual relations and less use of means of protection.⁹

Older married women also appear to be at high risk for HIV/AIDS. In sub-Saharan Africa, 60 to 80 per cent of HIV-positive women report having had sexual relations only with their husbands. On Colombia’s Atlantic Coast, 25 per cent of all HIV cases are among women, nearly 50 per cent of whom are either married or in a stable relationship.¹⁰

In India, “marriage is actually women’s primary risk factor,” according to Suneeta Krishnan, an epidemiologist studying HIV and gender issues in Bangalore.¹¹ A UNIFEM community-based research project in India pointed to some of the reasons for the increased vulnerability of married women: condom use was extremely rare, adult women had little negotiating power about sexual matters within marriage and men who suggested using protection were suspected of infidelity.¹² Another study, at a health clinic in Pune, India, found that of 400 women—93 per cent of whom were married—25 per cent had sexually transmitted infections (STIs) and 14 per cent were HIV-positive. Ninety-one per cent had never had sex with anyone but their husbands.¹³

Some of the reasons for the high rates of HIV infection among married women are linked to the very reasons that some people marry: they want to have children. But with no way to conceive and protect themselves from HIV at the same time, they frequently put themselves at risk of HIV infection. Often couples assume their marriage will be monogamous—even in communities where men’s promiscuity is encouraged—and stop using condoms as a sign of faithfulness. In many cases, gender roles make it dif-

difficult for women to discuss sex with their husbands and for men to admit they are worried about STIs.

Given unequal power within a relationship, it is frequently difficult for women, especially young women with older husbands, to refuse sexual relations. They may fear violence, rejection and abandonment, or they may simply believe that they are required by marriage to be sexually available.

The ABC approach will present viable options for girls and women only if it is implemented as part of a multi-faceted package of interventions that take into consideration the specific problems of girls and women. These interventions should aim to empower girls and women through assertiveness and self-esteem building and inter-personal communication and leadership skills development. They must be accompanied by changes in laws and efforts to transform social expectations that would allow women to live independent lives both socially and economically.

Encouraging dialogue between young men and young women will help ensure that young men are sensitized about respect and appropriate and inappropriate sexual behaviour, and that young women are able to articulate what they want as well as what makes them comfortable. Children should be socialized from an early age to respect the human rights of girls and women and to reject gender discrimination and violence.

Access to Prevention Services

Preventing HIV infection in girls and women requires a combination of interventions that offer tools to block the various routes of infection and provide information to enable those at risk to use these tools. Since the HIV/AIDS epidemic takes radically different forms in different communities, countries and regions, local responses must be guided by local conditions.

Globally, only one fifth of those who need prevention services have access to them, yet adequate levels of these services could prevent 29 million of the 45 million new infections projected to occur this decade.¹⁴ In parts of the world where HIV infection rates are threatening to explode, many people, especially in rural areas, have little or no access to health care in general, which is a primary source of prevention services. This is especially true for young people, who have few entry points to the existing health-care system.

Centres with comprehensive services could help adolescents and adults learn about modes of transmission and how to protect themselves. They could also provide testing and treatment for STIs, which can increase susceptibility to HIV infection by at least two to five times. Building these services need not require the expense of starting from the ground up. Existing health-care facilities, including reproductive health centres and antenatal clinics, can be strengthened. This will involve eliminating fees that prevent the poorest from accessing health care, integrating some services, adding and strengthening others, expanding outreach to new population groups, such as adolescent girls, and creating referral systems that function effectively.

Voluntary Counselling and Testing

Voluntary counselling and testing (VCT), which is currently available to only 12 per cent of the people who want to be tested,¹⁵ can facilitate behav-

our change that contributes to a reduction in HIV transmission. Studies show that VCT can contribute to a decrease in unprotected sexual relations, a reduction in multiple partners, an increase in condom use and more people choosing abstinence. Research in Kenya, Trinidad and Tobago and Tanzania found that VCT was more effective in reducing reported risk behaviours than just providing information on HIV transmission. Pilot projects in Côte d'Ivoire and India indicate that integrating VCT into sexual and reproductive health services also reduces the stigma associated with HIV/AIDS and increases utilization of other health services.¹⁶

VCT is also critical for reducing the numbers of infants born with HIV. Mother-to-child transmission (MTCT) is the primary cause of all HIV infections in children under 15¹⁷, yet in 2003, only 1 per cent of pregnant women in countries heavily affected by AIDS had access to testing and

A refugee looks at an HIV/AIDS prevention campaign poster at a refugee camp in northern Thailand.



© Pornchai Kittiwongsakul—AFP/Getty

treatment. That same year, more than 700,000 children were newly infected, mostly through mother-to-child transmission.¹⁸ Ideally, VCT should not only allow women who are HIV-positive to receive treatment that would prevent their children from becoming infected—known by the acronym PMTCT, preventing mother-to-child transmission—but also receive treatment for themselves (see Chapter 3 for more on treatment for HIV-positive pregnant women and mothers).

Once a woman has given birth, prevention concerns extend to infant feeding. A major risk of MTCT involves infants who are born free of HIV, only to be infected through breastfeeding. Public health facilities must seek to support optimal breastfeeding that helps prevent death and illness from diarrhoea and respiratory infections while avoiding the risk of HIV transmission. Given the importance of both these needs, WHO guidelines state that “when replacement feeding is acceptable, feasible, affordable, sustainable and safe, avoidance of all breastfeeding by HIV-infected mothers is recommended. Otherwise, exclusive breastfeeding is recommended during the first months of life.”¹⁹

Based on the importance of linking HIV prevention with reproductive health services, the International Planned Parenthood Federation and UNFPA have jointly issued guidelines outlining methods for integrating VCT services into reproductive health care settings that are applicable in developing countries in every region.²⁰

One project in Haiti—where there is an HIV prevalence rate of approximately 4.5 per cent—has already merged these services. Working with the Haitian Ministry of Health, UNFPA is supporting a series of reproductive health centres—the Gheskio centres—that merge VCT services with efforts to prevent MTCT. The centres, located countrywide, provide a package of integrated services for HIV/AIDS and other STIs, including information on transmission and prevention, and also offer individual and group counselling and psychological and social support. Some centres have also been able to use supplemental funding to provide ART to HIV-positive pregnant women. Over the course of several years, from 1996 to 2003, the Gheskio centres have been able to show that:

- 90 per cent of the women identified as HIV-positive returned for follow-up;
- 70 per cent of women chose a family planning method to prevent a new pregnancy;
- The MTCT rate was reduced from 30 to 8 per cent; and
- The contraceptive prevalence rate increased from 3 to 21 per cent.²¹

Both Zambia and Zimbabwe, among others, are also experimenting with expanding reproductive health centres and PMTCT sites to offer HIV counselling to male partners of pregnant women. In Zambia, male peer educators reach out to men at sports events or other public gathering spots to talk about the availability of anti-HIV services, including the possibility of visiting clinics on weekends and holidays when the men are off work.²²

“More money needs to be invested in marketing female condoms and making them affordable and accessible. Women and girls need prevention methods they can control. A lot of times, the girls will say they are abstaining but then you see many girls who are pregnant, and infected with HIV. It is easy to say you are abstaining, but it is harder to do.”

Margaret Muganwa, International President of the Society for Women and AIDS in Africa (SWAA)

Methods of Prevention

With no cure in sight, access to condoms and female-controlled methods of prevention, as well as information on how to use these methods, are an essential means of reducing the spread of HIV/AIDS.

Condoms: A recent analysis of 25 published studies found condoms to be about 90 per cent effective, with a high range of about 96 per cent effectiveness.²³ Yet condoms are still not readily available in many regions—less than half of all people at risk of HIV infection are able to obtain them, often simply because not enough are being produced.²⁴ According to the UN Population Division, only 4.9 per cent of married women of reproductive age use condoms. In poor regions, this ranges from 1.3 per cent in Africa to 10.5 per cent in Eastern Europe.²⁵ More condoms need to be made available, along with skills-building courses that can help men and women feel comfortable discussing how and when to use them.

Along with male condoms, female controlled methods of prevention have to be made available on a much larger scale. These methods—the female condom, which is available, and microbicides, which are being tested—have the potential to provide women with greater control over sexual relations.

Female Condoms: The female condom, which is even less available than the male condom and unless subsidized, costs more, has nevertheless proved to be a successful alternative for many women.

Sixty-four million female condoms have been distributed in over 100 countries. The largest and most successful programme is in Brazil, which has made female condoms a central component of its sexual and reproductive health programme.²⁶ Service providers promote its use, and women's and men's reactions to the female condom are analysed for clues on making it more 'user friendly'. Studies in over 40 countries in Africa, Asia, Latin America,

Europe and North Africa show acceptance rates ranging from 41 to 95 per cent.²⁷

In a small, UNIFEM-sponsored pilot study in Senegal involving 50 women factory workers, 73 per cent said they used the female condom successfully with their partners. Of these, 80 per cent found it easy to use and nine out of 10 said they derived sexual pleasure while using it. Among the 27 per cent who were unsuccessful in negotiating the female condom, three primary reasons were cited: low economic status, women in polygamous marriages fearing loss of their husband's affection or attention, and fear of social rejection because of religious strictures against condom use.²⁸

Calculations by The Female Health Company, the sole manufacturer of the female condom, indicate that with correct and consistent use, female condoms are 97 per cent effective. With a new, less expensive version expected in 2005, many more women may be able to take advantage of this method.

THE HIV VACCINE

Researchers have been working for several years to develop a vaccine against HIV. As part of the effort, various groups are working to ensure that both vaccine trials and inoculation programmes have a gender-sensitive approach. The International AIDS Vaccine Initiative (IAVI) is engaged in developing a framework to identify and address critical issues related to women's and men's participation in HIV vaccine trials and their future use. In India, where trials are already underway, IAVI consulted with numerous groups and individuals, including women's and reproductive rights advocates, people living with HIV/AIDS, NGOs, scientists and trial administrators to help set up an advisory group that will develop gender-sensitive trial protocols and create accountability mechanisms to review and monitor all aspects of the trial.

Source: IAVI

Microbicides: These products, which are undergoing research as a gel, film, sponge, lubricant or suppository, are among the most promising prevention options on the horizon because they are undetectable and can be inserted with relative ease several hours before sexual relations. Two types of microbicides are needed. One would be able to prevent pregnancy as well as HIV transmission. The other would act against the virus only and thereby offer the hope of conceiving while minimizing the risk of HIV transmission between partners and to an unborn child.

The desire or pressure to conceive has stopped many women and men from using condoms even though they know that they or their unborn child might become infected. In a study of Thai women who were HIV-positive, 17 per cent became pregnant after learning their status. “If we do not have children, the family will not be fully complete,” one woman told researchers. “If our child does not get HIV, he will carry on our name and bloodline.”²⁹

Microbicides are undergoing human trials in several sites, including Brazil, India and Zimbabwe. Researchers predict that a microbicide that is only 60 per cent effective could prevent more than 2.5 million infections within three years of its introduction. Promising microbicides are also being evaluated for use with diaphragms and cervical caps to offer additional protection against HIV infection. The Global Campaign for Microbicides estimates that \$775 million is needed to test existing products and move them through the development pipeline to be available by 2007. Although only \$230 million has been committed so far, many advocates are optimistic that more money will be raised in the near future. While microbicides may initially be more expensive than condoms, efforts must be made to ensure that cost does not become a barrier to their accessibility and utilization.³⁰

Prevention, whether in the form of behavioural and attitudinal change, public services or barrier methods that provide physical protection, is an important part of reversing the epidemic. While treatment, particularly universal access to antiretrovirals, will make a huge difference to the lives of people living with HIV/AIDS, prevention methods that promote gender equality and women’s human rights can stop the epidemic in its tracks, and steadily reverse the rate of infection.

Chapter 3



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In Peru, a mother who is HIV-positive kisses her daughter after learning that the child is HIV-negative.

TREATMENT

Recommendation: Ensure equal and universal access to treatment

The need for increased and equitable access to AIDS treatment cannot be overstated. In sub-Saharan Africa alone, it is estimated that only about 3 per cent of people in need of antiretroviral treatment (ART) received it in 2003.¹ Of the 1 million people receiving AIDS treatment worldwide, the overwhelming majority live in wealthy countries. Without concerted prevention efforts, the numbers needing ART will only grow.

The '3 by 5' initiative, created by the World Health Organization (WHO) and UNAIDS, which aims to provide HIV/AIDS treatment to 3 million people by the end of 2005, has made it possible to imagine a world in which HIV is no longer necessarily a death sentence in developing regions. But the challenge is literally of global proportions.

The promise of '3 by 5' and its expansion to all those in need (estimated at an additional 3 million as of 2004) can only be reached if treatment efforts are coupled with prevention and are based on knowledge of the conditions in regions where HIV has been most devastating. That means understanding the different problems men and women face when it comes to prevention and treatment, and the ways in which women have been affected differently.

The Challenges of Accessing Treatment

Recent experiences in Southern Africa point to the issues that affect women's access to treatment. Throughout the region, only one eligible person in 25,000 is receiving drug treatment. Most of them are educated men living in urban areas, where health services are generally better and more available than in rural areas. However, where testing and treatment are offered through public health clinics and reproductive health centres in Southern Africa, women have greater access.²

Nevertheless, women are not always able to use the services that are available. In Zambia, for example, the Government was able to dramatically reduce the monthly cost of ART from \$64 to \$8 per month after receiving support from the Global Fund to Fight AIDS, Tuberculosis and Malaria. Given that well over half—some reports put it as high as 70 per cent—of the 870,000 Zambians living with HIV/AIDS are women, officials expected to see a majority of women receiving ART. Instead, men began showing up in much greater numbers. In one rural town, of the 40 people on ART, only three were women.³

Zambian women reported various reasons for not accessing treatment, including:

- **Discrimination:** Where money was limited, families often chose to pay for medication for the men in the household rather than the women;
- **Property rights:** One couple, who could only afford treatment for one of them told reporters that if the husband died, his family would inherit his land and his wife would have no way to support their children. If the wife died, he would still have the land;

Bringing Treatment Home: Every morning and evening a group of women and a few men, many of them HIV-positive, fan out over the villages of the central region of Haiti bringing ART to more than 650 AIDS patients. These *'accompagnateurs'* distribute twice-daily dosages of antiretroviral drugs and provide other medications as needed, some food and a shoulder to lean on. For many patients, it is their first experience of sustained health care. Although renewed conflict and natural disasters in Haiti may make it more difficult to reach patients, the *accompagnateurs* continue to make their rounds as part of the HIV Equity Initiative (HEI), a joint programme between Haitian and US NGOs.

Based on the DOTS (directly observed therapy, short-course) method, first developed for TB patients, the *accompagnateur* system brings health care to the patient rather than the other way around. Fuelled as much by hope as by money, the Initiative provides treatment for opportunistic diseases to the overwhelming majority of its 6,500 HIV patients and ART to the 10 per cent with AIDS. Without money for more sophisticated testing, the Initiative's protocol for providing ART is also based primarily on direct observation: patients with visible conditions such as wasting or severe diarrhoea receive therapy.

The *accompagnateurs* factor women's caring responsibilities into their treatment in various ways, including by providing money to help pay school fees when possible. They also try to be aware of the circumstances under which the women became infected. "We realize that gender inequality is at the root of a lot of infectious diseases, including HIV/AIDS, because of the limited ways women can protect themselves," said Dr. Joia Mukherjee of Partners in Health, the US NGO that, along with the Haitian organization Zanmi Lasante, runs HEI. "Many women we see were domestic servants when they were young girls and were abused by their employers. Others had to do sex work for food or security," said Dr. Mukherjee. Many of them came home to their villages to die, she added, but thanks to HEI, they are still alive.

Sources: Mukherjee, J.S. et al., *Tackling HIV in Resource-Poor Countries*, *BMJ*, vol. 327, 8 November 2003; Joia S. Mukherjee, "HIV-1 Care in Resource-Poor Settings: A View From Haiti," *The Lancet*, vol. 362, 20 September 2003; and interviews

- Poverty: More women than men lacked the money to pay for monthly medication.⁴

Transportation is another major factor limiting women's access to treatment. A study in Rwanda found that many women who were receiving medication for opportunistic diseases had to stop because they could not afford transportation to the hospital.⁵

In Botswana, on the other hand, where treatment is available through the public health system to anyone who needs it, women have been utilizing testing and treatment services at greater rates than men. In the capital of Gaborone, some 57 per cent of the patients on ART are women.⁶ Observers believe this is because women have access through reproductive health services and are more comfortable in health-care settings. Nevertheless, the overall numbers remain low, most likely because of the stigma attached to HIV/AIDS. Only 11,000 people were on ART in Botswana at the end of 2003.⁷

Even in countries with more established treatment and prevention programmes, men's and women's differing health-care needs can get ignored in the struggle to provide care on a large scale. Brazil has universal health care and runs one of the world's most successful anti-HIV programmes. Rates of infection are down, with 7,361 new infections registered in the first nine months of 2001, compared with 23,742 cases registered in 1997.⁸ The campaign started out by focusing on urban men who had relations with other men, since they were the largest HIV-positive population in the early years of the epidemic. As the demographics changed, so did treatment programmes and now women have access to prevention and treatment services in urban areas.

Nevertheless, many rural women are still underserved. "The programme was not developed with their special needs in mind," said Astrid Bant, UNIFEM regional adviser for HIV/AIDS in Brazil. "There are a few clinics in rural areas, but it is hard for women to leave their families to travel by bus to a place with a clinic. In rural areas, women don't have the same mobility as men." Bant estimates that a fraction of the people living with HIV in rural areas are registered with the national health programme and receiving treatment. The rest, the majority of whom she and many others believe are women, never make it to testing facilities. "In some states, 90 per cent of pregnant women don't go for prenatal care because it is too far off. So you're not bringing women into prenatal care and therefore you're not testing them and introducing them to HIV programmes."⁹

Making Treatment Gender Equitable

Many advocates have already begun thinking about how to ensure that women have equal access to HIV/AIDS treatment. Recent guidelines produced by NGOs and international organizations on how to distribute medication equitably all start from the perspective that access to ART is a human right that should be available to anyone who needs it. Until full coverage is achieved, life and death choices will be made only slightly more bearable if they are based on as broad a range of criteria as possible. WHO has described the need to use human rights criteria in treatment guidelines, and the '3 by 5' campaign has noted that "special attention will be given to

South African AIDS activists lie down in front of parliament after hundreds marched through Cape Town 12 February 2001 to demand that the Government and pharmaceutical companies allow the importation of generic HIV/AIDS medicines.

protecting and serving vulnerable groups” 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.” The Global Coalition on Women and AIDS has called for half the recipients of ART through the ‘3 by 5’ campaign to be women.¹⁰

Providing treatment for girls and women requires focusing on the constraints that make it difficult for them to adhere to drug regimens. They will often need counselling to help them stay on treatment in the face of opposition and stigma. Many families will also need social services to ensure that sheer destitution does not interfere with women taking the drugs, which require a certain amount of food in order to be effective. In situations where poverty limits the amount of food available and where women are the last to eat, it is nearly impossible for them to follow anti-retroviral therapy without support.¹¹

Projects such as the HEI in Haiti and a pilot programme in Khayelitsha, South Africa, run by the NGO Médecins Sans Frontières (MSF) have shown that it is possible to include gender concerns even in programmes and



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regions with extremely limited resources. In Khayelitsha, for example, concern over high rates of rape and gender-based violence led MSF to include follow-up services for rape survivors, including post-exposure prophylaxis (PEP),¹² a short-term antiretroviral treatment that—if taken within 72 hours—reduces the likelihood of HIV infection after potential exposure.¹³

Voluntary Counselling and Testing (VCT)

VCT is the entry point for treatment of HIV/AIDS as well as for prevention. The majority of people living with HIV/AIDS do not know their status, and most men and women who are at risk of infection have not been tested. In many cases, testing services are not available—only 12 per cent of people who want to be tested for HIV are able to do so.¹⁴ In other instances, people do not want to know their HIV status: They may feel that without treatment options there is no point; they may not be emotionally prepared to deal with the possibility of bad news; or they may fear the social stigma and risk of violence associated with being HIV-positive.

For women, the stigma is even greater than it is for men. Both in the community at large and in their own homes, they are frequently blamed for infections and risk violence, abandonment or even being killed if they are found to be HIV-positive. The goal of VCT in terms of treatment is to ensure that those who test positive receive counselling about stigma and the impact of HIV as well as about ART. In order to achieve this, ART must be made more available and counselling services must also be improved and increased. Women should be able to discuss their fear of violence if they disclose a positive status, and receive referrals for help. Adolescent girls particularly need access to confidential counselling and care. Currently, many cannot be tested or receive treatment unless a family member gives permission. Counselling also helps clients adhere to treatment regimens. Studies in Brazil and South Africa show that intensive counselling, coupled with support from other HIV-positive patients, makes it more likely that AIDS patients will stay on drug therapy.¹⁵ For couples, having men and women in treatment together increases the chances for both of succeeding.

Evidence also shows that linking testing to treatment helps to reduce the stigma of HIV. In India, the Society for the Protection of Youth and the Masses reported a reduction in stigmatizing behaviour after a pilot project began

Only 12 per cent of people who want to be tested for HIV are able to do so.



training a core group of health professionals to provide care as well as education around HIV.¹⁶ Among Haitians participating in the HEI, the highly visible fact that they appeared healthy and were able to work after receiving ART has reduced stigma dramatically, according to Dr. Joia Mukherjee, a director of the Initiative (see Box, p. 24). The HEI found that in a 9-month period, 4,000 people were tested in HEI sites that offered testing and treatment, compared to only 43 people at a non-HEI site that only provided testing.

Ensuring Access

Projects such as the HEI and the Gheskio centres (see Chapter 2) show the importance of comprehensive programmes for reaching HIV-positive women. Because discrimination against women, gender stereotypes, women's domestic responsibilities and restrictions on their access to resources make it difficult for them to access health care unless they are pregnant, services need to be expanded to ensure that young women and women who are not pregnant are able to utilize a country's health-care system. Social stigma and the popular belief that infection is linked to promiscuity make it even more difficult for women than men to seek out treatment.

To counteract these problems, health services can use a variety of measures to reach women, such as providing mobile health centres, reducing or eliminating fees, providing child care at health centres and offering care to everyone in a family so no one member is being treated at the expense of others. Comprehensive care is essential to combating HIV/AIDS, but it means little if there is inadequate nutrition and food and no clean water, vaccinations or treatment for other major killers such as tuberculosis.

In some cases, reproductive health centres and family planning clinics are being expanded to offer this broader treatment to the community at large. Given appropriate training for health-care workers, these centres could provide vaccines and TB treatment, as well as integrated health services for HIV and STIs. Since women are often asymptomatic, STI testing is particularly important. To reach this goal, infrastructure must be improved, equipment and supplies must be provided and staff training must be intensified.¹⁷

The few programmes that exist for adolescents and youth living with HIV often have a judgmental attitude towards young people. One of the few exceptions is the Lovelife National Adolescent-Friendly Clinic Initiative (NAFCI) in South Africa, which is striving to provide comprehensive health services, including treatment for AIDS, to young people. In partnership with the South African Department of Health, Lovelife developed national standards for adolescent clinical services. It provides intensive technical assistance and training, as well as regular monitoring to ensure that quality care is maintained. A key part of the initiative is a peer outreach programme to make sure adolescents know about and take advantage of clinic services. The current goal is to pilot high-quality adolescent health services in 900 government clinics by 2006.¹⁸

Pregnancy and Treatment

Preventing mother-to-child-transmission (PMTCT) is an issue of prevention for infants, but it is an equally important potential entry point for treating pregnant women and mothers who are HIV-positive.

Antiretroviral drugs should be used within a framework of prevention, treatment and care both to prevent transmission to the child and to maintain the health of the mother and all other HIV-positive family members.

Unfortunately due to lack of resources, many PMTCT programmes focus only on the child. In much of the developing world, women's only access to ART is a single dose of antiretroviral medication at the onset of labour to protect the infant during delivery. Without ongoing treatment, HIV-positive women frequently give birth only to die a few years later. Stephen Lewis, the Secretary-General's Special Envoy for HIV/AIDS in Africa, described meeting three women in Rwanda who had taken nevirapine to protect their babies from HIV transmission. "They asked a poignant question that haunts me to this day," said Lewis. "They said, 'We'll do anything to save our babies, but what about us?'"¹⁹

Part of the answer to that question lies in the '3 by 5' campaign and increased access to AIDS drugs. Another important example of treating women in their own right is the MTCT-Plus initiative spearheaded by the Columbia University Mailman School of Public Health with other key partners. National AIDS plans are also increasingly recognizing that the growing number of AIDS orphans could be reduced if HIV-positive mothers and their partners were receiving ART. Many countries that are able to do so have already introduced ongoing access to ART for mothers, but these programmes are still limited.

Experience has shown that the best results come about when the larger community is involved in treatment. Treatment and perception are part of a reinforcing cycle, in which those who benefit from treatment become living testimony that AIDS need not destroy lives, and those who gain more knowledge about HIV/AIDS are able to support friends and family members who must learn to live with a chronic disease as well as prevent HIV from spreading further.

Chapter 4



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A grandmother in Zimbabwe with
some of her 15 dependents,
all orphaned by AIDS.

CAREGIVING

Recommendation: Recognize and support home-based caregivers of AIDS patients and orphans

When AIDS enters the household, women and girls provide the care. Globally, up to 90 per cent of the care due to illness is provided in the home by women and girls.¹ This is in addition to the many tasks they already perform, such as taking care of children and the elderly, cooking, cleaning and, in subsistence areas, fetching water and fire wood. Women are also deeply involved in work at the community level, often as volunteers. The value of the time, energy and resources required to perform this unpaid work is rarely recognized by governments and communities, despite its critical contribution to the overall national economy and society in general. The devastating effect of HIV/AIDS on women's work is even less recognized. Poverty reduction strategies and national AIDS plans seldom take women's caregiving into account; it remains unpaid and therefore undervalued in economic terms.

Yet the work is overwhelming. In developing nations, poverty and the privatization of public services have combined with AIDS to turn the care burden for women into a crisis with far-reaching social, health and economic consequences. In many of the hardest-hit nations—and increasingly in all countries affected by HIV/AIDS—women and girls take on the major share of care work by nursing the sick and taking in AIDS orphans, while trying to earn an income that is often their family's only means of support. In addition, women may be cultivating crops to feed their families.

The devastation is most evident in Africa. A study in 15 villages in Uganda found that many households had a 'missing' generation of family members: men and women who had succumbed to AIDS and would normally have been prime income earners.² The loss of the members of this generation robbed communities of more than financial support; farming techniques, culture and wisdom that were traditionally passed from one generation to the next were also lost.

There are areas in sub-Saharan Africa where the risk of famine has increased due to the death of farmers and the inability of others in the community to provide sufficient support to bridge the gap.³ Ethiopia, which has lost hundreds of thousands to famine in recent decades, is facing another major crisis as AIDS robs villages of young farmers, both male and female. In urban areas, women may not be able to hold a job in either

the formal or informal sectors because they spend so much time caring for others.

Throughout Africa, as more people die from the effects of AIDS, women become heads of households and sink deeper into the poverty that disproportionately affects female-headed households. Those who are already poor fall even further down the economic ladder. A recent study in South Africa found that households that had experienced illness or death in the recent past were more than twice as likely to be poor than non-affected households and were more likely to experience long-term poverty.⁴ The Secretary-General's report on Southern Africa revealed that two thirds of caregivers in the households surveyed were female, with almost a quarter of them over the age of 60.⁵

Much of the increased poverty in these households is directly related to their caregiving responsibilities. Many AIDS widows, for example, are young and have dependent children, which limits their ability to contribute to farm work and earn an income. Female-headed households also

tend to have more children, including AIDS orphans, than male-headed households. In Zambia, a study revealed that there were twice as many female as male-headed households caring for children who had lost both parents. In addition, female heads of household had taken on the responsibility for more orphans than male heads of household.⁶

Caring for an AIDS patient can increase the workload of a family caretaker by one third. This is a burden in any family but particularly onerous for the poor, who already spend much of their day earning a subsistence living. A rural woman interviewed in Southern Africa estimated that it took 24 buckets of water a day, fetched by hand, to care for a family member who was dying of AIDS—water to wash the clothes, the sheets and the patient after regular bouts of diarrhoea.

As the crisis deepens in Africa, girls are being taken out of school to provide home-based care. In Swaziland, school enrolment is estimated to have fallen by 36 per cent due to AIDS, with girls the most affected.⁷ At the same time, older women are pushed into the labour force to support their grandchildren and adult children with AIDS.⁸ Grandmothers, aunts and cousins may be caring for orphaned children from several families. In Kenya, a health-care trainer described a woman who was raising 10 children of her late brother and sister along with six of her own. She worked as a home health-care provider, in charge of 13 patients, four of whom depended on her for their daily provisions.⁹ The burden is enormous on women like this, who have nowhere to turn when the workload becomes overwhelming.

Conditions are most difficult for women in rural areas. Many people who migrated to cities in search of work return home to their villages when they develop AIDS—to be taken care of and to die. But since in the

FOOD FOR HEALTH

For several years, the United Nations World Food Programme (WFP) has been distributing food to families affected by HIV/AIDS. In May 2003, WFP began distributing food for the first time in Myanmar, where infection rates are among the highest in South-East Asia. The food is distributed as part of a package of home-based community care that is being administered by the Myanmar Nurses Association. "This one-year pilot programme is a first step in our efforts to ease the suffering of people in Myanmar living with the disease and help to slow its spread," said WFP Country Director Bhim Udas. The food gives poor families a better chance for survival, and serves to prevent the practices that trigger infection, like migrant or sex work.

Source: "UN begins food aid in AIDS-stricken Myanmar," *Reuters NewMedia*, 19 March 2004

developing world most health-care facilities are located in or near urban centres, the women in rural villages caring for AIDS patients have little moral or material support. Hardly any have received training or even minimal supplies to care for patients.

Women's role in the care economy intensifies their poverty and insecurity since a large proportion of an already meagre income is used to support their caregiving and purchasing of items such as water, gloves and medicines or paying for funerals. The increased workload, loss of family income and deepening poverty make women more dependent on others and exacerbate gender inequalities.

Ironically, even when community support programmes are developed to serve people living with HIV, they tend to rely on women as unpaid volunteers who—despite the fact that they are often as poor or poorer than the people they are assisting—receive neither stipends nor incentives. The Report of the Secretary-General's Task Force on Women, Girls and HIV/AIDS in Southern Africa points out that there is little recognition or compensation for volunteers, who may be subject to exploitation and severe stress. The most successful community-based mobilization efforts provide counselling and support for volunteers, try to provide incentives such as food or job training when possible and encourage men and boys to share the burden of care.

Commitments to Caregiving

The Millennium Declaration adopted by all UN Member States in 2000 declared that all people have the right to live free from fear and want. The eight Millennium Development Goals set up by the international community include eliminating poverty and hunger, reducing the spread of HIV/AIDS and achieving gender equality and empowering women. These goals will be impossible to achieve if women's caregiving work is not shared and given appropriate support.

Supporting Women's and Girls' Caregiving

There are many community-based programmes already operating that show how much can be done with relatively few resources. In Haiti, the HIV Equity Initiative (HEI) model, using paid *accompagnateurs* to provide in-home health services, has been successful at comparatively low cost (see Box, p. 24). The model is being expanded to other nations, according to Paul Farmer, a co-founder of Partners in Health, which helps run the HEI. The money saved by using *accompagnateurs* can be channelled into social services that are just as important as treatment for HIV. "Within every community beset by poverty and HIV are scores of willing individuals who wish to be trained as community health workers," he said. "Working with these *accompagnateurs*, we can develop lower-cost means of assessing impact so that resources may be channelled into food, water and improved housing for HIV-affected families....Such resources can be spent on improving TB diagnosis and treatment, and on linking HIV services to prenatal care."¹⁰

THE UNGASS COMMITMENT

The Declaration of Commitment approved at the UN General Assembly Special Session (UNGASS) on HIV/AIDS in 2001 calls on nations to "review the social and economic impact of HIV/AIDS at all levels of society, especially on women and the elderly, particularly in their role as caregivers, and in families affected by HIV/AIDS and address their special needs."

Source: UNGASS Declaration of Commitment 2001, www.un.org/ga/aids/coverage

In the Zambian Copperbelt, a region with high HIV prevalence rates, NGOs and churches are providing a service similar to the HEI's. Created with the help of Brigitte Syamalevwa, a renowned AIDS activist who died in 2003, the Copperbelt programme sends trained volunteers to patients' homes with medication for opportunistic diseases and TB. Volunteers take

MEN AS CAREGIVERS

Zimbabwean men have become increasingly involved in caring for AIDS patients, challenging the stereotype that caring for the terminally ill is women's work. For 48-year-old Luckson Murungweni, it would once have been inconceivable that he would care for the chronically ill, let alone those dying from AIDS.

"As men, we never viewed ourselves as crucial in providing care to those being claimed by the AIDS pandemic. But things changed last year when councillors approached us and urged us to become involved," Murungweni said. Now he is the focal point of a home-based care project in rural Goromonzi, some 35 kilometres east of the capital, Harare.

With the support of the Hospice Association of Zimbabwe (HOSPAZ), district councillors helped men form a group that would complement the efforts of the women providing home-based care. Although the men were initially reluctant to participate for fear of stigma, the relatively novel idea eventually took off and now has spread to other parts of the country. The Zimbabwe Red Cross Society currently has its own home-based project in which 105 out of 900 facilitators countrywide are men.

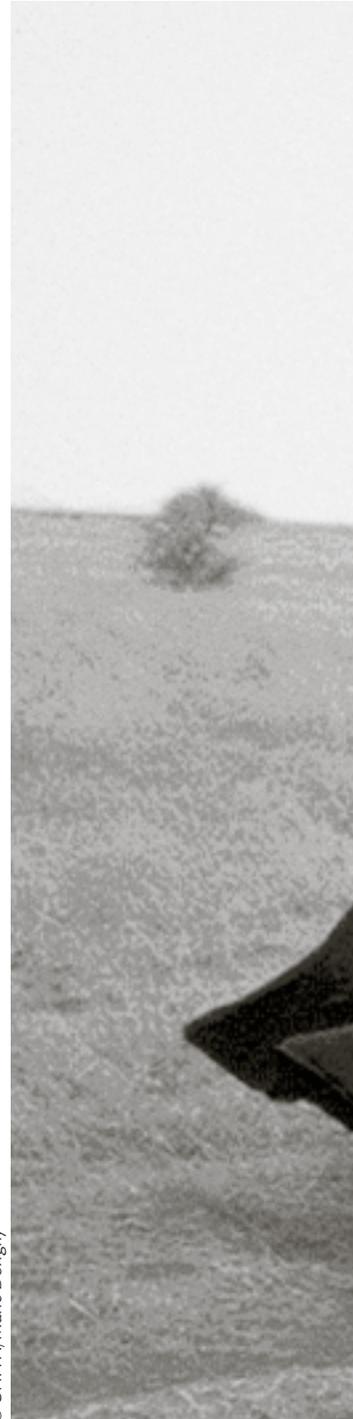
"To me it is encouraging to see men becoming less idle and less chauvinistic. Their decision to participate in community-based caregiving is a great shift in the way they have perceived the AIDS issue—they are coming to realize that AIDS is just one of the diseases that needs to be fought by society as a whole," said Murungweni.

Source: "Men Break with Tradition to Become AIDS Caregivers," *IRIN Plus News*, 17 May 2004

some of the burden off women who are caring for patients. They provide emotional support and counselling and help clean, dress and feed patients. They will clean the house, wash clothes and fetch and boil water if they see that family members cannot handle these chores.¹¹ Over 90 per cent of the volunteers are women and, as in Haiti, some are HIV-positive, although not all the volunteers are open about their status and many have not been tested. "I like my voluntary health work because I am able to reassure some of the patients who find it difficult to accept their HIV-positive status," said one woman who has been a volunteer for several years. "I share my personal experience that denying your status doesn't help to prepare your mind, body or your soul to live with the virus."¹²

Even when *accompagnateurs* or volunteers are available, family members remain the primary caretakers and need their own support services so as not to be overwhelmed by the responsibility. Training programmes are being set up in places like Kenya, for example, to provide basics such as nursing kits with rubber gloves and masks and to teach caregivers how to use them. These programmes also try to address HIV's emo-

tional and financial drain. When training involves entire communities, this approach can help relieve some of the stigma directed at AIDS patients and their families. Ghana has been experimenting with distance learning courses through the University of Ghana to train women and men in local communities as 'change agents' in the fight against HIV.



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Nationwide, 366 participants have taken part so far and are working in their communities to identify caregivers who need support and to provide information on HIV.¹³ The programmes in Ghana and Kenya have shown that communities are most receptive to new information about HIV when they learn from colleagues and neighbours whom they already know and trust.

One training programme that has been very effective is known as Stepping Stones. It involves a series of meetings where various peer groups such as young women or older men meet separately at first and then come together for larger discussions about issues that are important to them. It

In subsistence economies, women spend much of their day performing tasks that maintain their households, like gathering water. Caring for an AIDS patient can increase their workload by a third.



“Our grandma is really caring for and supporting us. She is doing her best to provide what we need, but I am in third grade, my brother in the first, and my youngest brother in pre-school. I am not sure my grandmother will be able to pay our school fees when we go to higher class.”

Jackeline, aged 14
Juba, Sudan

has been used in many parts of Africa to help communities decide for themselves how to respond to HIV and determine where the need is greatest. By also focusing on behaviour change, it allows community members to see how certain attitudes and actions may have contributed to the rise of HIV.¹⁴

Alice Welbourn, one of the creators of the Stepping Stones method, described a session in Uganda where some of the older women in a village drew a diagram about life in the community, the good and the bad, during one of their sessions. Then an elderly woman presented it to a larger group of villagers. This woman, who could neither read nor write, stood in front of a flip chart diagram and described what had only become apparent as the women began talking with each other: They were responsible for so many orphans among them that many were facing starvation. They did not have the time or capacity to tend the fields any longer, and crops were being engulfed by weeds.

The elders of the village were shocked, as the women themselves had been when they first began talking—each had thought the problem was hers alone because no one had ever discussed it publicly before. They were able to use that session to devise a plan for boys and young men in the community to help tend the fields so the women could feed their families again.

Training and support programmes need to focus on the needs of young girls who are nursing family members and supporting siblings. Many of these girls are invisible to service providers because they rarely enter the public health system. Programmes like SHAZ in Zimbabwe (see p. 15) are trying to build new models for providing emotional and financial resources to girls who are caretakers.¹⁵ In Rwanda, NGOs and international agencies are providing vocational training and skill-building classes to youths—mainly girls—who are heads of household and helping to create support groups for them. In Uganda, where one family in four is looking after children not their own, the Uganda Women’s Efforts to Save Orphans (UWESO) is working with girls who have become the main support of their families, providing training, paying school fees and helping them develop income-generating activities.¹⁶

Men are also playing an increasing role in taking on tasks and responsibilities within the household that are culturally perceived to be ‘women’s work’. As part of its strategy for addressing violence against women and its effect on HIV/AIDS, the Men as Partners (MaP) programme in South Africa (see p. 47) also focuses on the need to transform gender relations within the household. One MaP coordinator, Stephen Ngobeni, described the difficulties involved in getting men to take on responsibilities that traditionally have been viewed as women’s domain: “When I stand up and challenge men’s roles, I’m seen to be a rebel. People look at me and say ‘how can he do things like this?’” When Ngobeni tried to get villagers to contribute to the cost of hiring trucks to distribute water, in order to ease the burden on women caregivers, villagers turned on him. “They said that was what women did traditionally. They said that women must bring this water. That women are sitting doing nothing.” When Ngobeni took on the work with family members, carrying water to the village, others began to see how much work was

involved for women and agreed to hire trucks. “We need to stand up and talk even when people criticize us,” said Ngobeni.¹⁷

These training programmes and activities are only the beginning of what must be a massive effort—the needs of families affected by AIDS are enormous and growing. Even as prevalence rates come down in countries such as Thailand or Uganda, the impact of AIDS will continue for years afterwards in terms of orphaned families, wages lost to caregiving and death, and resources spent on health care. The social services that will ease some of this burden are a critical part of HIV treatment.

Chapter 5



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Since losing both parents to AIDS in 1999, Sarah, 15, has struggled to raise her younger brother and sister in northern Zambia. She attends school only a few hours each week.

EDUCATION

Recommendation: Promote girls' primary and secondary education and women's literacy

Education is key to an effective response to HIV/AIDS. Studies show that educated women are more likely to know how to prevent HIV infection, to delay sexual activity and to take measures to protect themselves. Education also accelerates behaviour change among young men, making them more receptive to prevention messages. Universal primary education is not a substitute for expanded HIV/AIDS treatment and prevention, but it is a necessary component that complements these efforts.

Using Education to Prevent HIV

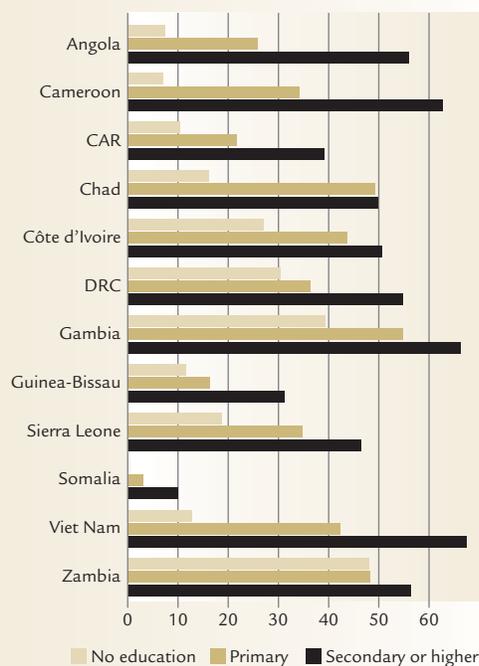
Schools can be a primary source of information about prevention methods in the fight against HIV. New analysis by the Global Campaign for Education suggests that if all children received a complete primary education, the economic impact of HIV/AIDS could be greatly reduced and around 700,000 cases of HIV in young adults could be prevented each year—seven million in a decade.¹ Earlier studies show that in many countries, including the world's poorest, the more educated and skilled young people are, the more likely they are to protect themselves and the less likely they are to engage in risky sexual behaviour. The benefits of education come from actual knowledge that students gain about HIV, from training in negotiation and life skills and from their increased ability to think critically and analyse situations before acting.

According to the Global Campaign for Education, “research shows that a primary education is the minimum threshold needed to benefit from [health information] programmes. Not only is a basic education essential to be able to process and evaluate information, it also gives the most marginalized groups in society—notably young women—the status and confidence needed to *act* on information and refuse unsafe sex.”²

A 32-country study found that women with post-primary education were five times more likely than illiterate women to know facts about HIV/AIDS. Illiterate women, on the other hand, were four times more likely to believe that there is no way to prevent HIV infection.³ In Zambia, during the 1990s, HIV infection rates fell by almost half among educated women but showed little decline for women with no formal schooling.⁴

CHART 3

Percentage of women who know main ways to prevent HIV transmission, by education level



Sources: MICS2 household surveys 2000/2001

Also in Zambia, other studies have shown that the more schooling young people have, the less likely they are to have casual partners and the more likely they are to use condoms.⁵ Other countries show similar patterns. In 17 countries in Africa and four in Latin America, better-educated girls tended to delay having sex and were more likely to insist that their partner use a condom.⁶

In contrast, unequal access to education, with fewer girls attending school than boys, correlates with higher infection rates among both men and women. A study in 72 capital cities found significantly higher infection rates where the literacy gap between women and men was large,⁷ and another study indicated that countries where the literacy gap between girls and boys was above 25 per cent were more likely to have generalized epidemics than countries with a smaller gap.⁸

Much of the research that has focused on women and education also shows that post-primary education has the most impact, providing the greatest pay-off for women's empowerment. Higher levels of education provide much more than specific information on HIV transmission. They also provide adults and young people with the larger life skills they need to make informed choices and to develop both economic and intellectual independence. Girls and women gain self-esteem along with knowledge. They are able to prepare for the work force, better able to protect their families' health and less likely to die during childbirth than those who are less educated. They are also more likely to marry at a later age. Girls with less than seven years of schooling are more likely to be married by

THE MULTIPLE BENEFITS OF GIRLS' EDUCATION

Education has an impact on young women's risk of contracting HIV. It can affect HIV rates and change women's lives by:

Reducing poverty

In Zambia, rural women with no education are twice as likely to be living in extreme poverty as those who have benefited from eight or more years of education.

Improving the health of women and their children

Educated mothers make more use of health care facilities, including the health services that effectively prevent fatal childhood diseases. Worldwide, the risk of a child dying prematurely is reduced by around 8 per cent for each year that its mother spent in primary school.

Delaying marriage

In Bangladesh and Ethiopia, increasing education has played a vital role in reducing child marriage, in part by ensuring that girls have access to the information and social networks that can protect them.

Reducing female genital cutting (FGC)

Educated women are less than half as likely to be subjected to FGC and four times more likely to oppose FGC for their daughters.

Increasing self-confidence and decision-making power

Evidence from across the world shows that, though women everywhere continue to be constrained by unequal power relations, increased education helps women to gain in status and secure greater decision-making power in the family and the wider community.

Source: Global Campaign for Education 2004, *Learning to Survive: How education for all would save millions of young people from HIV/AIDS*, Brussels

age 18, and early marriage is directly linked to an increased risk of HIV infection.⁹

Higher levels of education also seem to reduce—though not eliminate—girls’ and women’s risk of violence, another predictor of HIV infection (see Chapter 6). Regarding specific knowledge about HIV, a study conducted in Uganda over the course of the 1990s showed that both women and men who finished secondary school were seven times less likely to contract HIV than those who received little or no schooling.¹⁰

Despite the overwhelming evidence of education’s importance in helping to limit the spread of HIV, a recent worldwide study found that about 40 per cent of countries have not yet taken the basic step of including information about AIDS in their school curriculum.¹¹ Nevertheless, there have been some notable successes where such programmes have been introduced. The Government of Uganda estimates that approximately 10 million young people receive AIDS education in the nation’s classrooms, many of whom entered school for the first time when fees were eliminated in the 1990s. In one school district more than 60 per cent of students aged 13 to 16 had reported that they were sexually active in 1994. By 2001, that figure was reduced to fewer than 5 per cent.¹²

As part of its outreach to young people, Uganda also has a lively monthly newspaper called *Straight Talk* that contains articles on sexuality and intimacy written by secondary school students.¹³ Botswana, where girls are four times more likely than boys to be HIV-positive, has also created innovative programmes.¹⁴ It is currently training students to become peer facilitators for gender-sensitive clubs that will be based in public schools.

In Brazil, when HIV prevalence rates for teenage girls aged 13 to 19 shot up 75 per cent from 1991 to 2000, government officials turned to the secondary schools to build awareness of HIV and modes of transmission. Adolescents now learn about HIV prevention, often in same-sex classes so they can feel free to discuss fears and concerns about intimacy and sexuality without embarrassment. The Government is also distributing condoms through selected secondary schools, which are teaching young women how to negotiate condom use if their partner is hesitant.

These programmes can only be effective if they reach their target audience. Too many young people are not enrolled in school and many do not stay through the post-primary years. Globally, 115 million children do not attend primary school, and 57 per cent of them are girls. Studies find that 150 million children currently enrolled in school will drop out before completing primary school and at least two thirds will be girls.¹⁵ In sub-Saharan Africa, more than half of girls—54 per cent—do not complete primary school.¹⁶ And in South Asia, only one in four young women aged 15 to 19 have completed fifth grade.¹⁷ Girls’ enrolment rates are decreasing in some of the countries hardest hit by HIV.

Children in families affected by AIDS are more likely than others to be taken out of school. Illness prevents family members from earning an

WHY GIRLS ARE NOT IN SCHOOL

Girls are less likely than boys to attend school because:

- Parents are more likely to spend meagre resources on educating a boy;
- Many families do not understand the benefits of educating girls, whose role is often narrowly viewed as being prepared for marriage, motherhood and domestic responsibilities;
- Girls in many communities are already disadvantaged in terms of social status, lack of time and resources, a high burden of domestic tasks and sometimes even a lack of food; and
- The burden of care for ill parents and younger siblings often falls on girls, which jeopardizes their ability to attend school.

Source: Global Coalition on Women and AIDS, *AIDS and Girls’ Education*, www.unaids.org/en/events/coalition_women_and_aids.asp

income, and what little money is available for school fees often goes to cover boys' costs first. Girls are also more likely than boys to leave school to care for family members who are ill or to support siblings when parents die of AIDS.¹⁸ There are currently an estimated 15 million AIDS orphans around the world, and the number is expected to reach 25 million by 2010. Most of them will be unlikely to have the resources to pay school fees.¹⁹ When extended family members step in to help, once again they often choose to pay for boys.

Schools themselves are affected by HIV, making it difficult for students to get a decent education. Many schools in Africa are losing teachers to AIDS, and it is assumed that a similar pattern will develop elsewhere unless steps to slow infection rates are successful. In Zambia, three quarters of the new teachers trained each year are needed to replace those who have died of AIDS. In recent years, Malawi has lost so many teachers to AIDS that some schools have had student to teacher ratios as high as 96:1.²⁰

Challenges to School-based Education

Despite the many benefits of education, there are also challenges. The environment in which girls and boys learn is as important as the fact that they are in school. Where schools do not provide a safe environment for girls, where they do not address behaviour patterns that contribute to gender disparity, there is the risk that many young women will leave school early or graduate without the skills and self-esteem they need to participate as equals in the world. In the Caribbean, which has the second highest HIV prevalence rates after sub-Saharan Africa, girls outperform boys throughout the education system, including at the university level where there are many more women graduates. Nevertheless, the rate of new infections among girls aged 15 to 19 is five times higher than that of boys of the same age group.

This 'remarkable paradox' between higher education levels and higher rates of HIV prevalence is tied, says Sir George Alleyne, the Secretary-General's Special Envoy for HIV/AIDS in the Caribbean, to young women's inability to advocate for themselves despite their years of education. "Possibly, the skills and knowledge women acquire in the formal education system are not sufficient to enable them to take control over other parts of their lives...it may come too late to prevent them from being the victim of unwanted or transactional sex as adolescents," he says.²¹ A study by PAHO shows in fact that fully half of all young women in the Caribbean report that their first sexual encounter was forced or coerced. In the same study, only a third of respondents were worried about acquiring HIV, indicating that both young men and young women need a deeper understanding of their vulnerability to infection.²²

In too many instances, schools are the places where girls first experience discrimination, sexual harassment and abuse, either from other students or from teachers. These pressures are common in schools throughout the world, but young women generally find a way to stay in

A girl pins a red AIDS ribbon on her classmate's clothes as part of an awareness campaign at a high school in Gauhati, India.



school in the developed world. In poorer nations, where it may not be easy to transfer or where there is less accountability, girls frequently drop out of school. Reports indicate that approximately one-third of schoolgirls in Johannesburg have been subjected to sexual violence at school.²³ An Africa Rights report identified cases of teachers demanding sexual favours in return for good grades in several countries, including the Democratic Republic of the Congo, Ghana, Nigeria, Somalia, South Africa, Sudan, Zambia and Zimbabwe.²⁴ Research in Kenya has also shown that teachers undermine girls in the classroom, contributing to the girls' feelings that they do not belong in school.²⁵ In many cases, a vicious cycle is created where girls who drop out of school are then more vulnerable to unwanted pregnancy and STIs, including HIV/AIDS.

To be most effective in reducing the impact of HIV/AIDS, education systems must be transformed. Their mandate must include imparting more than pure knowledge. They should challenge gender stereotypes and misinformation, train girls in skills that can provide economic opportunities, reinforce girls' participation and empowerment and promote knowledge of sexual and reproductive health, including ways to prevent unwanted pregnancy, STIs and HIV/AIDS. This transformation of education systems requires changes to the existing curriculum, specialized training for teachers, outreach to communities and parents, a stronger link between schools and health care systems, and flexible timetables for HIV-infected children.

Change is under way in many countries, both in terms of improving education about HIV/AIDS and increasing access to schooling. In Viet Nam, the Government has decided to include reproductive health and HIV/AIDS education in the national curriculum for grades 10 through 12. This model programme also trains teachers and is developing a special curriculum on adolescent reproductive health. Some governments are abolishing school fees. When Kenya eliminated its US\$133 annual tuition and \$27 uniform fee in 2003, more than 1.3 million children entered school for the first time. Malawi, Uganda and Tanzania have also instituted free primary education, and several of these countries hope to make secondary schools free also.²⁶

Even without fees, many school districts will have to offer incentives to families to make it financially feasible for them to send their daughters to school. Some areas have experimented successfully with offering food or cash incentives to families in order to keep their daughters in school, instead of putting them to work in the home or as wage earners. Efforts to keep all children in school and make it easier for girls to attend will substantially reduce poverty, child mortality, HIV/AIDS and other diseases.

THE PRICE OF AN EDUCATION

Abolishing school fees can affect HIV rates by eliminating one of the reasons young women go to 'sugar daddies'. Angeline Mugwendere, a young Zimbabwean who is now a women's rights activist, described the terrible price some of her friends paid in order to get money for school fees. "My fees were paid by an NGO, but I had to watch with pain in my heart as my friends got desperate to find ways to stay in school. Like me, they wanted to be recognized because of their education, and knew that schooling was the only way out of poverty for them. So they took the shortest possible way to achieve that, dangerous as it was. They went on to sleep with sugar daddies in return for cash to pay their fees. And many of them contracted AIDS. With access to school, these girls would be alive today and would have had a chance to make something out of their lives, as I have....World leaders should do everything it takes to keep girls in school—whatever the cost, it's worth it."

Source: Global Campaign for Education. 2004, *Learning to Survive*

Chapter 6



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A widowed survivor of the Rwandan genocide holds one of her neighbour's children. She was raped several times during the 1994 genocide and two years later learned that she had been infected with HIV.

VIOLENCE

Recommendation: Promote zero tolerance of all forms of violence against women and girls

The Link Between Violence and HIV/AIDS

Violence against women is both a cause and a consequence of HIV/AIDS. It is a fact of life for too many women in all countries, whether in peacetime, during conflict or post-conflict periods. The true extent of violence against women is unknown, but current research indicates that intimate partner violence ranges anywhere from 10 to 69 per cent, and one in four women may experience sexual violence by an intimate partner in her lifetime.¹ To truly understand the extent of violence against women, the number of women who experience violence at the hands of strangers must be added to the above figures.

Economic disruption, war or conflict also exacerbate gender-based violence in numerous ways. The experience of women like Khadija Bah, who was abducted by rebels in Sierra Leone (see Box, p. 49), is repeated many times over in conflict zones. In Rwanda, during the 1994 genocide, hundreds of thousands of women were raped, many by men who were HIV-positive.² Globally, up to two million women are trafficked every year, many of them at great risk of sexual abuse, and all at risk of HIV infection.³

If their HIV-positive status is known, many women are in danger of being beaten, abandoned or thrown out of their homes. Many are afraid to ask their partners to change their sexual behaviour or to use protection. In Botswana, women have admitted to health professionals that they are afraid of their partner's reaction if he finds out they are HIV-positive. That fear has kept them from being tested, from returning for their results if they are tested, from participating in PMTCT and treatment programmes and, for those who agree to be treated, from adhering to the regimen because they are trying to hide their pills.⁴ While violence and the fear of violence make it hard for women to access prevention, treatment and care, the very fact that they are living with violence seems to increase their susceptibility to HIV.

According to a recent study, one of the first to show a firm link between violence and HIV, women who are beaten or dominated by their partners are much more likely to become infected by HIV than women who live in non-violent households. The research was carried out among 1,366 South African women who attended health centres in Soweto and agreed to be tested for HIV and interviewed about their home lives. After being adjusted for factors that could skew the outcome, such as whether

GENDER-BASED VIOLENCE:

- Undermines progress in stopping HIV/AIDS transmission;
- Directly affects women's access to services, including methods of protection;
- Jeopardizes informed choice;
- Poses serious challenges to sexual negotiations, including the use of condoms;
- Is a factor in the spread of HIV; and
- Burdens overwhelmed health-care systems.

Source: Interagency Gender Working Group, USAID and Center for Health and Gender Equity (CHANGE) 2002, *Gender-Based Violence and Reproductive Health and HIV/AIDS: Summary of Technical Update*

TRAFFICKING SURVIVORS: HELP THEM HEAL THEMSELVES

In Kolkata, India, an organization called Sanlaap (Dialogue) runs a psychological rehabilitation programme for young women who had been trafficked or involved in sex work. The group has established a shelter, which provides health and counselling services, along with emotional support and occupational training. ‘Help them heal themselves’ is the guiding principle of the home. For HIV-positive girls, the home has started a care and support group known as ‘Asha’, where the young women talk about their health and treatment and help newer members come to terms with their status. The group has become a powerful voice, campaigning for the right of HIV-positive persons to care, treatment and support and to protection from discrimination and forcible testing. For Shanti, who was sold to a brothel owner at the age of 19 and soon became HIV-positive and pregnant, the programme offers hope for herself and her young daughter. “I want to send her to a good school. I want to show people that even a girl like me can have a life in spite of everything.”

Source: Bahuguna, Nitin Jugran, “Self-Healing Helps Ex-Sex Workers Return to Society”, Inter Press Service, 30 July 2003

interviewees had engaged in casual sex or sex work, the figures showed that women who were beaten by their husbands or boyfriends were 48 per cent more likely to become infected by HIV than those who were not. Those who were emotionally or financially dominated by their partner were 52 per cent more likely to be infected than those who were not dominated.⁵

A smaller study in Tanzania found that HIV-positive women were over two and a half times more likely to have experienced violence by their partner than HIV-negative women.⁶

This increased vulnerability is tied to several issues. One is lack of control. Male condoms or other protection are irrelevant when a woman is being beaten and raped. Another is physiological susceptibility. WHO reports that during “forced vaginal penetration, abrasions and cuts commonly occur, thus facilitating the entry of the virus—when it is present—through the vaginal mucosa.”⁷

These conditions are magnified for young girls. Their reproductive tracts are not fully developed and are therefore prone to tearing during sexual activity. They are more likely to experience sexual coercion than adult women. In several studies around the world, up to one third of adolescent girls reported that their first sexual experience was coerced. Many are married at a young age to older men, and the power inequities inherent in these relationships can lead to violence or the threat of it.⁸ Adolescent girls are also prime targets for traffickers or militia groups. Worldwide, it is estimated that 800,000 to 900,000 people—women, men, girls and boys—are trafficked every year into forced labour and sexual exploitation, a highly lucrative global industry controlled by powerful criminal organizations.⁹ The UN Office on Drugs and Crime estimated that in 1997, these groups amassed some \$7 billion a year while making use of the Internet to expand their networks in both industrialized and developing nations.¹⁰

The risk of violence and sexual abuse is high among girls who are orphaned by AIDS, many of whom face a heightened sense of hopelessness along with a lack of emotional and financial support. In a study in Zambia, Human Rights Watch found that among girls who had been orphaned by AIDS, hundreds were being sexually assaulted by family members or guardians or forced into sex work to survive.¹¹

Violence During Conflict

As difficult as it may be for women who experience violence during peacetime, the challenges during conflict are even greater, as police and judicial systems crumble and health infrastructure and other services decline. Both UN Security Council Resolutions 1325 on Women, Peace and Security and 1308 on HIV and Conflict note that women and girls are disproportionately vulnerable to HIV infection during conflict and post-conflict periods. This is not only because they are frequently sexually abused by various armed groups, but because they may be fleeing their homes, may have lost their families and their livelihood, and may have little or no access to health care. Along the eastern border of the Democratic Republic of the Congo, an ongoing civil war has destroyed

lives, villages and livelihoods. Now the area is thought to be on the verge of a major HIV epidemic. Some 60 per cent of the militia who roam the countryside raping, torturing and mutilating thousands of women and girls are believed to be HIV-positive, and virtually none of the women have access to services and care.¹²

Ending Violence

Gender-based violence is now one of the leading factors for HIV infection.¹³ Unless the link between the two is broken, it will be hard to reverse the epidemic. While the challenges are daunting, there are many models already in place that use a variety of approaches: utilizing the health-care system, human rights protection, education, legal reform and working with community groups. When the rule of law has been eroded or has disappeared, as in conflict situations, efforts are being made to offer protection and prophylaxis through humanitarian agencies. One hopeful response is the involvement of men who are working in anti-violence projects, both because it is the right thing to do, and because they understand that changing behaviour is a way to safeguard their own health.

Involving Men

Men are both instigators of violence and essential to the solution—a reality that is recognized by both men's and women's groups in many parts of the world. In particular, men are beginning to organize effectively against violence against women by examining their own attitudes and behaviours. This is a rapidly growing movement that has been most visible in sub-Saharan Africa. It has emerged out of a concern that violence against women puts both men and women, young and old, at tremendous risk.

In Kenya, men are organizing with the support of FEMNET, a regional women's network. In November and December 2003, under the banner 'Men Working to Stop the Spread of HIV/AIDS', Men's Travelling Conferences were organized through urban and rural areas of Ethiopia, Kenya, Malawi and Zambia. Travelling in buses through the region, men stopped in towns and villages to lead debates, and discussions about how to change attitudes and behaviours. The conferences culminated in Malawi on World AIDS Day, with a commitment to expand the work into the coming months and years.¹⁴

In South Africa, 'Men as Partners' (MaP), initiated by EngenderHealth, an NGO based in New York, uses workshops to discuss gender roles and to train peer leaders.¹⁵ The programme has expanded throughout the country and is now being used in trade unions and the South African Defence Force. MaP urges men to challenge unequal gender roles and relationships within the household. "I realized it was impossible to work around issues of gender when you haven't started with yourself," said one peer leader. "I started becoming a counsellor to abusive men when I was actually getting assistance for myself. It is impossible to talk about HIV/AIDS when you are not talking about domestic and sexual violence."

A boy perches on his father's shoulders during a men's march to protest violence against women in Cape Town, 2001.



© Anna Zieminski—AFP/Getty

RWANDA'S PEACE BASKETS

AVEGA has helped its members, Hutu and Tutsi, create a project based on reconciliation that also helps support widows and orphans. Many women were weaving beautiful baskets but had no way to sell them until UNIFEM helped broker a partnership between AVEGA and the Business Council for Peace, an association of business women based in the US. Rwanda's 'Peace Baskets' were born out of that partnership, and are now sold throughout the world via a retailer on the World Wide Web.

Source: www.bpeace.com

“To reduce the acceptability of violence we need moral and credible leadership at all levels of society.”

Geeta Rao Gupta, President,
International Center for Research
on Women (ICRW)

Similarly in South America, several NGOs are trying to confront a sub-culture of male aggressiveness head on. Instituto Promundo, a Brazilian NGO based in Rio de Janeiro, identifies young men in low-income communities who are ‘more gender-equitable’ than most and trains them to become group leaders. Working with three other NGOs (ECOS and PAPA based in other cities in Brazil, and Salud y Género in Mexico), they developed training manuals for community interventions on sexual and reproductive health, mental health, violence prevention, fatherhood and care-giving, and HIV/AIDS. The manuals have been used in workshops where the young men lead discussions on male ‘honour’, condom negotiation and sexual coercion.¹⁶

BOTSWANA’S WOMEN AGAINST RAPE BATTLE VIOLENCE AND HIV

Breaking barriers, creating positive attitudes and changing behaviour are the main messages of Women Against Rape (WAR) in Botswana. The organization provides support for women and girls who are victims of violence and rape, and pursues activities aimed at preventing rape, all forms of sexual abuse, sexual harassment and violence in schools, at home and in the community. Together with some of the highest HIV prevalence rates in sub-Saharan Africa, Botswana has been experiencing a rising incidence of rape and so-called ‘love-killings’ by intimate partners.

In partnership with male activists, WAR, funded and supported by the African Youth Alliance (AYA),* held a national march in 2003 against all forms of violence that drew hundreds of primary and secondary students. They also developed and distributed 20,000 copies of a pamphlet whose title indicates how serious a problem gender-based violence has become: ‘My child has been raped... What should I do?’ The pamphlet aims to reduce the stigma attached to rape victims, increase compassion and ensure that girls and women receive counselling and medical care. The publication is targeted at primary school libraries, village reading rooms and community libraries, as well as parents.

WAR has also developed and supports Students Against Rape (SAR) clubs in schools. By the end of 2003, the clubs had reached 2,748 young people, the majority in the 15 to 19 age group with nearly equal numbers of girls and boys.

*The African Youth Alliance is supported by many organizations, including the Bill & Melinda Gates Foundation, UNFPA, PATH and Pathfinder International.

Expanding Health Care

Many countries, spurred by women’s rights activists, are using the health-care system as a major entry point for ending violence. When obstetricians in Nigeria were surveyed on violence against women among their patients, 99 per cent said they had managed a case of violence at some point. They estimated that about 7 per cent of their patients annually were women who had been abused, with the majority of cases involving pregnant women. In 70 per cent of the cases, the assailant was the husband.¹⁷

In several countries, health workers are being trained to recognize signs of gender-based violence and to provide medical care as well as counselling and referral services. Some clinics are able to offer post-exposure prophylaxis (PEP). In Brazil, health centres are a source of referrals to shelters and to peer groups such as the one run by Promundo. Médecins Sans Frontières added a rape clinic to their HIV prevention and treatment centre in Khayelitsha, South Africa (see p. 26) as a way to help their patients cope with the high levels of violence against women in the country. Within six months, 105 girls and women who had been raped visited the clinic; 75 were under 14 years of age and 37 required PEP treatment to prevent HIV infection.¹⁸

In many countries, health centres have been developed that offer medical attention to survivors of violence, along with counselling and legal referrals, all in one setting. Although still small in number, they could become an important source of HIV education and treatment in the coming years.

Promoting Women’s Legal Rights

Gender-based violence is commonplace in all regions. As a result, activists over the last few decades have turned to the courts and legal system to address it. Due to their advocacy in various countries, trials and convictions for rapists have become more common, domestic violence has been criminalized, health professionals have been obligated to report violence and the police have begun to

treat it as a crime. Many countries now have laws that recognize the rights of women who have been trafficked. In a few countries, marital rape has also been recognized as a crime.

These legal reforms have been supported by a human rights agenda based on a series of international conventions and agreements that recognize women's right to live free of violence. General Recommendation 12 of the Committee that monitors implementation of the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW), which had been ratified by 175 nations as of January 2004, requires signatories to take all appropriate measures to eliminate gender-based violence. These measures can include actions to end trafficking, to provide training for armed forces and police on women's rights or to protect children from sexual abuse.

Addressing Gender Violence in Conflicts

In most conflict settings, the rule of law is virtually nonexistent. But even under violent conditions, it is possible to provide at least a modicum of protection. International entities and NGOs are attempting to distribute emergency health kits to women in conflict zones that contain post-exposure prophylaxis, condoms and other medications that are a small but critical part of women's health-care needs.

Refugee camps and centres for the internally displaced are also becoming sites for education and services relating to HIV. As more women take on leadership roles in camps, they have also been able to bring about changes that make the camps safer for women. Peacekeepers are also being used to provide education and raise awareness. In Sierra Leone, one of the first programmes to acknowledge the critical role peacekeepers can play in preventing HIV/AIDS and protecting women's rights, UN peacekeepers are trained in HIV/AIDS prevention, gender awareness and peer communication.¹⁹

The challenge of repairing the devastation caused by violence continues long after the fighting stops. In Rwanda, ten years after the genocide, women's support groups are the glue helping to hold shattered communities together. One of the best known of these organizations is AVEGA, which was started to serve widows of the genocide. In the early years, members were dealing with memories of rape and torture and haunted by visions of their families being slaughtered while they watched. It was only the need to support their remaining children that kept many alive. AVEGA helped them get job training, acquire land and build houses. But with time, a new crisis emerged as HIV began to appear among the widows. In one survey of 1,125 women who had survived rape during the genocide, 70 per cent tested positive.²⁰ Now AVEGA devotes a substantial amount of time and resources to helping women get medical support for opportunistic diseases and counselling to prepare families for the ravages of HIV. "They have such courage," said one AVEGA officer. "The women have challenged everybody and everything. It is the challenge of life over death."

REBUILDING LIVES DESTROYED BY VIOLENCE

On the outskirts of Freetown, Sierra Leone, a makeshift shelter is home for a group of young women who have not had a home in years. One of them is 19-year-old Khadija Bah, who was forced to watch as her parents were killed by armed militia, was raped in front of her husband, and finally made to watch as he too was executed. She was abducted by the militia and forced to serve as a sexual slave. Eventually she escaped and made her way to Freetown, where like thousands of other young women with no means of support, she turned to sex work to earn a living and, like the others, every day risks becoming infected with HIV.

Today, hundreds of young women like Khadija receive care and attention at the Women in Crisis project started in 1997 on the outskirts of Freetown. The project was created by 'Auntie Juliana' Konteh, 42, an evangelist missionary, to help girls and women scarred by the nation's years of civil war. Two drop-in centres have been established where women and girls learn to protect themselves against HIV/AIDS and are trained in sewing and craftwork, skills that will eventually help them to give up sex work. They also learn to read and have a safe place to talk about their problems. As 14-year-old Christiana, who was repeatedly raped after watching her mother being tortured, says, "I lost my parents and my two brothers. But now I have a family again."

Source: UNFPA: *Building a Future in Sierra Leone*, www.unfpa.org

Chapter 7



© Jaime Razuri--AFP/Getty

HIV-positive activists stage
a protest on World AIDS Day,
1 December 2003, in Lima, Peru.

WOMEN'S RIGHTS

Recommendation: Promote and protect the human rights of women and girls

Protecting the human rights of women and girls also protects them from HIV/AIDS. More than any other disease in recent decades, HIV/AIDS has exposed the social inequities that make girls and women more likely to become infected, but women need more than rights in order to protect themselves. They need to know that they have such rights, that they can act in their own self-interest and that they will be supported by their communities and governments.

“We must have HIV/AIDS programmes, but not only that. There must be programmes in all other development areas, which address equality, autonomy, encouraging girls and women to be independent, and that must be extended to the political arena and every aspect of life.”

Nafis Sadik, UN Special Envoy to the Secretary-General on HIV/AIDS for Asia and the Pacific

In many countries, women cannot take human rights for granted. They do not have access to the education and information that would help them learn how to avoid HIV infection. They are subject to violence, which robs them of control over their bodies and limits their ability to use methods to prevent HIV infection. This chapter looks at two aspects of human rights: instances where these rights appear to come into conflict with traditional practices such as early and forced marriage, female genital cutting (FGC) and ‘widow cleansing’ (a traditional practice in which widows are expected to have sexual relations, often with a relative of their late husband, in order to secure property within the family); and instances where women’s ability to achieve economic independence is directly or indirectly affected by discrimination.

Freedom from Harmful Practices

Customary practices that seemed immutable when women’s rights activists began targeting them a few decades ago are now being called into question by leaders and policy makers. In many cases, the link to HIV/AIDS only makes the need to change practices such as early marriage, FGC and ‘widow cleansing’ more urgent. In South Asia and sub-Saharan Africa, for instance, the value of early marriage is being debated. In many developing countries, it is common to marry young people, especially girls, at an early age. But with the threat of HIV, many parents are marrying their daughters still younger in the mistaken belief that this might protect them from infection. Since the men who are financially able to marry are generally older and more sexually experienced, many are unwittingly bringing HIV and STIs to the marriage.

Despite laws in most countries establishing a legal age of 18 for girls to marry, many who are much younger continue to be married off. Worldwide, 82 million girls, generally from poor families, will marry before

“If you impose on me, I’ll fight. But if I am allowed the dignity and space to decide, I will fully cooperate.”

Imam Demba Diawara, a Senegalese religious leader, who walks from village to village in a personal campaign to end FGC

their 18th birthday, and will be more likely to become infected than their peers who are not married (see p. 16).¹

FGC may also increase the likelihood of girls and women becoming infected. The possibility of unclean instruments being used during cutting, as well as the increased likelihood of tearing and scarring during sexual intercourse or childbirth, have prompted activists and communities to seek out safer alternative rituals that still honour a young girl’s link to generations of women before her.

Since 1997, over 1,000 villages in Burkina Faso and Senegal have committed themselves to ending harmful traditional practices such as FGC and early or forced marriages after working with Tostan, an NGO based in Senegal. Using a human rights approach and programmes designed by the community, Tostan provides men and women with the information they need to weigh the value of a tradition against its costs.² Villagers decide the pace of the programme and air their support, concerns and fears about traditions, sometimes for the first time. It is up to the participants to decide what to do with the information they receive. “If you impose on me, I’ll fight,” said Imam Demba Diawara, a religious leader, who now walks from village to village in a personal campaign to end FGC. “But if I am allowed the dignity and space to decide, I will fully cooperate.”³

‘Widow cleansing’, practised in some communities in Africa and Asia, is also being targeted. Such ‘cleansing’ generally involves a widow having sexual relations either with a designated village cleanser or with a relative of her late husband. It has traditionally been a way to break with the past and move forward—as well as an attempt to establish a family’s ownership of the husband’s property, including his wife. In cases where a husband died of AIDS, this practice is just as risky for the men who are chosen to ‘cleanse’ as the women who are ‘cleansed’. It also prevents women from inheriting property that has been their family’s main source of support.

In a small village in western Kenya, a group of widows are challenging the practice with help from AMREF, an NGO based in Nairobi. They have refused to sleep with a cleanser, and have borrowed funds to create a brick-making business so they do not have to rely on men in the village for support. The women also talk to anyone who will listen about the problems associated with cleansing and have won converts among the men. “Slowly by slowly we must change,” said one elder. “We used to say we would die for our traditions. Even me, I used to say cleansing was good. But I think this attitude helps nothing. We all may die if we don’t stop this one.”⁴

Freedom from Discrimination

Discrimination against women is a fact of life in all regions of the world, to varying degrees, and manifested in varying ways. In many countries, women face difficulties finding and keeping paid work or earning a wage that is equivalent to men’s. In some regions, they are not allowed to inherit or own property or are discouraged from doing so, meaning that a woman without male protection has very few ways to support herself or her children. Stigma and ridicule are still common in many courts and prevent women from bringing cases that could rectify some of the worst injustices.

The abuses of human rights that women deal with on a daily basis can become nearly insurmountable obstacles when HIV/AIDS is involved. One of the most serious economic effects of HIV for women has been the loss of property. A study in Uganda of HIV-positive widows revealed that 90 per cent of the women interviewed had difficulties with their in-laws over property and 88 per cent of those in rural areas were unable to meet their household needs.⁵ Also in Uganda, another study found that 37 per cent of widows—compared to 17 per cent of widowers—had migrated from their original homes because they were generally not entitled to inherit their husband's property and their families were likely to live elsewhere.⁶

In many regions, the right to inherit land is linked to cultural practices like cleansing. Women have been thrown out of homes they helped pay for and lost all their property because they refused to have relations with a cleanser. Because of conditions like these, Human Rights Watch has called the problem of property rights in sub-Saharan Africa 'catastrophic', leading to women ending up "homeless or living in slums, begging for food and water, unable to afford health care or school fees for their children, and at grave risk of sexual abuse or exploitation."⁷

In most of South Asia, women also have difficulty inheriting or owning property, even in instances where they are legally allowed to do so. According to the Positive Women's Network of South India, widows generally have the lowest status in the household under normal conditions and rarely inherit the property they shared with their husband during the marriage. The same is true in Bangladesh where, according to a 1995 survey, only 32 per cent of widows received their rightful share of an inheritance from their husbands. Adding HIV/AIDS to the picture robs women of any remaining status or rights they may have had in a household. Women who are either widowed by HIV/AIDS or found to be positive themselves may be cast out of their homes by their in-laws, or sent back to

A PIECE OF LAND FOR PEACE OF MIND

Nyaradzo Makambanga tried to leave her husband once. He had been having relations with other women and was rarely at home. Her family insisted she stay with him, because they could not afford to return the 'lobola' (bride price) he had paid for her. But in 1998, when she became ill, her husband told her to leave and refused to support her. Eventually her brother gave her the money to get medical help and she spent three months in a hospital, where she tested positive for HIV.

"I was shattered. My hopes and dreams had come to an end. I thought I was going to die and leave my children," Makambanga remembers. Then she heard about the Network of Zimbabwean Positive Women and its 'Women, Violence and HIV/AIDS' programme. "All the time I was married I did not know that I was being abused. Now I can talk about it," said Makambanga.

With new-found confidence, and with the understanding that she actually had the right to own land, she asked her village chief for a plot to farm. The chief agreed and, with a loan from the Network's revolving fund, Makambanga bought seeds and began planting.

Makambanga receives medical help for opportunistic diseases through the Network, as well as skills training and emotional and economic support. She also works with other women to teach them their rights. "I would not want to see other women go through the difficulties I went through because of ignorance. If I had known that even though I was married I had my own rights, I would not have ended up being HIV-positive," Makambanga said. "What women need is peace of mind and a piece of land to cultivate and be equal to men."

Source: Network of Zimbabwean Positive Women, 2000, "Progress Report to UNIFEM Trust Fund in Support of Actions to Eliminate Violence Against Women", April-September 2000, p. 9; Actionaid Alliance, June, 2002 *Speaking Out: On HIV and AIDS*, Brussels

South African HIV/AIDS activists celebrate the decision by the Kwazulu-Natal province government to distribute the AIDS drug Nevirapine, which helps prevent mother-to-child transmission of the virus.



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their parents' home without their dowry, making it difficult for their parents to support them.⁸

Laws are not enough to change these conditions. India, for example, has a law dating back to 1956 that allows some women to inherit property from their fathers. Despite the law, women rarely inherit and are often unaware of their rights. According to a report by the UK Voluntary Services Overseas (VSO), many lawyers do not understand the law as it applies to women's inheritance rights and do not know that a case can be expedited if it involves a person living with HIV/AIDS.⁹

Change is coming about slowly, although the pace is likely to increase as the link between discrimination and HIV becomes clearer. International human rights instruments can give structure and direction to activists' efforts. For instance, the CEDAW Committee has called on governments to go beyond simply passing laws and implement measures that can eliminate the bias that makes it difficult for women to act on their rights. In cases where poor women from rural areas do not have access to legal representation, governments are expected to find ways to provide subsidized or free legal advice even in isolated areas.

In sub-Saharan Africa, the 2003 Protocol on the Rights of Women in Africa was added to the African Charter on Human and Peoples' Rights, thanks to lobbying by several advocates, including Julienne Ondziel-Gnelenga, a Congolese lawyer who was formerly the African Commission's Special Rapporteur on the Rights of Women in Africa. Ondziel-Gnelenga worked for seven years to get the protocol written and approved. Its guarantees include property and inheritance rights, the right to reproductive health care and the right to be free from harmful practices and gender-based violence. "We realize it will not be easy to implement

the agreement," said Ondziel-Gnelenga, "but a legal basis of that kind is vital."¹⁰

Even before the protocol was passed, several countries, including Rwanda, had acted to increase women's human rights. The 1994 genocide had left Rwanda deeply damaged in numerous ways. It was a nation being rebuilt by women, who were farming land they had no legal right to own. The 1999 Rwanda Inheritance Law is an effort to change this by giving widows the right to inherit their deceased husband's property and granting

equal inheritance rights to male and female children. Despite the importance of recognizing girls' and women's rights in this area, implementation has been hindered by the fact that customary law still holds sway in parts of the country and women are disinherited. Rwandan human rights activists warn that a nationwide education campaign to inform men and women about women's right to own property is essential if the law is to have an impact.¹¹

Ultimately, implementation and enforcement are essential. The political will to implement laws that have been passed is critical to ensuring women's human rights. But political will is easily deflected by economic concerns, military threats and limited resources. It has long been recognized that ensuring women's human rights is essential to growth and development. Now, with HIV/AIDS decimating nations, guaranteeing those rights is essential for survival. It is up to policy makers to ensure that these human rights have pride of place alongside more commonly acknowledged development goals.

HUMAN RIGHTS ACCORDS AND COMMITMENTS

1979 Convention on the Elimination of All Forms of Discrimination against Women (CEDAW):

Article 10 provides that States must take measures to ensure women's equal rights with men to education. Among the provisions of *Article 12* is the requirement to take all appropriate measures to eliminate discrimination against women in the field of health care in order to ensure, on a basis of equality of men and women, access to health-care services, including those related to family planning. *Article 16* requires States Parties to eliminate discrimination against women in the context of marriage and family relations.

1993 World Conference on Human Rights, Declaration and Programme of Action ('Vienna Declaration'):

Article 41 recognizes the importance of women's right to enjoy the highest standard of physical and mental health throughout their life span. Throughout the document there are significant statements relating to women's human rights and violence against women.

1993 Declaration on the Elimination of Violence against Women: *Article 4* calls on States to condemn violence against women and not invoke any custom, tradition or religious consideration to avoid their obligations with respect to its elimination. States should pursue by all appropriate means and without delay a policy of eliminating violence against women.

1994 International Conference on Population and Development (ICPD), Programme of Action: *Article C, Chapter 7* addresses sexually transmitted diseases and the prevention of HIV from the perspective of women's vulnerability to the epidemic, setting out key recommendations for addressing HIV through reproductive health services.

1995 Fourth World Conference on Women ('Beijing'), Declaration and Platform for Action: *Strategic Objective C.3* is to "Undertake gender-sensitive initiatives that address sexually transmitted diseases, HIV/AIDS and sexual and reproductive health issues".

2000 Millennium Declaration and Development Goals: *Goal 3* calls on nations to "Promote gender equality and empower women" and *Goal 6* is to "Combat HIV/AIDS, malaria and other diseases".

2001 UN General Assembly Special Session (UNGASS) on HIV/AIDS, Declaration of Commitment : *Article 14* of the Declaration stresses "that gender equality and the empowerment of women are fundamental elements in the reduction of the vulnerability of women and girls to HIV/AIDS".

Chapter 8



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Participants in a 'March for the Sake of Life' marking World AIDS Day, 1 December 2003 in Moscow.

CHARTING THE WAY FORWARD

As this report shows, the growing impact of HIV/AIDS on women and adolescent girls has reached crisis proportions, particularly in Southern Africa. A massive, concerted effort at all levels is required to address the needs of women and adolescent girls and the human rights violations and gender inequalities that drive the epidemic. Increasing the involvement of men and boys is critical. The real challenge is political will, commitment and accountability. But goals cannot be achieved without the requisite resources—not only through increasing the amount of funds available globally, but through ensuring that current funding is directed to gender-sensitive programmes that benefit women and adolescent girls.

The time for action has not only come, it has passed. It is imperative to recoup lost time and to move ahead on a global scale.

Immediate action is needed in the following key areas. In each area, women and girls, especially those who are living with HIV/AIDS, must be involved.

ACTIONS THAT MUST BEGIN WITHOUT DELAY:

Support positive women and their organizations and networks

- Listen, respond to and include the voices and demands of positive women who are living with HIV and AIDS in efforts to bring about critical changes that are needed in policies, strategies and laws as well as funding for programmes ranging from the national level to community-based initiatives.

Make AIDS money work for women

- Ensure fully resourced programmes that respond to women's needs and circumstances—in prevention, treatment, community-based care, education, violence and human rights.
- Ensure that new and existing funding is channelled rapidly in this direction. This requires tracking and monitoring resource flows to ensure that women and adolescent girls benefit.
- Undertake gender analysis at every stage of policy design, implementation and evaluation to ensure that all forms of gender discrimination are eliminated and to protect and promote women's human rights.

- Undertake gender budgeting exercises to ensure that budgetary allocations match policy commitments.

Ensure that adolescent girls and women have the knowledge and means to prevent HIV infection

- Institute population-wide gender-sensitive communication and advocacy campaigns that:
 - convey basic facts about HIV/AIDS prevention;
 - dispel harmful myths and stereotypical notions of masculinity and femininity that underlie destructive behaviours and attitudes;
 - provide a warning that marriage does not necessarily offer protection from HIV/AIDS transmission; and
 - involve both young men and women in promoting sexual and reproductive health among their peers.
- Empower women and girls economically by providing them with access to credit and business and leadership skills in order to break the cycle of poverty, gender inequality and vulnerability to HIV transmission.
- Increase access for women to both male and female condoms and skills in negotiating their use. Increase provision of disposable needles and syringes and harm reduction programmes for men and women who are injecting drug users.
- Provide HIV prevention in all health-care settings.

Ensure equal and universal access to treatment

- Ensure that women have equitable access to treatment and resources through the WHO/UNAIDS '3 by 5' campaign.
- Ensure universal access to voluntary counselling and testing that addresses stigma, discrimination and gender-based violence and encourages partner testing, couples counselling and confidentiality.
- Strengthen and expand sexual and reproductive health services and training for health-care providers to provide HIV/AIDS treatment and prevention.
- Conduct and widely disseminate research on the short- and long-term effects on women and infants of antiretroviral drugs used to prevent mother-to-child transmission.

Promote girls' primary and secondary education and women's literacy

- Eliminate school fees to keep girls in school.
- Promote zero tolerance of violence against women and girls in schools and sexual harassment policies with strong and swift penalties for those who abuse students.

- Provide life-skills education both in and out of school that fosters mutual respect and equality between boys and girls.
- Ensure that school curricula remove gender stereotypes, promote girls' leadership and self-esteem and include age-appropriate information on sexual and reproductive health and HIV/AIDS.
- Expand literacy classes for women of all ages

Recognize and support home-based caregivers of AIDS patients and orphans

- Provide social protection mechanisms for caregivers to help relieve women's heavy burden of caring for sick and dying family members and for orphans.
- Undertake campaigns to raise the visibility of the burden of care on women and encourage equitable sharing of household and caregiving responsibilities throughout the life cycle.
- Provide training, counselling, and psychosocial support to home-based caregivers and volunteers.
- Strengthen public health and caring facilities and services to relieve the workload entailed in providing community and home-based care.
- Establish financial support for community gardening, cooking and other activities that support and/or replace individual household tasks and responsibilities.

Promote zero tolerance of all forms of violence against women (VAW) and girls

- Engage in dialogue with community and religious leaders about human dignity and negative effects of violence against women and girls.
- Develop broad-based media campaigns to combat violence against women and girls and promote zero tolerance for VAW at the community and household level.
- Actively involve men in campaigns that address masculine norms and behaviours that heighten the risk for both men and women of HIV infection.
- Provide counselling services for girls and women who have experienced sexual violence to address their trauma and mitigate long-term consequences.
- Ensure that humanitarian responses to crisis situations include sexual and reproductive health services and counselling.

- Provide easily accessible and free post-exposure prophylaxis (PEP) to all rape victims within 24 to 72 hours.

Promote and protect the human rights of women and girls

- Codify and revise laws and practices to protect and promote the rights of women and girls in line with the United Nations Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW) and ensure their implementation.
- Include in country reports to the United Nations Committee monitoring CEDAW information on both the violations of women's human rights in relation to HIV/AIDS and measures taken to redress such violations.
- Protect and promote women's property and inheritance rights, as well as the restoration of confiscated property and the provision of alternate shelter and livelihoods.
- Support free or affordable legal services, including by training paralegals, to protect the rights of women and girls affected by HIV/AIDS.

CONCLUSION

Strong leadership at all levels is required to address gender inequality as a central driver of the HIV/AIDS epidemic and to reverse the spread of the disease. Heads of State, government officials, policy makers and community and religious leaders must speak out strongly and urgently on the need to protect women and girls from violence and discrimination and to make gender and HIV/AIDS a highly visible priority.

But leadership alone will not resolve the crisis. Governments and economic policy makers must redirect existing resources to address the needs and realities of women and girls, and the entire international community must mobilize new resources. Most importantly, government officials at all levels must guarantee that these resources are made available where they are most needed, in programmes for the women and girls affected by HIV/AIDS.

Without leadership and political will, without the necessary funding, the situation for women and girls will continue to deteriorate and the hope of achieving the Millennium Development Goals by 2015—particularly reducing extreme poverty—will not be fulfilled. We can no longer look at women as victims; it is time to recognize and build on their strengths. Strategies to reverse the AIDS epidemic cannot succeed unless women and girls are empowered to claim their rights.

A Positive Network for Women: Kousalya Periasamy was 19 when she got married. Marriage and children had always been her dream. But a few weeks after the wedding, her husband told her he was HIV positive. “It was very cruel of him to marry me because he tested positive before the wedding. The doctors asked him not to marry, but he did not pay attention,” she said.

Seven months later Periasamy’s husband died; his legacy to her was HIV and the stigma that surrounded it. She was forced to leave her home and move in with relatives because of the fear and public disapproval that surrounded her as a woman living with HIV. “All my dreams were shattered,” she said. “I could only wait for death.” But as the months went by, she began to come alive again and decided that her legacy would be different from her husband’s one of secrecy and deceit. She decided to fight AIDS by educating young girls like herself.

Periasamy began appearing in public, speaking at schools and gatherings, and eventually on television when the media picked up on her efforts. She also began visiting other HIV-positive women, trying to get them to go public also. Most were not ready to face up to the social disapproval that was being heaped on Periasamy for daring to talk about her HIV status in public.

When Periasamy moved to Madras, she discovered the Indian Network of People Living With HIV/AIDS (INP Plus), an NGO that gave her the idea of starting a group specifically for women. With help from INP she called the first meeting of the Positive Women Network of South India. Eighteen women showed up to talk about their lives and the impact HIV had had on them. Now the group’s members number in the hundreds, and meetings feature doctors, dieticians and social workers. Members can take advantage of counselling and social services as well.

“Most of our members are housewives,” said Periasamy. “We tell them to go out and seek employment. If they sit at home they will brood about their troubles. Widows have the worst deal. They have to look after the children and provide for their education. It is very difficult to do this when you are sick too.”

“I thought I would not be able dream again, but I do have dreams now,” Periasamy said. “I dream of helping the unhappy. People should know everything about the HIV virus. I want to make everyone aware of the disease so that nobody will get this virus in the future!”

“As a teenager, there was only me in my dreams. But today, I see many people.”

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CHAPTER 7: WOMEN'S RIGHTS

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