Chapter 1

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.

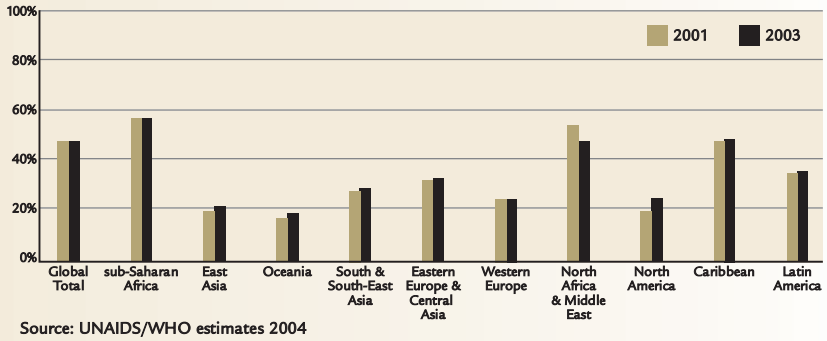
An 18-year-old Mozambican girl with her brothers. She has become the head of her family since both parents died from AIDS. In her local school, there are 200 orphans out of a thousand students.

Gender and Regional Differences[1]

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

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

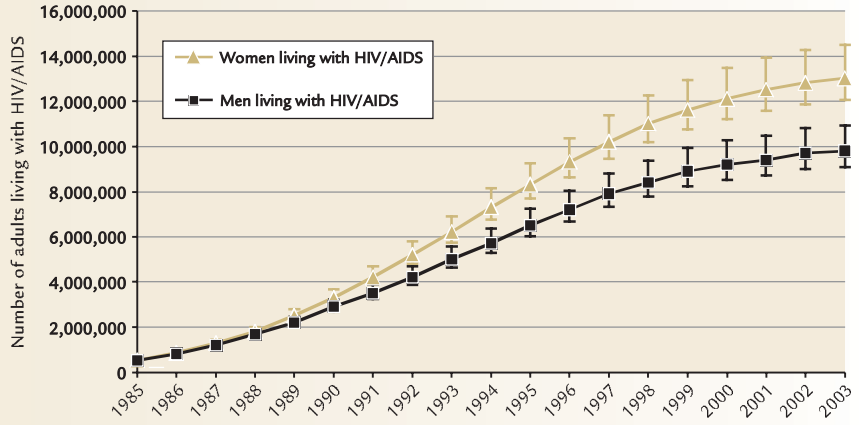
from particular population groups—such as sex workers or injecting drug users—into the general population, with women and girls increasingly affected. The distinct differences in regional trends in terms of modes of transmission and burden of disease—and the cultural, social and economic environments 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.

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

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.

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.