Introduction

The Durban Monitoring the AIDS Pandemic (MAP) Network Symposium, *The Status and Trends of the HIV/AIDS in the World* was held on 5-7 July 2000. This was an official satellite symposium of the XIIIth International AIDS Conference, 9-14 July 2000.

The three-day MAP Network symposium held in Durban was the seventh symposium formally organized by this global network formed in December 1996. It was part of a continuing series of regional and global symposia that have been organized to understand the trajectory of the HIV/AIDS epidemics. Starting with *The Status and Trends of the HIV/AIDS Epidemics in Africa Symposium* that was held in Kampala, Uganda in December 1995, a team of internationally recognized technical specialists in epidemiology, modeling, economics, demography, public health, and international development was formed to monitor the dynamics of the HIV/AIDS pandemic and various regional epidemics. By collecting, analyzing, and disseminating information on HIV/AIDS, this team of experts, which has grown rapidly over the course of four years into a global network, seeks to assist governments, organizations and the world at large to respond more actively and effectively to the challenges posed by the HIV/AIDS pandemic.

The MAP symposium in Durban brought together 38 global and regional experts, including MAP members and some specially invited participants, to achieve the following objectives:

- To present and share new information on the status and trends of the HIV/AIDS epidemics in the world;

- To review the epidemiological and behavioral patterns among the HIV/AIDS epidemics affecting the different populations;

- To identify specific data needs for monitoring and estimating the HIV/AIDS epidemics; and

- To produce and disseminate a consensus report on the current status of the HIV/AIDS epidemics in the world.

This report, co-authored by the Durban MAP Symposium participants and produced in less than 24 hours, reflects a consensus of the analysis, projections and recommendations brought forward during the symposium. Its aim is to provide information that can be used by international bodies, to briefly review the most important aspects of the history of the HIV/AIDS epidemics to date, to recognize the current status of and trends within these epidemics, and to take immediate action to affect the course of these epidemics in the future.

Statement of the Global Network of People Living with HIV/AIDS (GNP+):

Impact of data on the HIV/AIDS epidemic on the lives of people living with HIV/AIDS

The importance of data concerning the trends and determinants of the HIV/AIDS pandemic cannot be denied. For people living with the virus it impacts us in many ways. Data can help improve the level and scope of care and treatment services which we receive and it can contribute to mitigating at least some of the impact of the stigma and discrimination which we face on a daily basis.

Governments, donor organizations, communities, NGOs and the private sector all need HIV/AIDS monitoring data. Data can be used to mobilize political will in order to increase the scale of both prevention and care interventions, to identify priorities for the allocation of scarce resources, to select and target activities, and to monitor the progress in the response to the epidemic. True, accurate and reliable data regarding the pandemic are essential to ensure that the scale of the crisis is both understood and to improve our collective response.

People living with HIV/AIDS, organized under GNP+, are concerned when different information about the epidemic is collected and presented by different groups of people and institutions. Information about the global and national trends which is not consistent cannot be used for planning and setting priorities for prevention and care investment. This directly affects the lives of people living with HIV in the respective countries as time is lost in debating the validity of the sources of information and preference is often given to the source that paints the picture less gloomy. We are concerned that those who wish to deny the true scope and nature of the crisis can also misuse data. In addition, endless debate can yield ongoing inaction or misallocation of funds.

We therefore call upon the International Organizations, National Institutes/Ministries of Health and the National AIDS Control Programs to emphasize the need for reasonably accurate statistics on the epidemic for planning and making the right decisions. Factors that bring about the inaccuracies should therefore be isolated and corrective measures put in place. At the same time, academic discussion about the validity of the data should give room to concrete action for preventing further spread of HIV and ensuring access to care for those infected.

People living with HIV/AIDS can be a valuable resource to assist epidemiologists and program managers in their difficult work to provide a true picture of the situation. From our participation in cohort studies to assistance in identifying potential sample populations for participating in behavioral surveillance investigations, we offer our experience and abilities to assist in ensuring that data collected are not only valid but are further transformed from mere numbers to action and hope for our future.

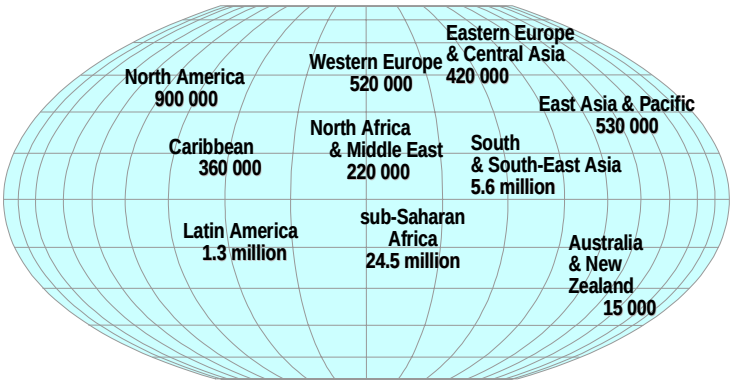
Milly Katana, Board Member for Africa
Joseph Scheich, International Coordinator

The AIDS Pandemic at the start of the 21st Century

Global and regional overview

At the turn of the millennium, UNAIDS and WHO estimated that 34.3 million adults and children were living with HIV/AIDS. More than 18 million have already died of the disease. The vast majority – about 95 percent – of all people living with HIV/AIDS (PLWHA) live in developing countries. The proportion will continue to rise in these countries, where poverty, poor health systems, gender inequality, limited resources for prevention and care, as well as denial and stigma fuel the spread of the virus.

Adults and children estimated to be living with HIV/AIDS, end 1999



Total: 34.3 million

Africa

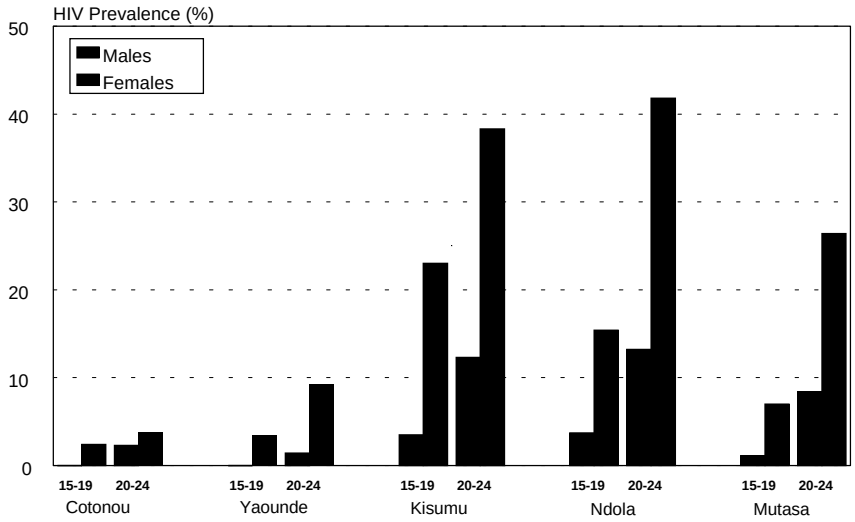
As seen above the situation is worst in sub-Saharan Africa. With 24.5 million infections, almost one in ten adults 15-49 years of age is already living with the virus throughout the sub-continent. The spread is not equal within sub-Saharan Africa. While the first major epidemics were described in countries of central and eastern Africa, the epidemic is now far worse in the southern part of the continent. In South Africa, infection rates increased from less than 1 percent in the adult population at the beginning of the 90s to about 20 percent within less than one decade. Twenty percent and more of the adult population are also living with the virus in Botswana, Lesotho, Namibia, Swaziland, Zambia, and Zimbabwe. The latest data show that more than one-third of all men and women 15-49 years of age are now living with the virus. Such rates were never thought to be possible and are hard to grasp.

Women are harder hit in Africa than men. About 55 percent of all adults living in the sub-continent with HIV/AIDS are women. The difference between men and women is most pronounced in those less than 25 years of age. A population-based survey in Kisumu, Kenya, showed HIV rates in 15 and 16 year old girls of 8 and 18 percent while no infections were documented in boys of the same age. In 19 year old girls the rates were up to 33 percent, while that in boys was almost 9 percent. The reasons for these extremely high rates in girls are not fully understood. Biological vulnerability of young girls and the fact that girls frequently have sex partners of much higher age – with high levels of infection – likely play a role.

BOX: High Vulnerability to HIV Infection in Young Women in sub-Saharan Africa

Several studies in sub-Saharan Africa have noted that HIV prevalence is high in young women within the first few years of sexual activity but rises more slowly in young men. Recent data from four urban populations and one rural population confirm dramatic male-female differences in HIV prevalence in young adults (see Figure). To a degree, these differences could be an artifact due to inadvertent failure to include young men with higher rates of HIV seropositivity in the surveys but the consistency of the finding and the magnitude of the difference makes this unlikely as a full explanation.

HIV Prevalence in Young Men and Women in sub-Saharan Africa



Women may have higher HIV prevalence than men because they are more exposed to infected partners and/or because they are at higher risk of acquiring HIV infection from an infected partner. The risk of exposure to an HIV infected partner at a young age depends on the age at sexual debut, the number of partners, and the likelihood that those partners are infected. Reported age at first sex is similar for men and women, and even at young ages men generally report higher numbers of partners than do women. Since HIV prevalence increases with age, the tendency for young women to have older partners both within and outside marriage may increase their exposure to HIV-infected partners. Age differences between partners similar to those recorded in Mutasa have been found in a number of studies. In Mutasa, the older a woman's most recent partner, the more likely she was to be infected with HIV.

Although age difference between partners provides a partial explanation for the

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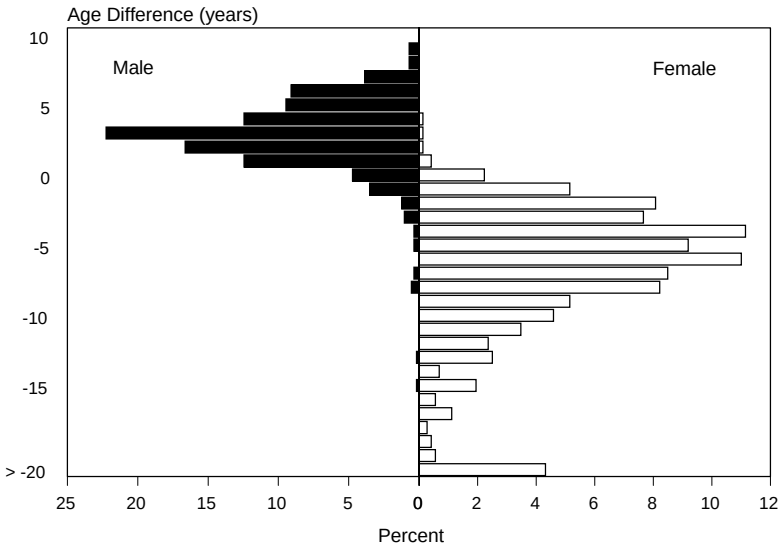
early rise in prevalence in young women, it does not appear to be the full answer. It has been estimated that, in Kisumu and Ndola, the risk of having an HIV infected partner is similar for young unmarried men as for unmarried women. This suggests that young women may be particularly susceptible to HIV. There is some evidence that HIV transmission from men to women is more efficient than from women to men. Several studies of discordant couples in Africa and elsewhere have found higher

Age Difference between Respondent and Partner



seroconversion rates in initially seronegative female partners of male index cases, than in the initially seronegative male partners of female index cases, though other studies have found similar seroconversion rates for men and women in HIV discordant partnerships. Susceptibility to HIV infection in very young women may be particularly high due to immaturity of the genital tract and laceration of the hymen at first sexual intercourse. Young women were also found to have high prevalence of other sexually transmitted infections, including HSV-2, in these studies. These infections, which are frequently acquired from older partners, increase susceptibility to HIV infection.

Asia

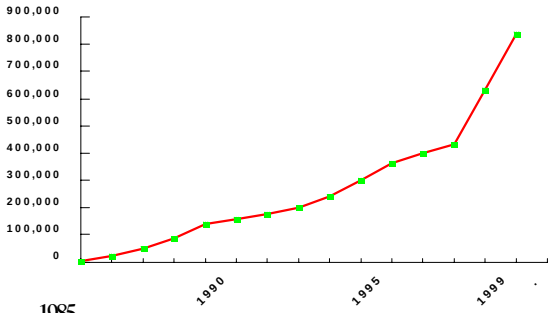
In Asia, rates of infection are generally much lower. They reach two percent or more of the adult population in three countries, Thailand, Cambodia and Myanmar. In many of the very populous nations of the region, prevalence does not exceed 1 in a thousand. However, nationwide average prevalence estimates do not tell the full picture. China and India are home to more than one-third of the world's total population. Each of these countries has more inhabitants than all African nations together. As in Africa, the spread of HIV is different from one province to another in China, or from one state to another state in India. In fact, while HIV seems to be extremely rare in some states in India, especially in the northern parts of the country, rates have reached 2 percent and more in the state of Tamil Nadu. One can easily imagine what it would mean in terms of total numbers if HIV would spread at similar levels to others states, given the sheer size of the country's population.

BOX: China

China's transition since 1978 from a planned economy to an open market has led to an unprecedented period of economic growth. However, these changes have also been accompanied by changes in social norms and individual behavior. Up until this point in time, the number of reported AIDS cases is quite small, but all 31 provinces have reported AIDS. With a population of over 1.2 billion even a limited epidemic could affect millions of people. Indeed, the China Government/UNAIDS/WHO estimate that 500 thousand Chinese were HIV positive at the end of 1999. Given the right conditions, China's HIV/AIDS epidemic could begin to spread even more rapidly.

One worrisome indication of the presence of just those conditions is the increasing number of reported cases of sexually transmitted infection (STI). Reported cases of STI have increased from 5.8 thousand in 1985 to over 836 thousand in 1999. Considering the fact that reported cases are thought to be seriously underreported, these data suggest the increasing potential for rapid spread of HIV.

China: Reported STIs, 1985 to 1999



According to official estimates, there are a minimum of 3 million drug users in China. Limited studies show that needle-sharing is common, with more than 45 percent of injectors sharing needles. HIV infection is reported among injecting drug users (IDU) from 25 provinces. In 1995, data from eight IDU sentinel sites found HIV infection ranging from 0 to 0.2 percent. By 1999, based on data from 19 sites, prevalence ranged up to over 77 percent.

There are also indications of increasing risk for heterosexual transmission in China. With official estimates of more than 3 million sex workers in China, condom use and HIV prevalence among sex worker populations are important indications of heterosexual risk of infection. Data from sentinel surveillance sites show that fewer than 10 percent of sex workers reported always using condoms with clients, and more than half reported never using condoms. Sentinel surveillance of this population in 1999 shows prevalence ranging up to over 6 percent.

China faces many challenges in the coming years in preventing rapid growth of HIV infection. Public resources for prevention are limited and some government leaders are not convinced of the potential for rapid epidemic growth. Information campaigns have been few and the level of knowledge of prevention measures is low. The illegal nature of injecting drug use and sex work make populations with these behaviors very difficult to reach. Finally, China's increasingly mobile population will pose challenges to effective implementation of public health interventions.

Latin America

In Latin America, the picture is diverse as well. Rates are generally highest in Central America and the Caribbean where heterosexual spread of HIV seems the predominant mode of transmission. In Haiti rates today exceed 5 percent, the only country with such

rates outside the African continent. In countries of South America, the epidemics are generally concentrated in sub-populations at highest risk, such as men having sex with men (MSM) and IDU. Trends seen in these countries are similar to the patterns in the United States. While overall incidence of HIV infection is rather stable over the past several years, the proportion of infections through heterosexual contacts and consequently in women is increasing. Countries such as Brazil, Argentina, and Mexico have also made strong efforts in the provision of adequate care for those infected. In Brazil, like in other countries of the continent, access to ARV (anti-retroviral) treatment through the public service is guaranteed by a presidential law. As a consequence, these countries have seen reduced morbidity and mortality from AIDS in recent years.

BOX: Brazil

The first Brazilian AIDS cases were diagnosed in the early 80's primarily in MSM and blood product recipients. Changes in the epidemiological profile have been observed over time. In the last three years, the incidence rate of new AIDS cases has stabilized around 14.0 per 100,000 inhabitants, the incidence among MSM and IDU has been decreasing and heterosexual transmission seems to be on the increase.

The role of local or regional NGOs, supported by the government, has been crucial for innovative approaches as well as reaching target high-risk and vulnerable populations. During the 1994-1999 period, 900 NGO projects were granted, involving an amount of US$ 25.2 million dollars.

Health promotion and intervention activities, considered the most important priorities, have been implemented all over the country. National campaigns have focused on information on modes of HIV/STD transmission and prevention, the preventive role of consistent condom use, as well as the importance of the human and civil rights of people living with HIV/AIDS. Educational school programs, including health promotion and sexual education, have been set up and teacher training has been done through long distance teaching by TV broadcasting networks.

A national survey conducted in 1998/1999 showed significant sexual behavior changes. Results suggested that condoms were used by 48 percent of all young males in their first sexual encounter. This proportion rises to 71 percent among individuals with higher educational level. Current use of condoms is 12 times higher than in 1986, when they were used by scarcely 4 percent.

Data from the same survey also show that 24 percent of the population regularly use condoms and this proportion reaches 44 percent among young people aged 6-25. In sexual relations with non-steady partners among males between 16-65 years old, 63 percent report consistent use of condoms. Additional evidence shows an increase in commercial sales of condoms from 70 million in 1993 to 320 million in the year 1999.

A national public laboratory network was set up to guarantee the availability as well as quality control of laboratory tests including: HIV infection diagnoses, opportunistic infections diagnoses, viral load quantification and CD4/CD8 count, HIV characterization and most recently, an HIV resistance monitoring and an HIV genotyping network. Free access to lab tests is guaranteed in the public health system, following the National ARV Consensus.

The most important policy decision on HIV/AIDS was taken in December 1996, when the President signed a decree assuring free access to anti-retrovirals and drugs for opportunistic diseases to all people living with HIV/AIDS, allocating at the same time the required financial resources.

By February 2000, 85,000 people living with HIV/AIDS were receiving ARV treatment provided by the Ministry of Health (MOH) 5 percent of them were children. Annual expenditures for ARV rose from US$ 34.3 million in 1996 to US$ 335.0 million in 1999 and to an estimated US$ 400 million in the year 2000. The number of new patients has also increased over time, from about 24,000 in January 1997 to more than

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75,000 in December 1999. However, during the same period, US$ 472 million was saved due to the reduction in hospitalization and the cost of drugs for treating opportunistic infections. This amount does not take into account the reduction of retirements supported by public funds, or the wages otherwise lost to the economy. It does not take into account a non-measurable return: the welfare of patients and relatives, better quality of life, and longer survival.

As a result of this policy, the AIDS mortality rate has decreased over time. At the national level, a reduction of 38 percent in the fatality rate is observed from 1995 to 1997. In Sao Paulo, where one-third of Brazilian AIDS patients are found, a reduction in mortality of 50 percent was observed from 1995 to 1999.

The decision of the Brazilian Government also covers technological support to national production of ARV. Five state laboratories are now responsible for providing almost 30 percent of MOH acquisition and this proportion will increase to 70 percent by the end of the year 2000. The state companies mostly produce generic copies of drugs. Due to the introduction of local state production, a very significant price decrease occurred over time. From 1996 to 2000, there was an average cost decrease of about 60 percent compared to a 9 percent reduction for drugs produced exclusively by multinational companies.

In conclusion, the Brazilian case shows the positive impact of strong societal concern and commitment in responding to the HIV/AIDS epidemic, followed by a very clear government political decision. Even in developing countries, it is possible to change the face of the epidemic and to create new hope for the future.

Economic Savings With Antiretroviral Therapy
(1997/1999 [1])

	US$
•Estimated expenditures for AIDS treatment and monitoring:	472 million
•Estimated savings:	
•ganciclovir	34 million
•avoided opportunistic infections:	16 million
•avoided hospitalizations *:	422 million

*** Estimated number of hospitalizations avoided: 146,000**

[1]= Projection using 1998 data **Source: Brazil Ministry of Health**

"Minority" countries: the small islands, nations and territories of the Caribbean and the Central American Isthmus

Rightly so, most HIV/AIDS prevention efforts and international resources are being channeled to developing countries with a high HIV/AIDS prevalence. However, some of the smaller nations and territories with a worsening or potentially significant HIV/AIDS epidemic have not received sufficient attention by the international community. The Caribbean has one of the most severe HIV/AIDS epidemics outside sub-Saharan Africa. PAHO/WHO/UNAIDS estimate that there are about 360,000 people living with HIV infection in the Caribbean and that 1 in 50 persons between the ages of 15 and 49 are already infected with HIV. As of the end of 1999, more than 26,000 AIDS

cases had been reported in 19 English and Dutch-speaking small countries and territories in the Caribbean representing a population of approximately 6.6 million. Yet, the size of individual country populations – ranging from 8,000 in Anguilla to 2.5 million in Jamaica (with a median of approximately 80,000 for Dominica and Grenada) – has limited both the availability of local full-time, qualified personnel and the much needed international resource mobilization efforts commensurate with the national and regional magnitude of the HIV/AIDS epidemic.

A similar situation prevails in some of the Central American nations with increasing HIV prevalence such as Honduras, Belize, Guatemala and El Salvador, where demand for HIV prevention and care services clearly exceeds current capacity for response. Characteristically, the Caribbean and Central American countries host highly mobile populations which travel from country to country (e.g. migrant workers, CSW, truck drivers, sailors) and have significant trade, tourism and migration movements to and from other regions of the world, especially North America and Western Europe. In a fast-moving and shrinking world, "size really doesn't matter", and the impact of an unchecked HIV/AIDS epidemic in the Caribbean and Central America may be felt around the world (see also box x).

The Former Soviet Union

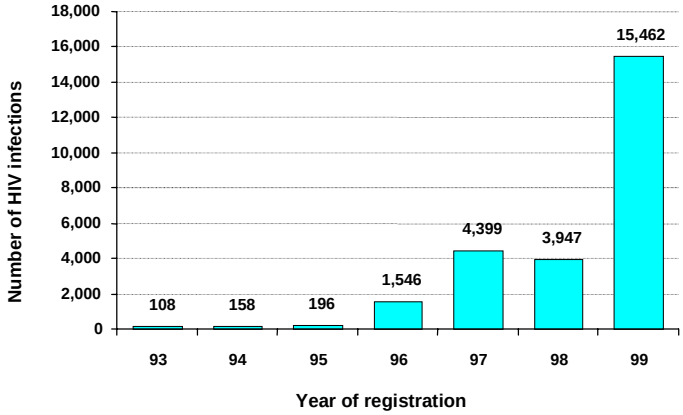
In the countries of the former Soviet Union, the HIV epidemics continue to be mainly concentrated in IDU. In the Newly Independent States, the IDU-associated epidemic only started in 1995/6, but now affects a large number of cities, and virtually all administrative regions in Ukraine, Russia, Belarus, and Moldova. In 1999, more than 5,000 drug injectors were identified as HIV infected in Moscow alone. Due to this outbreak in the Moscow region, more HIV infections have been registered in 1999 in Russia alone compared to all previous years put together (Figure CCC). HIV prevalence varies between less than 2 percent of IDU registered officially in Russia to about 30 percent in sentinel surveys in Ukraine and Russia and more than 60 percent in Svetlogorsk in Belarus and drug injecting sex workers in Kaliningrad. HIV prevalence among other population groups seems to have remained low so far.

While about 130,000 Russians are believed to be already living with the virus, the Russian Ministry of Health estimates the number of IDUs in Russia at about 3 million, 2 percent of the total population, providing for a large pool of highly vulnerable but not yet infected persons. Although not confirmed in scientific studies, similarly high estimates have also been made for Ukraine and other Newly Independent States. With the economic situation of women deteriorating, the number of women engaging in sex work, potentially at high risk of infection, is believed to have increased considerably.

At the same time, large epidemics of syphilis and other STIs have been reported from these countries. Between 200,000 and 400,000 new cases of syphilis have been reported annually in the past few years from Russia alone. And that my only be the tip of the iceberg, as under-reporting is believed to be high. Although major spread of HIV via heterosexual transmission in the population at large has not yet been confirmed, the massive increase in STIs in the populations of Eastern European countries does prove the

potential for more wide spread epidemics of HIV. Early and effective interventions are needed now to prevent what could develop into one of the major epidemics around the globe.

Annual number of newly registered HIV infections, Russia, 1993 to 1999



Source: *Russian Federal AIDS Centre, Moscow*

As described in more detail later in this report, the epidemics in industrialized countries follow a pattern with massive decreases in HIV morbidity and mortality since 1995 due to the introduction of Highly Active Anti-Retroviral Therapy (HAART). However, infection rates have been stable over the last decade and risk behavior seems to be increasing in some sub-populations.

The Demographic Impact of AIDS

Since the beginning of the epidemic, more than 18 million people have died of HIV/AIDS. However, with more than 30 million people currently living with the virus, and more than 5 million new HIV infections every year, this is only the beginning of the epidemic's impact. Globally, HIV/AIDS is now well established in the list of the top ten leading causes of death. It is only surpassed by disease groups such as ischiaemic heart disease, cerebrovascular disease, and lower respiratory infections – all typical causes of death among old people. In sub-Saharan Africa, where the epidemics are worst, AIDS kills by far more people than any other cause of death. More than 1 out of 5 deaths in the sub-continent are caused by HIV. And, unlike many other causes of death, AIDS deaths will continue to rise in the coming years. And it is highest in young women and men in their most productive years

As a result of high levels of HIV infection, estimated crude death rates including AIDS mortality are greater by 50 to 500 percent in eastern and southern Africa over what they would have been without AIDS. For example, in Kenya, with an adult HIV prevalence of 14 percent at the end of 1999, crude death rates in the year 2000 are estimated to be twice as high (14.1 deaths per thousand population), than they would have been without AIDS (6.5 deaths per thousand population). In South Africa, with an estimated 20 percent adult HIV prevalence level, crude death rates are also twice as high (14.7 per thousand population), than they would have been without AIDS (7.4 per thousand population). In Asia and Latin America the estimated crude death rates are also higher than they would have been without AIDS in many countries, although by a smaller amount.

AIDS deaths cause reduction in population growth

At the beginning of the 21st century the population growth rate in Zimbabwe has been reduced to nearly zero due to AIDS mortality, according to new population projections done by the U.S. Census Bureau. Other countries with sharply reduced growth rates include several other southern African countries: Botswana, Malawi, Namibia, South Africa, Swaziland, and Zambia. In Asia, AIDS mortality results in slightly reduced growth rates in Myanmar, Cambodia and Thailand.

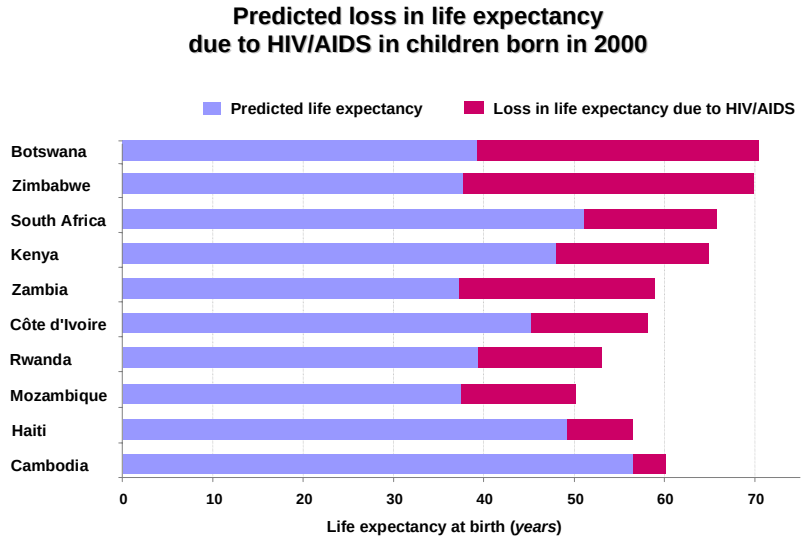
By the year 2003, Botswana, South Africa and Zimbabwe will be experiencing negative population growth, down to –0.1 to –0.3 percent from the 1.1 to 2.3 percent it would have been without AIDS. This is the first time ever that negative population growth has been projected for developing countries. Lack of growth is due to high levels of HIV prevalence in these countries coupled with relatively low fertility. In other countries, populations will still grow despite high levels of mortality, due to very high levels of fertility.

International development goals will not be achieved due to HIV/AIDS

Life expectancy and child mortality rates have been traditionally used as markers for development. While major achievements have been observed for both parameters in most countries over the past decades, AIDS has caused a reversal of these positive trends in many countries.

Children born today in Botswana, Malawi, Mozambique, Rwanda, Zambia, and Zimbabwe have life expectancies below 40 years of age. They would have been 50 years or greater without AIDS. In Botswana, life expectancy at birth is now estimated to be 39 years instead of 71 without AIDS. In Zimbabwe, life expectancy is 38 instead of 70.

In Latin America and the Caribbean, the impact on life expectancy is not as great as in sub-Saharan Africa because of lower HIV prevalence levels. However, they are still lower than they would have been without AIDS. In The Bahamas, life expectancy at birth is now 71 years instead of 80. And in Haiti, life expectancy is now 49 instead of 57. In Asia, Thailand, Cambodia, and Myanmar have lost three years of life expectancy.



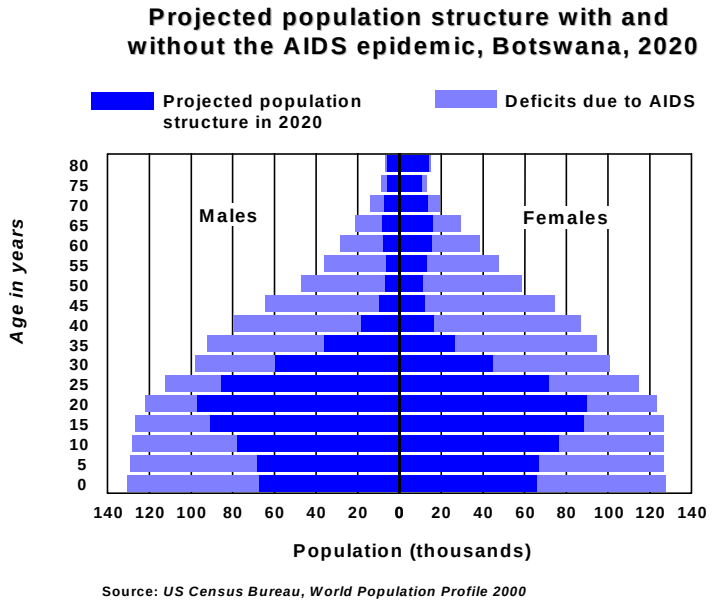
Source: *U.S. Census Bureau, 2000*

The impact on child mortality is highest among those countries that had significantly reduced child mortality due to other causes and where HIV prevalence is high. Many HIV-infected children survive their first birthdays, only to die before the age of 5. In Zimbabwe, 70 percent of all deaths among children less than 5 are due to AIDS. In South Africa, that percentage is 45. In The Bahamas, 60 percent of deaths among children less than 5 are due to AIDS. In Myanmar, Cambodia and Thailand, 1 percent of deaths among children are due to AIDS.

Due to these substantial increases in child mortality, only 5 out of 51 countries in sub-Saharan Africa will reach the International Conference on Population and Development goals for decreased child mortality.

AIDS mortality will produce population structures never seen before

Particularly in those countries with projected negative population growth, Botswana, South Africa and Zimbabwe, population "pyramids" will acquire a new shape "the population chimney". The implications of such new population structures are truly shocking. Large numbers of children will have lost their parents before graduating from school. Many of these will have to work to earn their living and that of their siblings. Increased child labor will be unavoidable. There will also be profound impacts on the labor force structure, which is already felt in many sectors in many countries. As projected by UNAIDS and UNICEF (see Progress of Nations, UNICEF, July 2000), the "teacher" to "pupil" ratio will be substantially reduced due to death of teachers from HIV/AIDS.



Source: *US Census Bureau, World Population Profile 2000*

Data on HIV infection rates and mortality do not tell the whole story

Many individuals have difficulty grasping the results of these high prevalence levels. The resulting AIDS mortality is difficult to comprehend. Given the current HIV prevalence rates, many more millions of individuals will die due to AIDS over the next decade than have over the past 2 decades. Many of the southern African countries are only beginning to see the impacts of these high levels of HIV prevalence.

Current prevalence data, horrifying as they are, do not convey the full picture facing individuals in high HIV prevalence populations. Because prevalence is a measure of current infection levels amongst living individuals, it does not capture infections amongst

those who have already died or who have not yet become infected but will be in the future. We can look at current incidence and mortality patterns and estimate the lifetime risks of contracting HIV and dying from AIDS faced by young people embarking on the sexually active phase of their lives. This analysis shows that in a country such as South Africa, or Zambia, where prevalence in the year 2000 has reached about 20 percent, a 15-year old teenager would face a lifetime risk of HIV infection and of death from AIDS on the order of 60 percent if experiencing current age-specific incidence rates throughout his or her life.

There have been success stories: Thailand, Senegal, and Uganda. In Thailand and Uganda, concerted efforts at all levels of civil society have turned around increasing HIV prevalence rates. In Senegal, programs put into place early in the epidemic have kept HIV prevalence rates low. These successes can be repeated. However, the current burden of disease, death and orphanhood, will be a significant and increasing problem in many countries of sub-Saharan Africa for the near future.

BOX: New Glimmers of Hope in South Africa and Cambodia?

Cambodia has the highest general population HIV prevalence in Asia. Prevalence in adult males and females aged 15-49 is estimated at 3.2 percent, with many women now being infected by their husbands, who form a bridge population with sex workers and other casual partners. National surveillance has monitored HIV since 1995 and behavior change since 1997.

Given the urgency of this situation, the nation has mounted a multisectoral, multilevel response. National AIDS Authority meetings, other national forums, and brochures on impacts have informed national and provincial authorities about the situation. The multisectoral National AIDS Authority, with 7 ministries represented, has enabled curriculum development for HIV/AIDS education in schools, condom promotion in the ministry of defence, and capacity building in the other ministries. Fourteen of 24 provinces have decentralised budgets for cross-sectoral HIV prevention and care projects, which are being mainstreamed into other activities. NGOs have been active in community level work with students, sex workers, police, military, and factory workers. Their Royal Highnesses the King and the Queen, held audiences for people living with AIDS on World AIDS Day in 1999 and His Royal Highness, Prince Norodom Ranariddh, chairs the National Assembly for AIDS Patients.

These combined efforts have produced a number of favourable outcomes. Twelve million condoms were sold last year, 80 to 90 percent of which were used for HIV and STD prevention. Consistent condom use in brothels increased from 42 percent to 78 percent between 1997 and 1999, accompanied by declines in a range of STIs among sex workers, who now receive correct treatment for these infections. HIV prevalence among sex workers under age 20 declined in 1999. These data offer glimmers of hope that another national response is having a substantial impact on HIV transmission.

Antenatal HIV surveillance data have been collected in South Africa since 1990, and indicate that HIV prevalence in pregnant women rose steadily until it reached 23 percent in 1998. However, there was no significant change in prevalence between 1998 and 1999. This slow down in prevalence change was due to very different trends in younger and older women. Teenage prevalence declined from 21 percent to 18 percent, prevalence in women in their twenties remained unchanged at 27 percent, whereas trends in those aged 30 and over rose from 17 percent to 20 percent. The decline in teenage prevalence occurred in most provinces, with the exception of West Cape (a low prevalence province) and North West and Free State. Age at first birth rose between 1998 and 1999, suggesting that the decline in HIV prevalence was very

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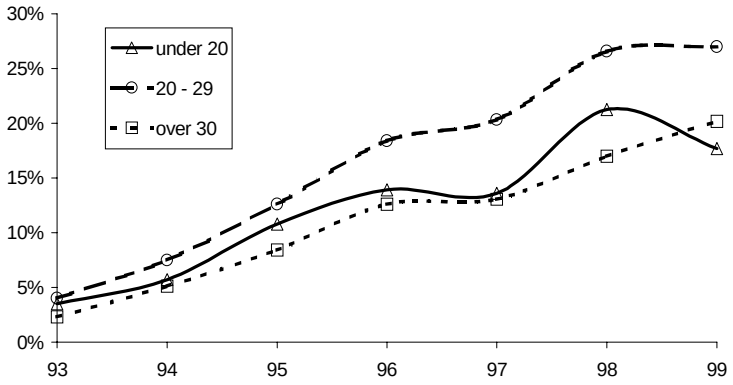
likely due to an increase in age at first sex among teenagers. Although this is an encouraging trend it might not lead to a sustained decline in HIV prevalence, unless it is followed by behavior change at older ages.

HIV prevalence by age,
South African antenatal clinics, 1993-99



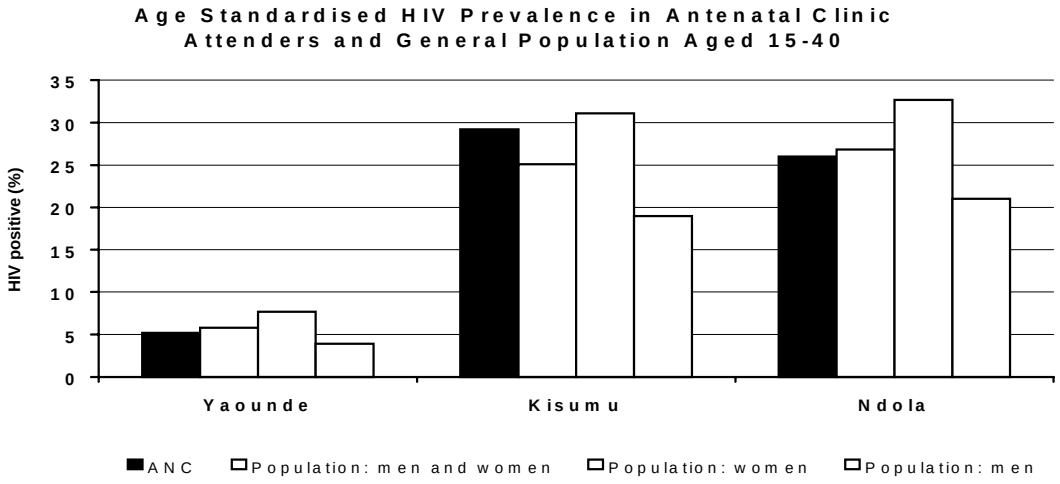
How reliable are antenatal clinic sentinel surveillance data?

Data on HIV prevalence are among the most complete disease-specific data available in the world. And countries in sub-Saharan Africa have some of the most complete sentinel surveillance programs. In the absence of widely available information from general population samples, the most widely used method of estimating general population HIV prevalence utilizes data on sentinel surveillance in antenatal clinics.

Despite this practice, HIV seroprevalence based on antenatal clinic data may likely be a biased estimate of prevalence in the population. Not all pregnant women attend antenatal clinics, and attendance will vary with age, locality, education level, parity, ethnicity and religion--factors also likely associated with HIV status. Data from pregnant women only provide information about those sexually active and tend to over-estimate the prevalence of HIV in the community, particularly in the youngest age groups. On the other hand, these data only pertain to fertile women, and HIV is associated with reduced fertility. These biases might lead one to question the use of data on pregnant women as a proxy for the general population. However, several studies have shown that HIV prevalence among antenatal clinic attendees still gives a reasonable overall estimate of HIV prevalence in the general adult population, although they tended to underestimate HIV prevalence among women and overestimate HIV prevalence among men. As a result of these concerns, there is a continuing interest in research comparing HIV infection in pregnant women and in the general population.

A new study, using identical methods in each site, has compared HIV prevalence measured in random samples of adults in the community with that measured in sentinel surveillance in antenatal clinics in Yaoundé (Cameroon), Kisumu (Kenya), and Ndola

(Zambia). In Yaoundé and Ndola, the HIV prevalence in pregnant women was lower than that in women in the population, overall, and for age groups over 20. In those under 20 in Yaoundé, HIV prevalence was higher in pregnant women than in the population. In Ndola the overestimate in young women was only seen up to age 18; thereafter HIV prevalence in pregnant women was lower than that in women in the population. In contrast, in Kisumu the HIV prevalence in pregnant women was similar to that in women in the population at all ages. The age-standardized HIV prevalence in pregnant women was similar to that in the combined male and female population aged 15-40 in Yaoundé and Ndola, but overestimated in Kisumu (see figure). These results, together with other studies, suggest that, in a generalized epidemic where the predominant mode of transmission is heterosexual, HIV prevalence data among pregnant women are a reasonable estimate of overall (male and female) HIV prevalence in the population, and are unlikely to overestimate HIV prevalence in women except in the youngest age group.



Epidemics in Russia and the other Newly Independent States, China and Vietnam: opportunities for focused prevention among injecting drug users and sex workers

In the countries of the former Soviet Union, as well as in China and Vietnam, the HIV epidemics continue to be heavily concentrated in IDU. Russia and many of the Newly Independent States have seen rapid growth of HIV among injectors in the last 3 or 4 years. In both China and Vietnam, over 60 percent of detected HIV infections have been among IDU. Yet, prevalence among other population groups has remained comparatively low so far. At the same time, large epidemics of other STIs have been reported from these countries. Between 200,000 and 400,000 new cases of syphilis are reported annually from Russia alone. China has seen a steady growth of STIs over the last several years. HIV prevalence among sex workers in southern Vietnam continues to grow, while studies of street sex workers have found many now injecting drugs. These data raise the possibility of major sexual epidemics that may bootstrap off of or run concurrently with the injecting drug epidemics.

Epidemics of this type are particularly sensitive to early and focused prevention efforts. Because the epidemic is concentrated in a limited number of smaller populations, efforts that work with the communities of IDU and with sex workers and their clients to reduce both their injecting and sexual risk can be particularly effective in slowing the spread of HIV to the general population.

However, as has been the case in many countries of the world, the major barriers to effective prevention remain in the policy arena. HIV prevention among marginalized groups such as IDUs and sex workers can only succeed in an environment that is conducive to the adoption of safe injection and safe sex behavior. Yet, IDU and sex workers face ongoing criminal sanctions in many of these places. This makes it difficult to work with the communities of drug users and sex workers and often keeps them from accessing prevention programs for fear of identification or arrest. Furthermore, public policies often prevent the distribution of clean needles or the possession of clean injecting equipment or condoms. For example, in other countries the police will often arrest those carrying injecting equipment. In other places, police will use possession of a condom as presumptive evidence of illegal sex work. Such policies discourage safer behavior among both injectors and sex workers. These public policies make it difficult or impossible for many injectors and sex workers to protect themselves.

The present epidemiological situation calls for an urgent coordinated response, before the window of opportunity to prevent a further spread from drug users and sex workers into the general population closes. Together with drug supply and demand reduction to reduce the number of IDUs exposed to HIV, harm reduction approaches, which international experience has shown to be effective to prevent HIV transmission, need to be adopted and operationalized. Similarly programs for sex workers and clients need to be expanded and strengthened to ensure that they have the coverage needed to contain sexual transmission. Approaches focused on greatly increasing condom use in commercial sex

have been effective in radically slowing HIV transmission in Thailand and now appear to be showing results in Cambodia.

These efforts need to be scaled up as a matter of urgency. MAP therefore calls upon all government sector in the countries concerned, including health, justice and internal affairs, as well as NGOs to join in a collaborative effort to establish effective HIV prevention programs that reach the majority of injecting drug users and sex workers in their countries.

BOX: HIV/AIDS in Nigeria – the fourth largest number of infections in the world

Surveillance is a crucial component of HIV/AIDS prevention and control in Nigeria. So, far four sentinel surveys have been successfully conducted among different sentinel groups in Nigeria: antenatal clinic women (ANC), STI patients, pulmonary tuberculosis (PTB) patients, long distant transport workers, and female sex workers. The last sentinel survey was carried out among ANC in 1999.

HIV prevalence in Nigeria has increased from 1.8 percent in 1992 to 5.4 percent in 1999 among ANC women. However, some hot spots have been found to have prevalence of up to 21 percent. The age group mostly affected is 20-24 years (8.1 percent). Rates were substantially higher in some high risk groups such as female sex workers (34.2 percent). HIV prevalence among blood donors has reached an alarming 11.0 percent, probably due to the lack of a national blood transfusion service in the country. It is hoped that the National Blood Transfusion policy, having just been launched, will have an impact on the safety of the blood supply.

Based on results of sentinel surveillance, the estimated number of adults and children living with HIV/AIDS in Nigeria is 2.7 million at the end 1999, the fourth largest number of infections in a country in the world.

Due to the level of the current epidemic and its dynamics, it has been recommended that HIV sero-prevalence surveys among ANC be conducted on an annual basis. HIV/AIDS sero-prevalence surveillance and behavioral surveillance among high risk populations is planned in 12 sentinel sites. The results of these surveys will provide a better picture of the dynamics and determinants of HIV spread in the country.

There is at the moment strong commitment by the Government to implement a multisectoral strategy with participation of all development partners to see how the epidemic can be controlled in the country. This has culminated in the inauguration of the Presidential committee on AIDS and the National Action Committee on AIDS to coordinate the implementation of this strategy.

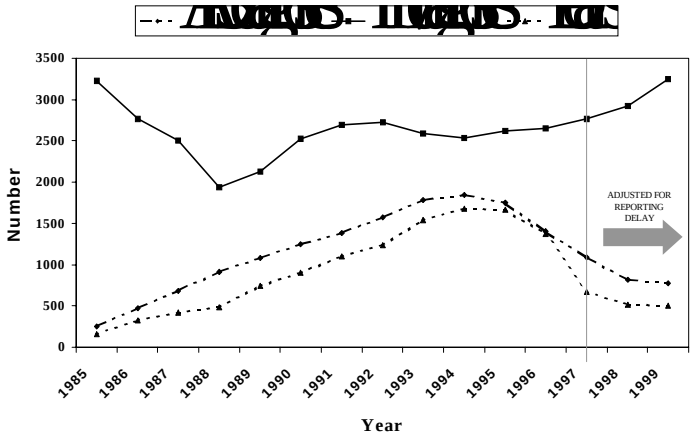
HIV/AIDS in Industrialized Countries: Have We Done Enough?

The HIV epidemics in most industrialized countries are concentrated in specific high-risk populations, primarily MSM and IDU. The epidemics in these populations are evolving at different speeds in each country, and in some, HIV is beginning to affect new population groups. Although there are differences in the specific aspects of these changes between countries, the major trends are common to many industrialized countries and are described in this section.

Reduced morbidity and mortality due to improved treatments

The overwhelming good news comes from improved regimens for treatment. The more effective Highly Active Anti-Retroviral Therapies (HAART) available in industrialized countries since 1995/1996 have prevented or delayed progression to AIDS and death in those treated. The resulting improved survival has led to decreases in annual AIDS incidence and in AIDS deaths since 1995 in industrialized countries, and data from the United Kingdom are shown as an example in the following figure.

HIV diagnoses, AIDS case reports and HIV/AIDS deaths by year, United Kingdom

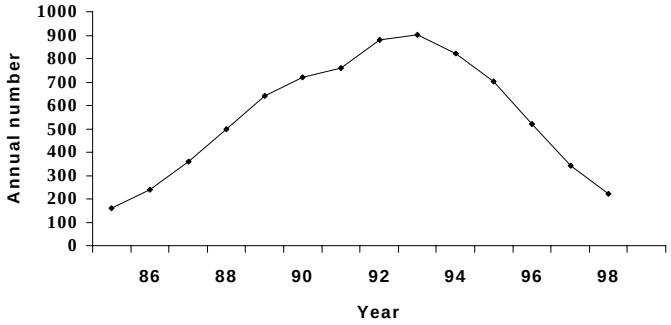


However, in the last two years there has been no further reduction in AIDS cases and deaths in many countries, as exemplified for the UK in the figure above. This is probably due to treatment intolerance, drug resistance, and diagnosis of HIV/AIDS late in the course of disease progression. Many newly diagnosed AIDS cases had not been tested HIV positive prior to AIDS diagnosis. These individuals have had little or no opportunity for treatment to halt progression to AIDS. Also, there are a number of people living with HIV/AIDS who refuse to take anti-retroviral treatments and those who are exhausted from taking large amounts of drugs every day.

Another benefit of treatment seen in most industrialized countries is reduced mother-to-child transmission of HIV. For example, the dramatic change in perinatal AIDS in the

USA during the 1990s is shown in the following figure. This has followed the rapid implementation of the use of zidovudine to prevent perinatal transmission and, more recently, improved treatments for infected children, delaying the onset of AIDS defining diseases in those children who were perinatally infected. Most perinatal infections now occur in women with no antenatal care or in whom HIV has not been diagnosed.

Perinatally acquired AIDS, 1985-98, USA



New treatments have not only improved survival, but also the quality of life. This is demonstrated by a change in the pattern of care for HIV-infected individuals. Decreased inpatient care (less hospitalization for opportunistic infections) has occurred with a shift to less invasive outpatient care. Outpatient care is now needed to monitor the efficacy of therapy, to assess side effects, and to evaluate HIV infected persons who are not yet on treatment in order to determine the optimum time to commence therapy. While these new therapies have resulted in an overall increase in treatment costs, there have been clear benefits in terms of reduced hospital costs and improved quality of life.

Despite the above, there is a critical need to develop simpler drug regimens, improved drug tolerance and ensure that all affected groups can take advantage of these new treatments. Not all groups benefit equally from the new treatments. For example, in blacks and women in the U.S. there has been less reduction in AIDS incidence with the therapeutic advances than in white MSM. In Canada, preliminary data show that, at least in some sites, relatively few IDUs have been started on anti-retroviral treatment within one year of being deemed medically eligible.

To take advantage of the benefits of the new treatments, HIV infection must first be diagnosed. However, data from several industrialized countries show that up to one third of HIV infections are undiagnosed. To bring treatment benefits to these individuals, industrialized countries need to continue to improve their voluntary counseling and testing programs for HIV.

Increasing numbers of people living with HIV/AIDS in most industrialized countries

The encouraging news with respect to treatment is tempered by the fact that there are still a considerable number of new HIV diagnoses each year in industrialized countries and the numbers have been rather stable after initial decreases in the mid and late 1980s.

Improved survival and reduced mortality has resulted in an increased prevalence of people living with HIV in most industrialized countries. For example, in England and Wales, the number of individuals living with diagnosed HIV infection has increased about 13 percent per annum each year since 1996. In Canada, the total number of prevalent infections (diagnosed and undiagnosed) is estimated to have increased from 40,000 infections at the end of 1996 to about 49,000 at the end of 1999. This will have a significant impact on the burden of known disease for costs of treatment, care, and support.

Risk behaviors on the rise

In industrialized countries, there is now increasing evidence that in some populations, reductions in risk behavior over the last decade are reversing. For example, in England and Wales, the proportion of injectors reporting sharing of needles and syringes has increased by over 30 percent since 1997. In Canada, the proportion of IDUs who report sharing of injecting equipment in the past six months has remained steady at around 40 percent, despite extensive interventions that include widespread availability of free needles.

Furthermore, sexual risk behavior also shows signs of worsening. Between 1995 and 1998 in England, there was a 25 percent rise in reported cases of gonorrhea. Surveys in San Francisco, USA, have shown an increase since 1995 in the proportion of MSM who reported unprotected anal sex in the past six months, and late breaking data suggest increasing incidence in selected urban sites. There have also been recent outbreaks of syphilis reported in Seattle, USA, (among MSM), Vancouver, Canada (among sex workers), and in some urban areas of England (among MSM).

These developments may be the result of a false sense of security following the perception that HIV is now a “normal” treatable disease. It might also be the result of a general fatigue in continuing with safe behaviors. Whatever the reasons, such trends are alarming and show the risks of complacency.

Vulnerable populations increasingly affected

Although the HIV/AIDS epidemic in most industrialized countries is still primarily concentrated among the recognized high-risk groups of MSM and IDUs, there are some important trends occurring in risk group patterns. There is now an increasing HIV/AIDS problem among ethnic minorities. In England and Wales, infections among heterosexuals are disproportionately high among black Africans who form only 0.7 percent of the population and yet comprise over half of the prevalent diagnosed HIV infections in this category. Similarly in the USA, population-based AIDS incidence rates among blacks

are much greater than among whites (eight times greater for men and 21 times greater for women).

Another pattern of change seen in industrialized countries is the slow but steady increase in HIV and AIDS diagnoses attributed to heterosexual transmission. Indeed, most industrialized countries are also seeing increasing HIV/AIDS among women. Although these increases have not been as dramatic as in many developing countries, they serve to reinforce that the HIV epidemic in these countries is not confined to the MSM and IDU risk groups.

Challenges for the future

Industrialized countries have not seen the generalized HIV epidemics that are present in many African countries. However, HIV remains an important issue and in spite of treatment advances and extensive interventions, significant numbers of new infections occur every year.

The changes that have been observed in many industrialized countries illustrate the need to supplement HIV/AIDS case reporting and targeted epidemiologic studies with surveillance of risk behaviors focussed on both those at risk for HIV and those already infected with HIV, including information on HIV testing behavior. Improved methods are also needed to assess HIV incidence.

In addition, systems must be developed to monitor the access to and utilization of care by infected individuals, regardless of risk category, race, or socioeconomic status. A necessary component of this is the availability of voluntary counseling and testing programs that are genuinely accessible and confidential.

Despite all the successes in treatment of those infected, we should not overlook the constant increasing number of people who continue to be newly infected with HIV in industrialized countries. Given the fact that everybody has access to information and to simple means to avoid infection, such as condoms, every infection that happens is one to many.

BOX: Ethnicity and public health data

There has been considerable debate internationally about the use of ethnicity as a classifying variable in public health data. Progress in civil and human rights has led to the conclusion that ethnicity itself has little or no relevance to societal issues such as disease distribution, educational potential or life achievements, but that societal disparities reflect persisting socioeconomic inequalities. Other variables such as socioeconomic status and country or region of origin can be equally or more relevant in risk factor analyses. As a consequence, documenting ethnicity in descriptive epidemiology and using it as a stratifying variable are controversial. Compounding the debate is the difficulty of defining race and ethnicity, concepts which carry different meanings in different contexts. For most applications, classification of ethnicity is limited by the categories used in the national census, but is self-defined by the persons enumerated. Even this approach is handicapped by lack of consistency over time, and thus the definition of ethnicity may be imprecise. Public health data in the United States

(continued on next page)

have traditionally included information on ethnicity as a descriptive characteristic almost as essential as age and sex. In contrast, some countries such as France have considered this inappropriate so that virtually no ethnicity-specific data are available there. In this brief commentary we discuss advantages and disadvantages of these opposing views.

A Utopian view is that public health data are objective, have no moral value, and so are beyond such political discussions. The history of HIV/AIDS surveillance illustrates the complexity of public health work on diseases that attract widespread societal attention and concern. Arguments in favor of collecting ethnicity data are that such information gives more complete insight into the epidemiology of HIV, and helps to identify relevant risk factors, and vulnerable population groups in need of interventions. Knowing the detailed epidemiology of a disease enables appropriate targeting and evaluation of interventions. Tailoring interventions to specific groups in need means that public health actions are not only more effective but also more culturally appropriate.

Mother-to-child transmission of HIV in England and Wales offers an example of the need for data on ethnicity. Because the majority of heterosexuals with HIV in this part of the United Kingdom are persons from sub-Saharan Africa, the overwhelming majority of children born to HIV-infected women are Black Africans (the census category used in UK). The United Kingdom lagged behind other countries in implementing antenatal screening and prevention for pregnant women, so that perinatal transmission of HIV continued at a higher rate than in other European countries. However, this was a problem selectively affecting African women, whose children suffered high rates of this lethal but preventable infection. Appropriate use of surveillance data could have led to earlier reduction of pediatric AIDS in African children. Other examples of the utility of ethnicity-specific data include syphilis in the United States, and tuberculosis in the United Kingdom. Syphilis in the United States is heavily concentrated in the African American community; efforts at elimination of syphilis, a national objective and achievable goal, have to take account of the epidemiology of the infection to succeed. Finally, there is good evidence that tuberculosis increased during the 1990s in Black Africans in the United Kingdom, partly in association with HIV infection. Targeting of tuberculosis prevention did not occur in a timely fashion because lack of routine data on tuberculosis incidence by ethnicity prevented the disparities in tuberculosis incidence from being recognized.

However, serious concerns exist in relation to ethnicity data. Stigma and discrimination can very easily result from such information being used inappropriately, especially for sensitive diseases such as HIV/AIDS, tuberculosis, sexually transmitted infections, etc. Such data can reinforce beliefs that immigrants and foreigners are the root cause of such infections, and lead to discriminatory and ineffective responses such as recommendations to restrict the movement of certain persons, compulsory HIV testing, etc.

On balance, MAP participants believed that, in countries where there is assurance that human rights will be protected, the benefits of collecting ethnicity data outweighed the disadvantages, but that great caution is needed in presenting, disseminating, and using these data. There should be guarantees that the recording of ethnicity, country of origin, and other personal data would lead to interventions for the groups identified. In countries where there is no tradition of human rights protection and/or no organized civil society, and where ethnic tension exists, such data collection cannot be recommended because of potentially severe adverse consequences. A neglected topic of discussion internationally is what limits should be set and how to set them, on non-public health uses of public health data that are collected confidentially (e.g. use of surveillance data by law enforcement agencies).

Behavioral Surveillance is not Enough

What is behavioral surveillance?

Behavioral data collection is an integral part of 2nd generation surveillance for HIV. Behavioral data help in determining where HIV and STI data should be collected to monitor the epidemic, help to validate the biological data collected, and assist in interpreting the trends seen in the epidemiological data. But as part of the overall system of responding to the epidemic, behavioral data collection is also essential to planning and evaluating prevention programs, directing prevention resources to the communities of greatest need, and identifying continuing risk behaviors and populations.

Behavioral surveillance surveys (BSS) are one of the most important methodologies for behavioral data collection developed in the last decade. They are considered to be an essential part of 2nd generation surveillance systems at any stage of the epidemic (see *Behavioral Data Collection Needs of National Programs* and *Guidelines for Second Generation Surveillance*). In a behavioral surveillance system, repeated surveys are done in a limited number of populations selected for their relevance to the spread of HIV in the country. Using rapid assessment methodologies and mapping techniques, a sample frame is designed to select as representative a sample of these important populations as is possible. A sample size sufficient to detect a specific level of behavior change is then chosen and a small set of key behavioral indicators is gathered from this group at regular intervals (usually on an annual basis). These behavioral indicators are then rapidly analyzed and disseminated to those who can act on the information including program managers, partners in responding to the epidemic, and, most importantly, the members of the communities from which the data were collected. (For more details, see *Behavioral Surveillance Surveys: Guidelines for Repeated Behavioral Surveys in Population at Risk of HIV*)

The recognition that behavioral surveillance is important has grown and most national programs have a strong interest in implementing some form of it. BSS has become "trendy." However, some major concerns have arisen among the members of the MAP network about the use of behavioral surveillance methodologies:

- *People often "compromise" in implementing the BSS methodology*. For example, they may accept an easy convenience sample in one or two locations for a marginalized population rather than carefully mapping out risk behaviors and trying to select representative samples of these important at-risk populations. This may occur because they don't know how to access the most critical marginalized populations or because they are concerned about the higher cost of applying the behavioral surveillance techniques carefully.
- *They expect more from behavioral surveillance than it can deliver*. BSS is specifically intended to track a *limited* number of *important* behavioral factors in *relevant* populations. It cannot answer all the questions that need to be answered in formulating, directing, implementing, and evaluating effective prevention efforts. However, a lack of understanding of the strengths and limitations of

different behavioral approaches leads to an over-reliance on BSS to answer questions it is not capable of answering.

- *Other important behavioral data collection techniques are underutilized*. Few national program staff are behavioral scientists. As such, they frequently lack a detailed understanding of the strengths and limitations of different behavioral data collection approaches. Because they expect too much of behavioral surveillance, they fail to apply the other techniques which are so essential to guiding the national response effectively.

Advantages of doing "rigorous" behavioral surveillance

Good behavioral research takes time and effort. While great attention is often paid to the details of serological data collection, behavioral data collection is frequently done with far less care and attention. Sometimes this is due to mistaken assumptions about the "ease" of behavioral data collection. Sometimes it is because one cannot successfully access the relevant populations. Often it is due to the lack of understanding of different behavioral data collection methodologies and approaches. And other times it is due to unwillingness to involve experienced behavioral scientists in the process or to obtain the technical support needed to do a good job.

While these concerns apply to all forms of behavioral data collection, they are particularly critical when conducting behavioral surveillance. Developing a behavioral surveillance system is a process requiring careful attention at each step: 1) determining which populations to include in behavioral surveillance and the sample sizes required in each; 2) building trusting relationships with the communities to be surveyed; 3) mapping the risk territory so that the sample frame maximizes the representativeness of the sample; 4) designing and ensuring the local relevance and acceptability of the instruments; 5) training and monitoring the interviewers; 6) collecting the data and ensuring quality control in the field; and 7) analyzing and disseminating the data.

Sometimes researchers cut corners at various stages of this process. For example, because they haven't worked closely with marginalized communities who are often at-risk, they may not take the time to build support for the process within the communities, producing a lack of cooperation. Instead of mapping, they may just take the one or two locally known locations where members of the community meet, a convenience sample. They don't obtain a representative sample. Thus they remain uncertain that their data really represent what is happening in a specific at-risk population.

Implementing behavioral surveillance requires careful attention at each of these stages. But it pays major benefits. The data collected will accurately reflect behavioral trends in the selected population as a whole, rather than that of a small "convenience" sample. This makes it more meaningful for monitoring behavior change and evaluating the effect of combined prevention efforts in the surveyed populations. For those with limited access to at-risk populations, learning to access and building trust in the communities to be surveyed will open the doors for later prevention efforts. The mapping will provide expanded knowledge of the extent and forms of risk behavior, which will inform the

targeting and implementation of prevention programs. While the cost will be somewhat higher, the benefits paid will more than offset those costs.

What behavioral surveillance can and cannot deliver

Even when a good behavioral surveillance system is implemented, it is not enough to provide all the behavioral information a national program needs.

Behavioral surveillance can fill a number of important needs:

- *A sustained focus on relevant behaviors*. Behavioral surveillance helps to keep the attention on the most relevant behaviors driving the growth of the epidemic. Because it is repeated periodically, this focus is sustained over time.
- *Trends over time in key behavioral indicators*. The most important behaviors such as condom use, risk behavior, or number of partners, in the populations selected for surveys can be tracked to determine if changes are occurring.
- *Immediate effects of prevention efforts.* BSS provides information on whether the combined prevention efforts in the surveyed community are having an impact on those behaviors driving the epidemic.
- *Understanding of HIV and STI epidemiological trends*. BSS helps to determine if epidemiological trends in serosurveillance populations are related to observed behavior changes.

But there are also many types of information that behavioral surveillance cannot provide and should not be asked to provide:

- *Contextual understanding of sexuality and local risk behaviors*. Understanding the multiple complex factors that influence risk behavior is not really possible in a short quantitative questionnaire of the type used in behavioral surveillance.
- *Why?* BSS cannot answer why people continue to engage in risk behavior. Behavioral surveillance can point to those behaviors that are particularly resistant to change, but the system itself cannot answer the very important question of why they continue.
- *The distribution of and level of risk in the overall population*. Behavioral surveillance focuses on specific at-risk populations. The act of identifying these populations initially, and determining *who* is at-risk in the larger "general" population is not possible with the types of focused surveys in specific populations used in BSS.
- *The detailed information needed to design specific prevention programs*. Designing an effective prevention program for a given community requires far more information than can be gathered in behavioral surveillance surveys. Each new prevention effort requires a careful evaluation of contextual, demographic, social, access, and other issues which are better obtained by working closely with members of the target communities using qualitative techniques.

The role of other behavioral data collection techniques

But that does not mean that these questions must go unanswered. *Instead national programs need to supplement behavioral surveillance with other forms of behavioral data assessment*. A brief summary of the types of information programs might need and the behavioral assessment methodologies that can supply this information is given in the box below.

BOX: Behavioral assessment techniques

Information needed	***Behavioral assessment techniques***
Levels of risk in the general population, demographic, social and economic correlates of higher risk.	Population/Household based surveys in the general population.
Locations where risk behavior occurs and size of important at-risk populations.	Social and geographic mapping, rapid assessment methodologies.
Contextual understanding of risk behaviors and sexuality. Understanding why risk behaviors do and don't change.	Qualitative approaches including focus groups, in-depth interviews, key-informant interviews.
Detailed understanding of communities and risk behaviors to design prevention programs	Qualitative approaches including market research, focus groups, in-depth interviews.
Evaluation of specific prevention efforts.	Qualitative and quantitative techniques conducted in the project-specific target population.
Impact of all prevention efforts in key populations at community level.	Behavioral surveillance.
Trends in risk behavior in key populations.	Behavioral surveillance.

In short, *behavioral surveillance is NOT enough* and those responsible for national programs should make better use of other behavioral data collection techniques to guide their efforts. The MAP Network recommends the following:

- Countries should expand the involvement of local behavioral scientists in the development of national behavioral data collection systems.
- National behavioral data collection systems should use a combination of behavioral assessment techniques depending upon the type of information they need for their programs.
- Programs should be as rigorous as possible in applying behavioral surveillance techniques. This will not only increase the quality of the data, but will open the doors for prevention efforts in important populations.
- Programs should determine the gaps in knowledge of behaviors and determinants of risk, and then, with a careful consideration of what different behavioral data collection techniques can do, apply the appropriate technique to gather that information.

Monitoring the Cost of Care for HIV/AIDS

Collecting reasonably accurate and representative data in a periodic fashion on the cost of care for children and adults with HIV/AIDS is neither highly complex nor very expensive. In fact, the benefits in improved allocation and management of health resources would likely result in cost savings.

There are four major areas of decision-making that could benefit from the availability of such data:

i. ***Decisions about which prevention interventions to fund***. Since averting future treatment costs is one of the important benefits of preventing new HIV infections, estimating those costs can inform prevention decisions. Although averting future costs of care is an important benefit of prevention programs, it is obviously not the most important benefit – that of averting the illness, death, suffering, orphans and impoverishment caused by the epidemic. Government decisions should consider all averted treatment costs, regardless of who pays for them, although the health ministry may be especially interested in averted costs for the government health care system. Private-sector decisions about prevention also depend upon averted future treatment costs.

ii. ***Decisions about which package of HIV/AIDS care services should be funded by the government health care system*.** These decisions could be informed by data on the likely costs and benefits associated with different packages of care services. Because of the heterogeneity of services currently available in most countries, information about the cost of providing different services is likely to already be available locally. Where cost information about different packages is not available locally, or is likely to change if implemented on a larger scale, then simple cost modeling can provide valuable additional information.

iii. ***Program decisions, such as affordability, planning and forecasting services.*** In any country with a significant epidemic, the decision about which package of care to fund is one that has major financial implications, regardless of whether the package is more or less cost effective than those funded for other diseases. By combining micro-level costing data with epidemiological data and projections of the number of patients who will need care, planners will have an indication of the resources needed to fund the program in the short- to medium term.

iv. ***Management decisions aimed at reducing inefficiency.*** One of the best ways to identify inefficient provision of services for people with HIV/AIDS is by collecting data on how the cost of care varies among institutions. This is especially useful when the cost data are associated with quality of care indicators.

Although there are some differences in the data needs for each of the four areas above, all fundamentally require results of micro-costing studies that collect cost data for individual patients. The evaluation of cost-effectiveness of prevention interventions [**i.**] requires estimates of the average cost savings associated with averted treatment per case. If interventions are targeted to specific sub-populations (such as the workforce for a particular firm) then sub-population-specific cost estimates may be desirable, but such sub-population-specific cost estimates can be seen as a second-level priority.

However, it is essential that the cost estimates capture the full expenditure for health care. These must include costs borne by the patient/family, those borne by insurers/employers, and those borne by the government. They should also include a breakdown of the cost of services obtained from the traditional/alternative sector, from the range of private providers and from the public sector – to the extent that any of these represent an important proportion of total costs.

Comparative data on the cost of different packages of services [**ii.**] can be collected as part of the above described micro-costing, provided that a spectrum of packages are offered in different health systems/services being surveyed. These estimates will likely need to be adjusted for use in decision-making by government health services because of differences in salary and procurement costs that likely would exist between small-scale private provision of a package of services and large-scale public provision of the same package. This latter type of modeling/adjustment would need to be tailored to the specific policy questions under consideration at any particular time.

In countries considering the introduction or augmentation of ARV or prophylaxis against opportunistic infections (OIs), then the cost analysis must consider not only the additional costs of the new therapy, but also the costs averted or postponed because OIs are averted or postponed. A first step in this direction has recently been undertaken in Brazil, where an estimate was produced of the hospitalization and drug costs averted in one year as a result of the introduction of ARVs [See Box on Brazil]. Further analysis will need to consider the level of future costs; i.e., what will ARV costs be over time in a group of patients compared to the costs associated with OIs. To the extent that OIs are only postponed rather than averted altogether and to the extent that ARV therapy is continued beyond the expected life span in untreated patients, then the cost ratio [cost of ARV / cost savings of averted OIs] will rise as the analysis is extended in time.

This discussion is limited to the net cost of different packages of care ("net" cost is the cost of providing the intervention minus the cost savings associated with prevented illness). More difficult/complex issues entail how to value the effectiveness/benefits of the range of care alternatives.

Use of micro-costing data to estimate current and future affordability of service packages and to plan for financing and organization of the delivery of the planned services [**iii.**] requires examination of the micro-cost data described above, albeit limited to the health system doing the planning. It also requires health system-specific epidemiological estimates and projections. These epidemiological data should already be available at the national level. Health system-specific data for many countries are simply the proportion of people with care needs who use government health services. In some countries, particularly in many Latin American countries, governments have multiple health systems (e.g., different systems for employed formal sector workers and for the poor/unemployed). Thus, the situation is more complex because epidemiological estimates must be generated for the different systems. Fortunately, countries with multiple systems are typically upper-middle income or high-income countries with relatively sophisticated epidemiological monitoring systems.

Finally, the use of cost data can be invaluable in a program to improve the management/delivery of health services [**iv.**]. However, these data must be sufficiently detailed and of sufficient sample size to permit analysis at the level of individual facilities. The sample does not need to be comprehensive (inclusive of all health facilities) in order to be useful in describing the range of costs/efficiency among facilities. However, at the local level, monitoring results will be of relatively little use to facilities that were not included in the survey. Similar to the use of cost data to compare the cost-effectiveness of different care packages, comparisons of delivery efficiency require linking cost estimates to estimates of quality/benefit of the services. These quality/benefit indicators can be relatively crude (such as mortality rate and average length of stay for an indicator diagnosis) because the initial goal of the exercise is simply to draw the attention of program managers to those facilities where it appears that not only are costs higher, but quality is worse.

BOX: New model to estimate costs for prevention and care

An assessment of the resource needs to substantially scale up prevention and care programs is critical for advocacy and resource mobilization at global and national levels. The model that is presented here is a work in progress and is based on ongoing work of several institutions and experts, including the World Bank, UNAIDS Secretariat, the London School of Hygiene and Tropical Medicine, WHO, Options Consulting London, the National Institute of Public Health in Mexico, and USAID.

Estimates for scaling up HIV/AIDS prevention and care activities in sub-Saharan Africa utilize targets for population coverage in the year 2005 that are ambitious, but achievable. Assumptions of target coverage for 2005 were made looking at successful programs. The costs represent the additional spending needed to bring the majority of countries to levels currently seen in countries with generally successful prevention programs, such as Uganda or Senegal. Countries whose programs are currently strong should, at these levels of spending, be able to increase the strength of their programs to significantly higher levels.

- For prevention programs at least 1.5 billion US$ are needed per year.
- For basic care programs at least 1.5 billion US$ are needed per year. If limited access to anti-retroviral treatments is included, there would be the need for an additional 0.6 to 1.2 billion US$ per year. This assumes that the annual cost for the combination of ARVs per person year would equal 1,400 US$.

The following prevention programs components have been used in the calculations: youth-focused interventions, interventions focused on sex workers, increased public sector condom provision, condom social marketing, strengthening STI services, voluntary counseling and testing (VCT), workplace interventions, strengthening blood transfusion services, mother to child transmission (MTCT), mass media campaigns, start-up capacity development (for countries with very weak programs only), and surveillance, monitoring and evaluation. The following care programs components have been used in the calculations: palliative care, treatment of opportunistic Infections, HIV testing in treatment sites (excluding VCT centers), prophylaxis of opportunistic infections, service delivery cost (in- and outpatient visits), care for orphans, and ARV (including basic lab monitoring).Coverage and cost are estimated only for of the public portion of the health sector (no valid information exists about quality and coverage of the private sector for the vast majority of developing

(continued on next page)

countries). A feasible ceiling is estimated for "access to care for HIV/AIDS" in the public sector. This is estimated using the median of three generally available indicators: proportion of births attended by a trained health care worker, proportion of all TB cases covered by DOTS, and vaccine coverage rate for infants (DPT). It is assumed that coverage beyond this estimated ceiling cannot be realistically achieved within the near future. All current and future target coverage rates are given as a proportion of this estimated ceiling (rather than as a proportion of all people needing care). The population "in need" of treatment is defined as those who would die from HIV/AIDS within two years if untreated with anti-retrovirals. The value is estimated as two times the number of people who die of HIV/AIDS without treatment in a given year.

The following table presents the target care coverage for the year 2005.

Major components of care	Coverage of all who need care
Palliative care	40%
Treatment of opp. Infections	25%
Prophylaxis of opp. infections	20%
HAART	12%

The above cost estimates do not include resources needed to increase the basic capacity of the health system (including the building and upscaling of facilities) in order to achieve the scaling up to the targets set for 2005.

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