

**MAP**



**Provisional Report**

**The Status and  
Trends  
*of the* HIV/AIDS  
Epidemics  
in the World**

Geneva  
Switzerland  
June 26, 1998

# Monitoring the AIDS Pandemic (MAP) Network

MAP is a collegial network of internationally recognized technical experts seeking to assess the status and trends of the global HIV/AIDS pandemic. Created in 1996, MAP is jointly sponsored by its founding institutions:

- **Family Health International, funded by the United States Agency for International Development,**
- **The François-Xavier Bagnoud Center for Health and Human Rights of the Harvard School of Public Health, and**
- **The Joint United Nations Programme on HIV/AIDS (UNAIDS).**

MAP's more than 120 members in 40 countries are epidemiologists, modelers, economists, and social, behavioral, public health and international development specialists, recruited through a nomination process and currently guided by an Interim Global Steering Committee.

MAP hopes to make its greatest impact by providing objective, timely and high-quality analyses of the most current information on the pandemic, for the improvement of prevention, care and social interventions worldwide.

MAP workshops and membership meetings are held in conjunction with regional and international HIV/AIDS conferences. This enables MAP to function on a small budget and to distribute results from its analyses promptly to conference participants.

AIDS service organizations and regional networks of people living with HIV/AIDS are invited to participate in MAP workshops. MAP works towards building consensus in an atmosphere of collegiality, cultural sensitivity, and mutual respect for conflicting points of view. It functions on the basis of volunteerism and personal and institutional contributions, with limited financial support from international organizations, including UNAIDS, and provides an independent perspective on issues raised by the HIV/AIDS pandemic.

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### **Previous Reports Produced by MAP**

- *Workshop on the Status and Trends of the HIV/AIDS Epidemics in Africa: Final Report*, Kampala, Uganda, December 1995 (English and French)
- *The Status and Trends of the Global HIV/AIDS Pandemic Final Report*, Vancouver, Canada, July 1996 (English, French, Spanish, Japanese, Chinese and Russian)
- *The Status and Trends of the HIV/AIDS Epidemics in Asia and the Pacific: Final Report*, Manila, Philippines, October 1997 (English, French, Japanese)
- *The Status and Trends of the HIV/AIDS Epidemics in Latin America and the Caribbean: Final Report*, Rio de Janeiro, Brazil, November 1997 (Spanish and English)
- *The Status and Trends of the HIV/AIDS/STD Epidemics in Sub-Saharan Africa: Final Report*, Abidjan, Côte d'Ivoire, December 1997 (French and English)
- *The Status and Trends of the HIV/AIDS Epidemics in Eastern Europe*, Veyrier du Lac, France, June 1998 (English, Russian) *Forthcoming*

MAP reports are available through the following websites:

Family Health International

<<http://www.fhi.org>>

FXB Center for Health and Human Rights

<<http://www.hri.ca/partners/xfbcenter>>

UNAIDS

<<http://www.unaids.org>>

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This meeting included discussions on themes which were introduced through the presentation of working papers. The authors of these working papers are gratefully acknowledged here:

- The Global epidemiology of HIV/AIDS: Bernhard Schwartländer
- The HIV/AIDS Epidemic in Europe: Jean Baptiste Brunet and Françoise Hamers
- The HIV/AIDS Epidemics in Eastern Europe: Vadim Pokrovski and Karl-Lorenz Dehne
- The HIV/AIDS Epidemics in Africa: Tom Zhuwau
- The HIV/AIDS Epidemics in Latin America and the Caribbean: Carlos Carceres and Euclides Castilho
- The HIV/AIDS Epidemics in North America: Kevin De Cock, Donald Sutherland and Chris Archibald
- The HIV/AIDS Epidemics in Asia and the Pacific: John Kaldor
- The Global Epidemiology of Sexually Transmitted Diseases: Antonio Gerbase
- The Global Patterns of HIV Transmission: Karen Stanecki DeLay and Jim Chin
- Global Migration and HIV/AIDS: Michel Caraël, Alix Adrien and Jacqueline Weekers
- Transmission of HIV in the Health Care Setting: Anne Buvé
- The Global Map of Neglected Behaviors: Knowledge and Action Gaps: Tim Brown
- Mother-to-Infant Transmission of HIV: Richard Marlink
- Orphans of AIDS: A Demographic and Socioeconomic Impact of HIV/AIDS Epidemics: Peter O. Way
- The Interaction Between HIV and Tuberculosis Control Programmes: Peter Godfrey-Faussett
- The Global Inequity in HIV Care: Eric Van Praag

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| Publications and other work products arising from the work of the MAP Network are the sole responsibility of the Network. The contents of this report and other work products do not necessarily reflect the views or policies of MAP's founding and sponsoring institutions |
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## **1. Introduction**

This MAP Symposium was the fifth in a continuing series of regional and global MAP “Status and Trends” symposia organized to expand the understanding of the trajectory and determinants of the HIV/AIDS pandemic. The symposium on the Status and Trends of the HIV/AIDS Epidemics in the World was held at the Mérieux Foundation, Veyrier du Lac, France, June 23-25, 1998. It preceded by a few days the 12th World AIDS Conference on AIDS held in Geneva, Switzerland, June 28-July 3, 1998.

The previous “Status and Trends” MAP symposia contributed to focusing the international attention of policymakers, programme managers and the media on the global and regional HIV/AIDS epidemics. The MAP Status and Trends Symposium in Veyrier du Lac brought together 59 MAP members and invited participants from around the World (see list of participants in Annex). The symposium aimed at the following objectives:

- To present and share current knowledge on the status and trends of the HIV/AIDS epidemics in the world;
- To review the various epidemiological and behavioural patterns among the HIV/AIDS epidemics and explore current critical issues;
- To determine specific data needs for monitoring and forecasting the HIV/AIDS epidemics in the world and identifying response gaps; and
- To produce and disseminate a report to participants attending the 12th World AIDS Conference and to those who, although concerned with HIV/AIDS, were unable to attend it.

MAP structured its symposium agenda so as to add its analysis of specific features of the pandemic to the excellent June 1998 report on the Global HIV/AIDS epidemic released by the Joint United Nations Programme on HIV/AIDS (UNAIDS) and the World Health Organization (WHO). As UNAIDS and WHO prepared their report in collaboration with national experts including many MAP members and in consultation with the MAP secretariat, it was possible to ensure that the reports produced by UNAIDS/WHO and by MAP complemented each other optimally.

The June 1998 MAP symposium built on a series of regional MAP meetings which examined the HIV/AIDS situation Asia and the Pacific (Manila, Philippines, October 1997), and Latin America and the Caribbean (Rio de Janeiro, November 1997), Sub-Saharan Africa ( Abidjan, Côte d’Ivoire, December 1997). Reports on these symposium have been widely distributed at regional conferences on AIDS and through the worldwide web (see web sites below). A regional meeting on HIV/AIDS in Eastern Europe (Veyrier-du-Lac, France, June 1998) resulted in a report which will be released shortly. The descriptive and analytical contents of these regional MAP reports fed into the present reports in the form of brief summaries only.

Co-authored by the MAP Symposium participants, the present report reflects as best it can the analysis, determinations and recommendations brought forward during the symposium. Its aim is to provide information that can be used by international, national and local bodies to review the most important aspects of the evolution of the HIV/AIDS epidemics in the world, recognize the current status of and trends within these epidemics, and take action to advance the regional and global responses to these epidemics. It is hoped that the MAP report will bring into focus the multifaceted aspects of the most critical gaps in the information needed to monitor effectively the HIV/AIDS epidemics and the responses brought against them around the world.

## **2. The State of the HIV/AIDS Epidemic**

As of mid-1998, the HIV/AIDS pandemic continues to spread unequally around the world. In many cities in sub-Saharan African countries more than a quarter of young and middle-aged adults are infected with HIV, whereas in most developed countries, the number of annual AIDS cases continues to decrease. The status of HIV epidemics in most other areas of the world remains uncertain because of inadequate data on the prevalence of HIV-risk behaviours. This report complements the UNAIDS/WHO report on the global HIV pandemic released in June 1998.

### **HIV epidemics in Africa: unabated, diverse, and complex**

Of people living with HIV around the world, six in every 10 adult men, eight in every 10 adult women and over nine of every 10 children infected are in sub-Saharan Africa. Of the global estimated 16,000 HIV infections a day, 7,500 of them occur in sub-Saharan Africa. Such factors as growing economic disparity, social and cultural uprooting linked to intense migration, insufficiencies in prevention and care programmes and power gaps linked to gender, age and economic differences continue to fuel HIV epidemics across the continent.

Africa is not uniformly affected by HIV/AIDS: a mosaic of epidemics is progressing with varied intensity and velocity. For example, in antenatal clinics of several cities in southern Africa, up to 45 percent of women tested during pregnancy carry HIV, a rate ten or more times greater than in pregnant women seen at urban antenatal clinics in most countries in Central or West Africa. Subregional boundaries which, until recently, helped in the mapping of the epidemics in Africa can be misleading. In West Africa, HIV rates in pregnant women may be ten times higher in Abidjan, Côte d'Ivoire, than in Dakar, Senegal. In urban areas, a much higher proportion of adults are HIV-infected than in trading sites along highways where, in turn, the prevalence of HIV is higher than in rural villages. While local migratory and behavioural patterns have been suggested to explain these differences, how these patterns interconnect through complex social and sexual networks remains insufficiently explored.

Heterosexual contacts and mother-to-infant transmission of HIV account for the vast majority of HIV infections in the region, and ongoing prevention programmes must expand their reach in order to curb the spread of HIV through these routes. The information required to monitor these trends and the impact of prevention programmes remains incomplete. For example, while data exist on the proportion of 15- to 49-year-old pregnant women who are infected with HIV, little is known about the levels of infection in girls younger than 15. In a community-based study near Lusaka, Zambia, 6 percent of girls aged 15–16 were found to be HIV-infected, a rate far higher than in boys of the same age. Apart from occasional and rarely published studies in the military, knowledge is also incomplete about trends of HIV in sexually active men. Among women, the dynamics of HIV infection are interpreted on the basis of prevalence rates of HIV infection - the proportion of women infected, regardless of when they acquired HIV infection. However, there is a paucity of incidence data - the proportion of women in a specific age group who acquire infection within a time period.

Anecdotal evidence supports the assertion that sex between men does occur in the region. In the absence of documented evidence that such a pattern of sexual behaviour prevails, in particular in single-sex male communities around industrial sites and in prisons, prevention programmes are neglecting the needs of these vulnerable populations. Likewise, the rising availability of injectable substances such as heroin, especially at new transit points for drug trafficking, creates an additional risk for HIV spread in sub-Saharan Africa. The transmission of HIV infection through unscreened blood transfusion continues to be a concern in several countries in sub-Saharan Africa. In this region in 1995, over 2.5 million blood transfusions were administered - most of them to women and children - and of those, nearly a quarter had not been screened for HIV antibodies. Similarly, occupational exposure to HIV by health care workers has received too little attention (refer to section 6).

## **Asia Pacific region**

With over 60 percent of the world's population, the Asia-Pacific Region presents a wide diversity of HIV-related risk environments, in terms of behavioural, political and cultural factors. Within the framework of this diversity, there has also been a wide range of HIV epidemics and responses, both across and within countries. It is not therefore possible to present a simple analysis of the actual and potential occurrence of HIV infection in this vast region.

Our understanding of the HIV epidemic and its determinants in the Asia-Pacific Region has improved substantially over the past 3-5 years, as a number of countries have implemented comprehensive surveillance systems for HIV prevalence, and sexual and injecting risk behaviours. Despite these advances, a number of countries still have a limited capacity to assess the occurrence of HIV infection and related behaviours, and to monitor the impact of interventions.

A recent factor of importance in the Asia-Pacific environment has been the economic tumult of the past year. While various predictions have been made of the potential impact on the HIV epidemic, it is not possible to state with any certainty whether their net effect will be to increase or decrease the incidence of risk behaviour or HIV transmission.

Since extensive HIV transmission has been a very recent phenomenon in a number of Asia-Pacific countries, there has so far been little experience with the care and support of people with HIV-related illness. Apart from Australia, Thailand and Japan, few countries have a healthcare workforce, which is adequately prepared to care for substantial numbers of people developing HIV-related illness.

Without simplifying too much, it is possible to classify the differing patterns of HIV transmission into broad categories, based on available surveillance data. In Australia and New Zealand, the virtually all HIV transmission has been through sex between men, and the incidence of transmission via this route has long been recognized as having declined substantially in the 1980s. In a few countries, such as Thailand, Cambodia and parts of Myanmar and India, heterosexual transmission has been extensive, mediated through large-scale sex industries but extending now to the regular partners of sex workers' male clients.

Some countries have HIV epidemics among injecting drug users (IDU) with limited associated heterosexual transmission. These include countries such as Thailand, Malaysia, Vietnam, and some areas of India and China.

Other countries have limited, but well documented spread of HIV infections, such as the Philippines, Indonesia, Japan, and South Korea. Several countries have not reported substantial numbers of HIV infection, but do not appear to have comprehensive, ongoing surveillance systems. Papua New Guinea, Pakistan and Bangladesh are countries which may have a substantial risk environment, and need to strengthen their surveillance activities.

The analysis of HIV epidemic trends in the region becomes more meaningful when a focus is placed on populations whose cultural and social affinity and networks transcend geopolitical borders. A new geography of HIV/AIDS in the region then emerges that helps recognize the foci of intense HIV spread. These include large metropolitan areas in western and southern India (Mumbai, Chinnai); the India/Nepal border area; the larger "Golden Triangle," which reaches out to northern Thailand, eastern Myanmar, but also encompasses the areas of Manipur in India and Yunnan in China; and the Mekong delta area, which includes Cambodia and southern Vietnam. To gain better understanding of the dynamics of HIV epidemics, factors of affinity between populations as well as mobility patterns must be explored and mapped out.



Large-scale heterosexual HIV epidemics ahead? Sudden and sharp increases in HIV incidence among persons engaged in very high-risk behaviours can and have occurred in Asia. However, the lack of quantitative and qualitative epidemiological, behavioural and social information on the nature of and linkages between sexual networks in any of these countries rules out any reliable prediction of the future course of HIV epidemics in these countries. To recognize the threat of emerging or fast-growing epidemics in certain populations is essential to an early and effective response. To acknowledge the possibility that, in other populations, rapid and extensive spread of HIV may not occur is equally crucial as policy and decision-makers may, on the basis of this information, orient efforts and resources towards people who are most at risk.

### **India: the epidemic continues**

With a population of close to one billion - roughly half of them in the most sexually active age group of 15 to 49 - an estimated adult prevalence rate of about 0.6 to 1 percent translates to between three and five million infected persons, a figure higher than any other single country. However, the distribution of HIV/AIDS in India is not uniform. The epidemic is focussed very sharply in a few states with most of India having extremely low rates of infection. It is noteworthy that 21 of the 31 states only report four percent of the total AIDS cases. The major impact of the epidemic is being felt in Maharashtra in the West, Tamil Nadu in the South with adjacent Pondichery, and Manipur in the northeast. While the epidemic is predominantly heterosexual in nature over most of India, the northeastern states have a severe epidemic among IDUs. In Manipur, IDU infection rates are now 70 percent or more.

In those parts of India where the epidemic is most firmly entrenched, the infection has spread out of those groups traditionally considered most at risk. From being highly concentrated in sex workers and patients attending sexually transmitted infection (STI) clinics, the HIV has spread to the general population. In Maharashtra, antenatal clinics in Mumbai now report a 4.5 percent prevalence, and one clinic in Pune reports over 5 percent. In Chennai between 1.2 and 2.3 percent of antenatal cases are reported to be HIV positive. Even in Manipur, where the infection is largely focussed on IDU, ANC attendees have a prevalence rate of 1.2 percent. The sentinel surveillance reports for early 1998 have brought to attention the fact that not only is the epidemic spreading to previously less affected groups within the severely affected states, but states that had relatively low infection rates are now beginning to have a serious problem. A case in point is the state of Andhra Pradesh, which has reported a 24 percent prevalence rate in STI patients and about one percent in antenatal clinics.

The data from India highlight the fallacy of considering average national figures for measuring the epidemic. India clearly has areas very severely affected by the epidemic, and yet the major portion of the country has a very minor HIV/AIDS problem at this time. Unless this differential is taken into account for planning interventions, efforts are likely to be inadequate in some areas, and inappropriate in others.

Data on both the distribution and the molecular epidemiology, also point out that HIV does not respect national or state boundaries. Plans for coping with the epidemic have to be regional rather than confined to political boundaries. Clearly the epidemic in Manipur is closely linked to that in the adjacent parts of Myanmar, Bangladesh and Thailand. The nature of the virus and the route of transmission are the same. To be effective, the interventions must also be in concert.

### **HIV/AIDS in Latin America and the Caribbean**

The Latin America and the Caribbean region encompass the countries and territories in the Western Hemisphere from Mexico south and east to the tip of the Southern Cone of South America. The aggregate population of the forty-four countries in the region totals 476 million people, 8.4 percent of the global total of 5.7 billion people. An estimated more than 1.6 million people are living with HIV/AIDS in Latin America and the Caribbean, equivalent to 5.4 percent of the total number of people around the world living with HIV/AIDS as of January, 1998.

HIV epidemics in Latin America and the Caribbean reflect the heterogeneity of HIV epidemics worldwide: they differ from country to country and within countries. For the most part, HIV in this region is concentrated in populations living on the social and economic margins of society. HIV/AIDS has taken its greatest toll on men who have sex with men (MSM) and injecting drug users, and in some places there is clear evidence of increasing spread among the impoverished and illiterate segments of society. Systematic data collection on these groups is difficult, and information currently is scant.

Rising rates in women show that heterosexual transmission is becoming more prominent. The extent to which infections in MSM and IDU may fuel extensive spread of HIV in the heterosexual population remains unclear. In Brazil, the male/female ratio of AIDS cases has decreased, due to the spread of HIV in women through heterosexual transmission as well as among women who are using injecting drugs. Although rates in pregnant women are still comparatively low in the region in general, they have reached levels of one percent in Honduras and more than three percent in Porto Alegre, Brazil. Rates are substantially higher in the Caribbean. In Haiti, more than eight percent of the pregnant women in the country were found to be infected with HIV in 1996.

As limited as the region's HIV epidemic has been so far, AIDS already has had a major impact. In Mexico, AIDS was the third leading cause of death in men between 25 and 34 years of age in 1995, and the trend is increasing. In the Brazilian State of São Paulo, AIDS has been the leading cause of death among women aged 20 to 34 since 1992. There are, however, two reasons for hope: injecting cocaine use has decreased in some areas, including in São Paulo, and a recent drop in AIDS mortality - similar to that seen in Western Europe and North America - also has been recorded in São Paulo and is attributed to the increasing use of antiretroviral therapy.

Like other regions of the developing world, Latin America and the Caribbean encompasses countries spanning the whole spectrum of development and contains highly diverse and localized epidemics with different driving forces and transmission routes. In Mexico, sex between men is the main transmission route in major cities, and drug-related transmission has begun in the northwestern part of the country; heterosexual transmission is more common along the southern border and in rural areas. Transfusion-related infections have diminished dramatically in the last eight years.

Five countries of Central America appear to have epidemics that are either in an early phase or show slow growth. In Honduras, however, the epidemic appears to be more established. While Honduras accounts for only 17 percent of the subregion's population, it has reported more than half of the AIDS cases from Central America. Infections in this subregion are seen mainly in capitals and major cities, where commercial sex plays a role, while rural cases are related to migration. Since 1987 there has been a dramatic shift to heterosexual transmission and to younger population groups.

In Haiti and the Dominican Republic in the Latin Caribbean, HIV is spreading mostly through heterosexual intercourse. These countries have reported HIV prevalence rates among pregnant women attending antenatal clinics ranging from one to nine percent while Cuba is showing rapidly increasing infection among MSM. In the other countries of the Caribbean, a few epidemics are evident in IDUs and MSM. Heterosexual transmission, however, has been the main route since 1986, and HIV prevalence in pregnant women ranges from one to seven percent. Tourism and high population mobility characterize these island nations, and both factors can influence the spread of HIV.

The predominant mode of transmission in the five countries of the Andean Area continues to be sexual contact among MSM. In general, HIV prevalence among pregnant women is less than one percent, although it has shown an increasing trend in the last few years. This slow increase probably reflects transmission from MSM and IDU to their female sex partners.

A mosaic of transmission routes accounts for the more than 500,000 HIV infections currently estimated in Brazil. Transmission through MSM and IDU has dominated so far, but there is a growing epidemic fueled by heterosexual transmission. In urban areas, HIV prevalence in pregnant women ranges from one to 5 percent. Prevalence among female sex workers is around 5 percent and in injecting drug users ranges from 33 to 60 percent. Overall, the epidemic is moving into younger, more impoverished and more rural populations.

The Southern Cone shows a mixed picture, but transmission occurs mainly among MSM and injecting drug users. The epidemics are occurring in major urban areas. Argentina reports HIV prevalence now ranging from 1 to 3 percent among pregnant women and 6 to 11 percent among female sex workers. Uruguay also shows an epidemic concentrated on MSM and IDU with some limited spread to the general population, while Chile and Paraguay show low grade epidemics.

### **HIV/AIDS in North America**

HIV infection incidence and HIV case surveillance: Approximately 40,000 new HIV infections occur in the US annually, over one third in women and over two thirds in ethnic minorities. Recent studies in STD clinics in seven US cities showed HIV infection incidence rates in MSM ranging from 1.5-8.2/100 person years (PY), and in heterosexuals from 0.06-1.1/100PY. In IDUs attending drug treatment centers the annual incidence was higher on the east (0.9 percent, one percent) than west (0.5 percent, 0 percent) coasts. HIV incidence rates among MSM in Canada's major cities have declined from a range of 7 to 11/100 PY in the 1980s to 1 to 2/100PY in 1995-97. There were an estimated 4,200 new HIV infections in Canada during 1996: 29.5 percent among MSM, 46.9 percent among IDU, 6.9 percent among MSM-IDU, and 16.7 percent among heterosexuals. This estimated incidence is lower than the peak annual HIV incidence of about 5,000-6,000 in the mid-1980s, but higher than the estimate of 2,500-3,000 per year for the period 1989-94. Most of this increase in HIV infections has been in IDUs whose recent annual incidence has been as high as 6.5/100 PY in Montreal and 18.2/100PY in Vancouver

HIV case surveillance data represent reports of persons diagnosed with HIV infection and offer minimum estimates of the numbers of persons infected with HIV who require medical services. Despite potential lack of completeness, HIV surveillance provides a more up-to-date description of the epidemic than reported AIDS incidence, especially since the advent of more effective antiretroviral therapy. In Canada, the percentage of new HIV diagnoses in MSM declined from 74.6 percent in the period 1985-1994 to 37.6 percent in 1997; the percentage in IDU increased from 8.4 percent to 33.2 percent; and among women increased from 9.8 percent to 21.8 percent. In the US, HIV surveillance data show communities of colour, especially African Americans, to be disproportionately affected. Other groups in which HIV infection is occurring disproportionately include women and youth, especially those of colour.

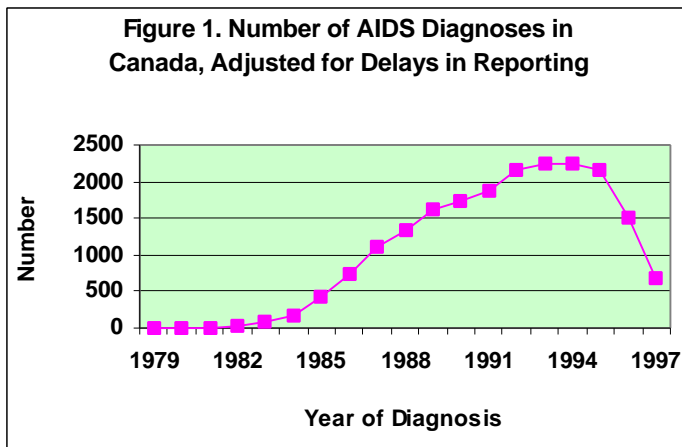
An estimated 400-650,000 persons in the US are living with HIV without AIDS-defining diseases or symptoms. The prevalence of HIV infection in MSM attending STD clinics is elevated more homogeneously than in other populations, ranging from 3.7 percent in the mid-west to 31.4 percent in Houston. Among IDU HIV infection is concentrated along the east coast and in the south, with highs of 32.2 percent in Baltimore, 28.5 percent in New York City, and 25 percent in Atlanta. The overall prevalence of HIV infection in childbearing women in the US in 1994 was 0.15 percent, the geographic distribution of infection mirroring that in IDU and being highest along the Atlantic coast and in the south. Extreme differences existed in the distribution of HIV infection by race/ethnicity; prevalence was 22 times higher in blacks than whites in New York and 16 times higher in Florida. Approximately two thirds of infected persons in both countries are believed to be aware of their HIV status.

An estimated 50,000-54,000 cumulative HIV infections had occurred in Canada by the end of 1996, with an estimated 40,100 Canadians living with HIV infection at end-1996 (including those living with AIDS). By exposure category, 63.1 percent of prevalent infections were among MSM, 4.2

percent among MSM-IDU, 17.7 percent among IDU, 13.7 percent among heterosexuals, and 1.3 percent among recipients of blood or blood products. HIV prevalence among IDU has increased dramatically in many Canadian cities (in Ottawa, from 10 percent in 1993 to 21 percent in 1997).

By end-1997, a cumulative total of 641,086 persons had been reported with AIDS in the US, of whom 84 percent were male and 16 percent female. A total of 60,634 cases were reported in 1997, with 35 percent of adult cases in MSM, 24 percent in IDU, and 13 percent attributed to heterosexual contact. Important recent trends have been an increasing proportion of cases in women; a decreasing proportion among MSM; an increasing proportion attributable to heterosexual contact; and an increasing proportion in racial/ethnic minorities. In 1997, 45 percent of new AIDS cases were in non-Hispanic blacks, 33 percent in non-Hispanic whites, and 21 percent in Hispanics. The population-based incidence rates of AIDS in African American men and women in 1997 were seven times and 20 times greater, respectively, than in whites. Among males with AIDS, twice as many whites as blacks were MSM, while the proportion of AIDS cases in blacks that were in IDU or

resulted from heterosexual exposure were three times greater than in whites.



By end 1997, a total of 15,528 cumulative AIDS cases had been reported in Canada (approximately 20,000 after adjustment for reporting delay). The proportion of new AIDS cases attributed to MSM has steadily declined from nearly 80 percent in the 1980s to just over 50 percent in 1997. By contrast, 20 percent of adult AIDS cases were in IDU in 1997, compared to less than 2 percent prior to 1990. The proportion of annual AIDS cases among women has increased from 4-6 percent during 1982-91

to 14 percent in 1997. Persons with IDU-associated AIDS were disproportionately of Aboriginal origin; compared with non-Aboriginal cases, the proportions of cases attributed to IDU in Aboriginal persons were 19 percent vs 3.2 percent for men, and 50 percent vs 17.4 percent for women.

The incidence of AIDS in the US in the first 9 months of 1997 was 14 percent lower than that in the same period for 1996. Better survival of persons with HIV/AIDS has resulted in an increase in the number of people living with AIDS to some 247,571 at end 1997. There has also been a sharp decrease in the trend in delay-adjusted AIDS cases since 1995 in Canada (Fig. 1). The total number of reported deaths from AIDS in the US in 1997 was 29,039, representing a 44 percent reduction compared with 1996. AIDS had emerged in 1993 as the leading cause of death in Americans aged 25-44 but dropped second after unintentional injuries in 1996. HIV infection remains the leading cause of death for black men and women of this age group but a decline in mortality has occurred in this population also.

Only 473 cases of AIDS in children were reported in the US in 1997, of which 62 percent were in blacks, 13 percent in whites, 23 percent in hispanics, and 2 percent in other or unknown groups. Between 1992 and 1996, the incidence of perinatally acquired AIDS declined 43 percent.

### **Implications for the future**

The reductions in AIDS incidence and deaths in North America after 1995 are largely attributable to more effective antiretroviral therapy, although prevention efforts and the natural evolution of the epidemic may have contributed. Since the duration of benefit from antiretroviral therapy is unknown, it remains essential to monitor HIV infections, AIDS incidence, and deaths to detect changing trends, should they occur, in a timely fashion. HIV case surveillance should be conducted in an integrated fashion with AIDS case surveillance, but special studies of HIV infection incidence and prevalence, especially in high risk populations, will remain necessary. Behavioural surveillance and monitoring of access to care, adherence to therapy, and resistance to antiretroviral drugs will also be required.

Trends in pediatric AIDS reflect reduced mother-to-child transmission from increased adherence to guidelines for antenatal HIV testing of pregnant women and provision of zidovudine to those infected. Elimination of pediatric HIV infection is a realistic goal for industrialized countries, and will require HIV surveillance in women and infants, as well as monitoring of access to and quality of care.

Trends in HIV/AIDS in Canada and the US show common themes of reducing impact in MSM but an increasing burden among women and youth, and especially in communities of colour. Increasing proportions of new HIV infections and AIDS cases in Canada are IDU-associated, especially in Aborigines. IDU-associated HIV/AIDS continues to play a central role in the epidemic affecting minorities of colour in the United States.

### **The HIV/AIDS Epidemic in Europe**

Following detection of the first cases of AIDS in the early 1980s, AIDS incidence in Europe increased rapidly throughout the decade, continued to rise but at decreasing rates in the early 1990s, stabilized in 1994-1995 and declined since then. This overall trend is dominated by the trends in Western Europe that still accounts for over 90 percent of AIDS cases reported each year.

AIDS incidence should be interpreted keeping in mind that it reflects patterns of infections which occurred on average 10 years earlier and that HIV incidence peaked in the mid 1980s in western Europe. However, the size and abrupt nature of the decrease suggest that the recent and rapidly increasing uptake of new antiretroviral therapies has contributed significantly to AIDS trends since 1996.

Although in Europe the epidemic originally occurred predominantly among MSM, the subsequent predominance of IDU cases is due to the rapid and intensive spread of HIV through injecting drug use in countries of south-western Europe, particularly Spain, Italy and, more recently, Portugal. Heterosexual contact accounts for an increasing proportion of AIDS cases (24 percent in 1997). The diffusion of HIV in the population outside these high-risk groups appears to have remained limited. HIV prevalence among pregnant women, which provides an indication of the spread of HIV among women of childbearing age, has been fairly stable over time. In large western cities, it ranges from around 0.5 per 1000 in Berlin to 4.5 per 1000 in Barcelona. Although blood donors are clearly selected individuals at low risk for HIV and donor selection may have improved over time, the low (less than 5 per 100,000) and stable or even declining prevalence in blood donations in Western Europe is another indication that HIV tends to have remained confined to high-risk population.

Until 1995, Eastern European countries including the Asian republics of the former Soviet Union reported few HIV cases, mostly among homosexual men. Screening of both low risk groups such as blood donors and pregnant women and high-risk populations such as STD patients and drug users showed very low proportions infected in 1990-94.

Since 1995 HIV has spread rapidly among IDUs in cities of several countries, including Ukraine, Belarus, Moldova and the Russian Federation. Epidemics among drug users are also emerging in the Caucasus, the Baltic States, and in Kazakhstan in Central Asia. More than 20,000 cases of HIV

infections among drug users in these countries have been reported by the end of 1997. UNAIDS and WHO estimate that the total number of HIV infections in the region may have risen from less than 30,000 in 1995 to more than 190,000 in 1997. Although HIV rates among STD patients in Ukraine are now growing at the same rate as they were among drug users two years ago, there is no clear sign of a substantial spread into the general heterosexual population yet. HIV prevalence rates among blood donors and pregnant women have increased, but most persons testing positive may have been drug users.

Fears of a second wave of HIV infections spread through sexual intercourse and following the current IDU associated epidemics are aggravated by the fact that the NIS are experiencing an epidemic of classic STIs, especially syphilis. In 1997, reported rates were as high as 262 per 100,000 population in some countries in the region.

Several factors seem to have been fuelling the HIV epidemic among IDU, including increased drug demand, supply, and consumption, migration and widespread local drug production. Despite shrinking resources, drug treatment services and police in Ukrainian, Russia and other countries have registered increasing numbers drug users, with estimates of their true number reaching more than one million in Russia alone. Most IDUs use home made opiates, but ephedrine use is also common. Local patterns vary and seem to change rapidly, with the use of synthetic drugs such as heroin and cocaine becoming increasingly widespread in major urban centers. No systematic assessment of geographical variations in drug use prevalence has been carried out.

HIV risk appears to depend on specific drug preparation and distribution patterns. Needle/syringe sharing has been reported from all categories of injecting drug users, but the use of home made opiates may be particular risky in that: a) equipment used during the preparation may be contaminated; b) ready-made drugs are sold in used and potentially contaminated syringes or other containers c) human blood is added to the drug solution as a cleansing agent during the production process (often coming from HIV infected persons). Ephedrine use is reportedly associated with increased sexual activity.

Several countries have started implementing harm reduction projects, although at a small scale. A few outreach and needle exchange programmes are operating in Ukraine, Belarus, Russian Federation and Kazakstan, and substitution therapy has been introduced in Latvia and Lithuania. In the Russian Federation, information about the risk of using human blood during drug preparation has been disseminated. In Ukraine, HIV information and disinfectants are provided to incarcerated drug users. Behavioural assessments suggests that these pilot projects have been successful in decreasing the number of IDUs who share equipment and in increasing the number of dealers who sell drugs in clean syringes.

Little is known about the size of sex workers populations in the Newly Independent States, and hardly any data on HIV levels and trends among sex workers exist. Several categories of sex workers have been described, including hotel and escort agency prostitutes, women who offer their services through advertisements, railway station and street prostitutes. In some countries most sex workers are foreigners, whereas in others most are local girls. A large number of women from Eastern European countries also work as sex workers in Western Europe, the Middle East, and even in India and China. No systematic assessment of the organization of the sex industry, including migration patterns has been conducted.

Preliminary situation assessments in several cities showed that young railway station and street prostitutes were most vulnerable to violence by clients and pimps and least able to negotiate safer sex. A substantial proportion of sex workers also appears to inject drugs. The specific situation of increasing numbers of street children, who are likely subject to multiple risks including sexual abuses and drug use, is unknown. Similarly, little is known about male sex workers, a small but particularly vulnerable group of the population. Except for one recently established outreach project in Odessa,

Ukraine and small scale projects in the Baltic States, no prevention programmes specifically targeting sex workers exist.

Rapid assessments of the potential for sexual transmission of HIV between men conducted in four countries in the region showed that although legislation which made homosexuality punishable has been repealed in several countries, hostile public attitudes persist, and same-sex is largely taking place in underground circuits structured around cruising areas, pick-up points in public parks, parking places, bus and railroad areas, bathhouses restaurants and discos. The assessments found a high prevalence of risk behaviour in terms of unsafe anal sex and multiple partners. The validity of available HIV data among homosexual men is limited, as many men are reluctant to disclose their orientation. MSM might therefore be underrepresented among STI patients and blood donors found HIV positive, for instance.

### **3. Migration and HIV**

In some regions, migration is believed to contribute significantly to the spread of HIV. Several countries of Sub-Saharan Africa such as South Africa, Zimbabwe, Angola, and Uganda are cases in point. While only a few studies have provided reliable data on the specific factors that facilitate transmission of HIV in the context of migration, the focus of research was, and continues to be on certain highly mobile populations such as truck drivers and itinerant traders. The role of migration in the spread of HIV therefore remains largely unknown, and as a result HIV/AIDS prevention and care programmes are largely deficient in this area. Several previous MAP reports have included region-specific discussions of this issue.

A migrant can be defined as someone who changes residence voluntarily, either permanently or temporarily, across a geographical or political boundary. This definition does not include refugees, internally displaced persons, and (international) tourists, particularly sex tourists--a group that may also be contributing to the spread of HIV in many areas of the world. Using the more restrictive definition of migrant, it is estimated that in 1996 there were 2 to 4 million international migrants in the world, and 16 million internal migrants (who move within a country).

Migrants are often subject to HIV testing, which is used by many States as a criterion for exclusion or expulsion. Much attention has been given to the likelihood of migrants becoming a burden on the health and social services of receiving countries. In contrast, little effort has been made by governments toward the responsible collection of data to ensure proper attention to the health needs of migrants.

#### **Global patterns of migration**

The past 10 years have seen rapid growth of urban populations in Africa as a consequence of rural-to-urban migration. Many migrants are unaccompanied young men seeking seasonal work. For example, there are currently about 350 thousand people employed in the gold mines in South Africa. Approximately 95 percent are internal migrants. While few data are available on HIV rates in these populations, there is evidence of high levels of STIs.

In most of Asia, travel between countries has been facilitated by new highways, increased trade, and tourism. Labour-driven migration, high population mobility and the possible interaction of international tourism with the sex industry has been associated with the spread of STIs and HIV in, for example, Thailand and neighbouring countries.

Most migration in South America is economically motivated, while a combination of economic migration and civil unrest has been of prime importance in Central America. For example, in both Mexico and Central America, migrants tend to flow northward, often moving toward the United States. In Mexico, 25 percent of cases of HIV infection are rural workers with a history of temporary

migration to the United States. In the Caribbean, the risk of HIV spread may be more attributable to international tourism than to long-term migration.

Historically, both documented and undocumented migration have been characteristic of population movements in North America. It is therefore of particular concern that the United States has maintained and enforced an HIV testing policy for migrants in the absence of evidence that this is effective for the protection of public health.

In Europe, Eastern Europe and the Commonwealth of Independent States (CIS), economic migration, wars and the opening of internal and external borders have led to increased population mobility both within and between countries. The break-up of the USSR and the formation of independent states in the early 1990s have created a shift in migration patterns, with many CIS migrants emigrating to non-CIS countries. The degree to which this will result in the movement of HIV within these populations is still unknown.

HIV can potentially have a devastating social and economic effect on the lives of migrant communities. While HIV and STIs are only part of the larger health challenges facing migrants and refugees, policies should be developed at the national and international levels to ensure that social and health services for migrants include components aimed at reducing the spread of STIs and HIV.

### **Refugees and internally displaced persons**

Refugees are those who have fled their countries because of a well-founded fear of persecution for reasons of race, religion, nationality, political opinion, or membership in a particular social group, and who cannot or do not want to return. Internally displaced persons are those who have fled their homes, but remain within the borders of their own nation. It is estimated that globally in 1996, there were 22 million refugees and 30 million internally displaced persons.

The United Nations High Commissioner for Refugees (UNHCR) has estimated, for example, that there were approximately 1.3 million refugees from and in eastern African countries in 1997. These populations tend to be heavily concentrated in rural camps and holding areas. In addition, between 1989 and 1996 there were more than 900 thousand refugees, 1.1 million internally displaced persons, and 4.2 million repatriates in the Commonwealth of Independent States. The vulnerability of these populations to becoming infected with HIV is high, yet few interventions to date have focused on preventing the spread of HIV among them. HIV remains low on the list of international priorities considered relevant to responding to large flows of refugees, particularly in the early, acute stages of a crisis. However, UNAIDS has produced current Best Practice guidelines which include refugee-specific recommendations.

Currently there are few effective HIV prevention efforts for refugees and displaced persons due to such factors as: inadequate STI treatment, lack of information and education, lack of access to HIV screening, inadequate access to condoms, unscreened blood transfusions, lack of sterile injection equipment, and inadequate diagnostic facilities.

### **Surveillance and research gaps**

There is a lack of adequate surveillance data on the specific relation between migration and HIV. The inclusion of migration status and ethnicity in national level surveillance systems has traditionally been precluded in fear of stigmatisation. However, where this barrier has been overcome, active participation of migrant communities has stimulated the design and implementation of effective intervention programs. Insufficient attention has been given to the impact of gender and age differences on the risk of HIV infection for migrants, refugees, and internally displaced persons.

Data collection and analysis should help shape prevention and care programmes relevant to migrants, refugees, and internally displaced persons with attention to the differences in needs when targeted at



different stages of the migration process (e.g., at the point of origin, transit, destination, and again for communities of origin in the case of return).

Recognition must be given to the heightened vulnerability of migrants in the process of data collection and analysis, and every effort must be given to ensuring that the human rights of migrants are adequately protected in this process.

#### **4. Inequities in Care and Support for Those Infected With and Affected by HIV**

As HIV/AIDS continues to spread unabated in most developing regions of the world, one of the most profound challenges manifested in this pandemic is how to care for the millions of people infected with and affected by the virus. The lack of options for care is further complicated by the lack of a dynamic response in most professionals toward realizing the provision of holistic care, including medical treatment, psychosocial support services and linkages between the clinical and home-care settings across the care continuum. The time when individuals infected with HIV, no matter where they live, are able to rest assured that while they face chronic and possibly terminal illness, they will have access to fully knowledgeable, adequate and sustainable treatment and other forms of care over the potential long-term is not yet in sight.

Daunted by the lack of resources and other structural impediments to organized care-for HIV, many in positions of power still shy away from the topic of care. The increase in the number of people in need of care globally, the limited coping capacity of health services, and the recognition that care needs go well beyond clinical therapies to psychosocial support and community-based care for the burgeoning populations of the HIV/AIDS-infected, especially in sub-Saharan Africa, can and do frighten some donors and governments.

Yet the right to health is a basic human right. HIV-positive individuals must be able to receive a full-spectrum of care. While rights do not lose their importance in low-resource settings, the reality is that they often are not fully protected. The mandate to protect health, to improve health, to care for those in ill health is a growing dilemma around the world, especially where masses of people are infected with or affected by HIV.

Medical, nursing and social support personnel in many countries, already stressed by the burden of other common, chronic diseases of public health that are difficult to care for, are frightened by confronting HIV/AIDS. Woefully inadequate services compounded by the fear of infection arm these workers with judgmental attitudes, moral impunity, and lack of caring behaviours. The obvious result is poor medical care for those with diagnosed or suspected HIV infection; consequently, comprehensive holistic treatment in these settings is not offered. In some countries, especially in east and southern Africa, the problem is exacerbated by the high percentage of health care providers in urban areas living with HIV themselves, leading to an extremely high proportion of patients per health care worker in clinic and hospital settings.

Knowing of the problems encountered in hospitals, many, if not most, known or self-suspected HIV-positive individuals frequently turn to health care providers only in the terminal stage of their illness. Others choose to never attend these clinics at all. By not availing themselves of voluntary counseling and testing at an early entry point, preventive therapies, or not being given access to these services, many find themselves unable to resist other opportunistic infections. The result: overflowing hospitals, some with 60 percent of their beds in medical wards accommodating the HIV-infected or terminally ill AIDS patients. Complicating the situation further is the lack of standardized HIV/AIDS treatment and management protocols, safety precautions, safe blood, and often other medical supplies. Limited or complete lack of counseling services and in many cases lack of confidentiality provides patients with few, if any, positive psychological or emotional benefits of clinic visits. Many patients,

especially women and in particular adolescent girls, can fear stigmatization and community ostracization from such a lack of confidentiality and, as a result, do not come forward for HIV testing or care.

Already bearing the burden of socioeconomic and political inequality, women who are HIV-positive may have less access to health care and psychosocial services than men. They also have less free time to access what is available and less expendable income to devote to their own comprehensive health care. Due to their low social status, lesser educational background, and generally lower level of self-esteem, many women cannot practice health-seeking behaviour, or are simply unaware of their potential for HIV infection. Frequently, their families and communities expect them to put the care needs of their spouses and children ahead of their own. Attitudes toward HIV-positive women can be especially discriminatory, even violent, with domestic violence not uncommon. When it comes to HIV care and support, the lack of access to such services for women may shorten their lives and tends to diminish the overall productivity of the community. However, there is a need for more data on these topics for more responsive policy formulation and better programmatic planning.

As well as care and support barriers to women, adolescents are ill-positioned for care and psychosocial support, especially if they are HIV-positive. At the time of their lives when they most need the support of parents, peer groups and in some cases medical care and psychosocial support from professionals, their concerns, which may relate to their future survival, may not be taken seriously. Adolescent girls, who are generally at the height of human emotional vulnerability, are in the worst societal position and can be ridiculed for asking the type of questions, which if answered comprehensively, can save their lives. In Nepal, where more than 200,000 girls are estimated to have been trafficked to India for sex work in brothels, a growing number are returning to their home villages HIV-positive. In many of the rural areas of the country, health care is scarce; to get any treatment at all, the girls need familial support, which can in itself be impossible to access when care needs are related to infection with HIV.

Underreporting of AIDS cases as well as HIV infections by health administrators is a large hurdle that seriously reduces the necessary basis for realistic design and planning of health care structures, staff and basic support systems. Caseload numbers are needed for costs to be estimated accurately, showing the benefits for all of holistic, community-based programmes linked to hospital care. For this effort to work, the voluntary diagnoses, and the provision of treatments, other forms of care and support for all who are HIV-positive, including the most marginalized segments of society, such as drug users, need to be respected equally with those for individuals whose social acceptability is unquestioned. If access to care and support is measured, a real picture of the HIV situational status will emerge relative to local environments, which are suitable for associating real costs. With the emergence of powerful but complex regimens and also the evidence of feasible and affordable preventive therapies and opportunistic infection prevention, the chance to introduce holistic therapies through clinical attendance is increasing. All communities need to recognize that antiretroviral therapies, available to all groups in some industrialized and middle income countries, are extremely expensive and not a panacea. Adherence to the complicated regimens is a universal problem. The short-term side-effects of many of these regimens are just starting to become known, and the long-term effects are completely unknown. Additionally, some populations are finding it difficult to return to lives they thought they had lost; their need for psychological support during this period has grown, not lessened. More data are needed to track the positive and negative aspects of these therapies, as well as the estimated all-inclusive, long-term costs.

The flowering of some care and support programmes in non-industrialized countries proves that, with courage, communities can create programmes to provide safety nets to those with HIV/AIDS even in the most dire economic settings. Linkages of hospital and community-based HIV/AIDS care and support need examination, wide dissemination of pertinent information and replication internationally. Linking clinical, community- and home-based programmes by taking a participatory approach to HIV/AIDS care and support options will facilitate the betterment of both and, likewise,

provide the type of caring and sharing that needs to be borne by and balanced among community networks at this time when individuals and families are increasingly unable to bear the burden of HIV/AIDS alone. Both access to and the quality of HIV care and support services need to be measured and monitored to ensure overall adequacy and sustainability, however comprehensive the response.

## **5. Mother to Child HIV Transmission: The Potential Global Impact**

In 1998, approximately 600,000 children will be born with HIV infection worldwide. Unfortunately, the biomedical advance demonstrating the dramatic reduction of mother-to-child transmission of HIV with zidovudine (ZDV) treatment has yet to be translated into widespread use of antiviral treatment to help prevent HIV infection in infants. The 1994 ACTG 076 clinical trial follow up now shows a greater than 80% reduction in the vertical transmission rate of HIV, but this complex regimen may cost between \$800-900 per woman treated, even without including other required costs of the regimen, such as voluntary counseling and testing (VCT) for HIV of the pregnant woman or formula feeding rather than breast-feeding for the infant. Primarily because of the ACTG 076 regimen's high cost and impractical logistics for resource-poor settings, where the vast majority of mother to child HIV transmission occurs, other options are also being pursued.

### **Types of intervention**

Transmission of HIV from an infected woman to her offspring could be prevented in a number of ways. For many reasons, the best way to prevent transmission would be through primary prevention, that is either prevent the mother-to-be from becoming infected with HIV or prevent unwanted pregnancies in HIV infected women through contraception. In addition to primary prevention, other types of potential interventions could be considered on a population basis, that is, without the need to know a particular woman's HIV status, which would require the training, infrastructure and expense of VCT programs. Potential population based interventions could relate to those changes in obstetrical care that could minimize delivery factors which have been known to increase the likelihood of HIV, e.g. minimize time after rupture of membranes.

At least two other specific types of interventions are being tested in resource-poor settings that, if successful, may not require the knowledge of the pregnant woman's HIV status. One type of intervention is vaginal or birth canal cleansing with chlorhexidine to reduce HIV transmission at or around the time of birth. This intervention has been tested in Malawi without success in relation to reducing transmission, but another trial is underway in Kenya presently. In a second type of intervention, micronutrient supplementation is given to the pregnant woman to attempt a reduction in the rate of HIV transmission. These intervention trials are primarily based on the previously observed association between maternal Vitamin A deficiency and the increased likelihood of HIV perinatal transmission. The results of these trials in at least four trials in African countries are not yet available.

Both passive and active immunization with HIV specific reagents are being tested in sites in North America, Europe the Caribbean and Africa. If active immunization to either the pregnant woman or the infant proved to be effective, this could be a cost-effective approach to preventing mother to child transmission. Unfortunately the results also are not available from these initial trials and further research into this approach is needed.

### **Antiviral intervention**

As noted, at least a three-quarters reduction in vertical transmission is possible with ZDV therapy, albeit with the complicated and expensive ACTG 076 regimen. Trials with other antiviral agents as well as multidrug trials are underway, but the costs and complexity of implementation may only increase as more antiviral agents are added.

A recent trial in Thailand looked at the contribution of oral ZDV given during the latter part of pregnancy and during delivery to the mother only. Results from the trial showed that this much cheaper and shorter course of ZDV could reduce the transmission rate from mother to infant by 50% (when given with formula feeding in the postnatal period). This important trial, unfortunately, did not achieve the reduction of transmission seen in the ACTG 076 trial and left open, therefore, at least two important questions: Would ZDV given either to the pregnant woman earlier in pregnancy and/or to the newborn after delivery reduce the transmission rate closer to that seen in the ACTG 076 regimen? A second trial in Thailand is in progress to help answer those questions by giving oral ZDV in two different dosing durations to a cohort of pregnant women, in addition to two different dosing duration of oral ZDV to the infants born to those mothers. Since we now know that oral ZDV is effective in this setting, this second trial will help determine the most effective oral regimen to further reduce transmission during pregnancy, delivery and during the immediate postnatal period. More research into other antiviral regimens to block transmission is a priority.

### **HIV and infant feeding**

Unanswered are the issues and questions concerning preventing transmission of HIV by breast-feeding. Rough estimates of a 10-14% additional risk of transmission via breast-feeding have been given when various observational studies and estimates have been combined. This added risk when compared to the 25-35% known risk of HIV transmission during pregnancy and delivery means that perhaps a quarter to a third of all the HIV infections in infants worldwide occur via breast-feeding. As success in reducing mother to infant transmission progresses, the dilemma of postnatal transmission of HIV being balanced with optimal postnatal feeding and care will only increase. With any policy decisions concerning breast feeding versus any other form of infant nutrition are considered, the importance of collecting local data cannot be overemphasized, in that the risks, affordability, nutritional quality and logistics of alternative forms of infant feeding (e.g. formula feeding) are not constant, nor uniform throughout specific regions of the world. In addition, not only are the costs and risks of alternative infant feeding high, this type of feeding may also be associated with social stigma. Urgent research is needed, therefore, to determine how to reduce HIV transmission via breast milk, in addition to determining safer ways to provide nutrition to infants.

### **An agenda for action**

Translating the advances in preventing mother to child transmission into practice demonstrates the difficulty of translating clinical research findings into public health reality. This year UNAIDS and especially two of its cosponsoring agencies, WHO and UNICEF, have developed several guidelines and overview documents for use in the area of preventing mother to child transmission of HIV and in the area of HIV and infant feeding. These documents are the result of much work and expert opinion concerning how healthcare decision-makers and managers could proceed with the opportunities now available. These documents are recommended as important blueprints for proceeding.

Concerning the future trends of the epidemic in light of the recent advances in preventing mother to child transmission, one must look at the positive and potentially negative outcomes of proposed interventions, including parameters as infant morbidity and mortality, costs, breast feeding rates, adherence rates, as well as the HIV specific outcomes, including transmission rates, the impact of new maternal HIV infection diagnoses and the development of drug resistance. To implement the new regimens and programmes now being recommended by UN agencies, therefore, it is recommended that demonstration projects be created in a variety of epidemiological and economic settings, within which such necessary operational research could then be conducted. Only in planned data gathering during the implementation of new prevention interventions, can the hope of blocking mother to child transmission be realized in a sustainable and feasible manner.

## **6. HIV Transmission in the Health Care Setting**

HIV and other blood borne infections such as Hepatitis B and C and HTLV I are transmitted in the health care setting

- To patients through transfusion of infected blood or injections or cuts with inadequately sterilised equipment.
- To health care workers through percutaneous injuries with infected needles or other sharp instruments or through exposure of mucous membranes or breached skin to body fluids of infected patients.

Transmission of HIV infection from infected health care workers to patients has been documented in a few instances only.

The contribution of these modes of transmission to the spread of HIV in the general population is generally very limited and as a result prevention of these infections in low resource settings has received little attention. Yet, it has been estimated that in Uganda 5 to 10% of HIV infections were attributable to transfusion of infected blood. Also, at a population level HIV transmission in the health care setting may be a small problem, but for certain subpopulations, i.e. users of health services and health care workers, the risks of transmission may be far from negligible.

### **HIV transmission through blood transfusion**

In the US and in Western Europe the risk of infection through blood transfusion is now extremely low, in the range of 1 in every 440.00 to 1 in every 660.000 donations. Although considerable progress has been made in developing countries since the late 1980's, provision of safe blood is still not universal nor consistent. For example a study carried out in Kenya estimated the risk of HIV infection after blood transfusion at 1 in every 50 donations, although nearly 100% of blood bags were reported to have been screened for HIV.

Several strategies for the provision of safe blood have been proven to be effective in reducing the risk of transmission of HIV and other infections, i.e. hepatitis B and C and HTLV-I. Strategies, which include avoidance of unnecessary transfusions, recruitment of low risk donors and screening for HIV and hepatitis B, have been shown to be feasible and cost-effective even in low resource settings. However consistent implementation of these measures remains problematic in many areas of the world, the ultimate reason for this failure being the low priority given by policy makers and donor agencies to prevention of infections through blood transfusion.

### **HIV transmission through injections and cuts with inadequately sterilized equipment**

There have been several reports in the literature on HIV transmission through inadequately sterilized equipment. The most widely publicized outbreaks have occurred in Rumania and in Russia in the late 1980's but other outbreaks have occurred in various parts of China due to the reuse of plasmapheresis equipment. The data on this mode of transmission are virtually non existent for developing countries. Yet, the circumstances that led to the outbreak in Russia, i.e. re-utilization of disposable injection material, are prevalent in many resource poor settings. Failure to detect infections - or even outbreaks - acquired through inadequately sterilized equipment, can be attributed to poor monitoring systems (or even lack of monitoring systems) and low awareness of the problem.

### **Occupational HIV transmission**

In industrialized countries the reported numbers of health workers infected through this mode of transmission are very small compared to the numbers of HIV infections in other transmission categories. For instance, by June 1996, U.S Center for Disease Control had reported only 51 documented cases and 108 possible cases of occupationally acquired HIV infection.

As for developing countries, a few studies have attempted to document the risk of occupational exposure by comparing HIV prevalence rates in different categories of health services employees.

These studies did not find a significantly increased risk of HIV infection associated with patient contact, suggesting that the proportion of HIV positive health care workers who acquired their infection through occupational exposure is rather small. However this does not mean that the risk of occupationally acquired HIV infection is negligible. A study in Tanzania estimated this risk among health care workers in district hospitals, at 0.27% per year. In the same region, in the same year the incidence of HIV infection in the general population was 0.95%.

In resource poor settings, especially settings with a severe HIV/AIDS epidemic, the risk of occupationally acquired HIV infection can be expected to be several factors higher than in industrialized countries. Prevalence rates of HIV infection among hospitalized patients of over 20%, which was the rate used in the Tanzanian study, are not at all exceptional in hospitals in sub-Saharan Africa. The study in Tanzania also brought out an extremely high incidence of percutaneous injuries, i.e. 5 per health care worker per year.

Failure to ensure safe working conditions for health providers in developing countries is part of a general pattern of failure to address the welfare of people working in health services. Renumeration of health workers is generally low and investments in safety precautions assume low priority where resources for health are scarce. Yet, health care workers, especially in settings with severe HIV/AIDS epidemics, are a valuable asset and their anxieties and frustrations may have a negative impact on the quality of patient care.

### **A call for urgent action**

HIV transmission in health services in developing countries is a neglected problem. Interventions to prevent these infections will not have a measurable impact on the spread of HIV in the general population, but they have to be considered part and parcel of the provision of quality care. Inequity in access to antiretroviral therapy is now – rightly – in the centre of heated debates. It is high time we also address the issue of inequity in the prevention of HIV infection in health care settings. If not, we may soon face absurd situations where we provide expensive treatments to increasing number of people who acquire HIV infection through the health care setting because of our inability to ensure a safe blood supply or provide adequate universal precautions.

What needs to be done? First of all we need more and better data on blood safety, patient-to-patient transmission and occupational exposure. It may not always be feasible to set up sophisticated systems for surveillance of infections acquired through these transmission routes, but systems for the monitoring of procedures ought to be within the reach of most health services. Monitoring morbidity and mortality among health care workers should be quite straightforward and affordable, even in resource poor settings.

With regards to blood transfusion safety we basically know what needs to be done but policy makers and donor agencies need to be convinced of the necessity to allocate resources for the provision of safe blood on a consistent basis. Prevention of HIV transmission to health care personnel, whether through sex or occupational exposure should be part of a comprehensive prevention strategy. Other pressing problems in the health care setting include transmission of hepatitis B and C, both of which are preventable by improved universal precautions and a safe blood supply.

### **HIV infection through occupational exposure: How big is the problem?**

The average risk of HIV infection to a health care worker after percutaneous exposure to HIV is estimated at 0.3% (compared to a 0.1% probability of male-to-female transmission during sexual intercourse). Risk factors associated with an increased risk of transmission include injury with a large bore needle; deep injury; visible blood on the device; a procedure involving a needle in an artery or vein; advanced disease in the source patient.

Data on numbers of health care workers infected through occupational exposure are available for a number of industrialised countries

*US: By June 1996 CDC had reports of 51 documented cases and 108 possible cases of HIV infection after occupational exposure.*

*France: By early 1995 there were 10 proven cases and 27 possible cases reported.*

There are no hard data on numbers of health care workers infected through occupational exposure in developing countries.

*A study in nine hospitals in Mwanza Region, Tanzania, found an average of 9.5% prick incidents per week. This gave an incidence of 5 prick accidents per year per health care worker. With an estimated HIV prevalence among patients of 20% and a transmission probability of 0.25% this would give an incidence of HIV infection through occupational exposure of 0.27% per year.*

*Around the time this study was conducted the incidence of HIV infection in the general adult population was 0.95% in the rural areas and 1.2% in Mwanza town.*

*In areas in Sub-Saharan Africa, where up to 50% of hospital beds are occupied by HIV/AIDS patients, the risk of infection through occupational exposure may be much higher than reported in this study.*

*In comparison, a study in 6 hospital emergency departments in the U.S. found an incidence of 0.37% percutaneous injury per person per year and an annual risk of occupational HIV infection of .002-8.9%.*

Although no direct measures are available of the magnitude of the problem of HIV infection through occupational exposure in developing countries, the few estimates that are available give reason for concern. The study in Tanzania showed a worrying high incidence of percutaneous injury. This was explained by insufficient staff training, inadequate equipment, and poor waste disposal - a situation that may be found in most resource-poor settings.

## **7. Orphans**

It is generally accepted that children born to HIV-infected mothers have about a 33 percent chance of being infected through maternal transmission. This means that two-thirds will not be infected.

However given that the incubation period is approximately 6-8 years, those children not infected **will** be orphaned. Orphans continue to be considered orphans until they reach the age of 15. The importance of orphaning resulting from the epidemic has not been fully appreciated nor planned for, although there has been some consideration of this in certain countries and from certain agencies.

The MAP meeting reviewed the state of knowledge regarding orphans and examined alternative estimates on the numbers of orphans and likely future trends. A number of critical issues are at work which emphasise the importance of this issue. The number of orphans resulting from AIDS mortality is large and is expected to increase rapidly in the near future. UNAIDS estimates that already over 8 million children have lost their mother due to AIDS. As the peak in the incidence of orphaning will occur only once the peak in AIDS cases is past, the orphan issue is bound to be a long-term one, requiring increased attention and long-term solutions.

Furthermore, most analyses have not addressed the fact that estimates of the number of orphans due to AIDS are **in addition** to the number due to non-AIDS causes. This means that whatever the magnitude of orphans due to AIDS, the real problem will be much greater. In addition, due to technical difficulties, most analyses have only estimated the number of children whose mother has died. Some research has shown that the total number of orphans may be two to three times the number of maternal orphans.

Orphanhood impacts on children in a variety of ways. The following areas were discussed:

- Loss of family and identity;
- Psychosocial distress;
- Increased malnutrition;
- Loss of health care, including immunisation;
- Increased demands for labour;
- Fewer opportunities for schooling and education;
- Loss of inheritance;
- Forced migration;
- Homelessness, vagrancy, starvation, crime;
- Exposure to HIV infection;
- Exploitation and exposure to violence; and
- Gender differentials in impact.

Based on recent estimation efforts, the number of orphans created by current epidemics is reasonably well known. What is not known are the age patterns, gender differences, or the situation of these orphans in the households and communities in which they live.

The numbers of orphans in countries with severe HIV/AIDS epidemics is already straining the ability of extended families and communities to absorb and provide for these children's needs. It is unclear how much coping can be expected of families and communities. How much of the inevitable gap in support will be taken up by the state? And what can civil society, with the support of government and the international community, do to help? These are questions that must be faced in the next decade, and there are no easy answers.

In the countries of Eastern Europe and the CIS the numbers of AIDS cases and hence orphans may be small in absolute numbers, but may represent a significant increase in percentage terms. In addition, the effects may be exacerbated in this region, where there is a history of relying on the state for support, while the current state system is contracting and its capacity to provide care decreasing. Some examples of innovative community response include selected programmes in Uganda, the Child-Headed Household programme in Zimbabwe, and programmes in Zambia. Despite these examples of effective programs, none has been replicated even nation-wide, nor has there been any attempt to document "best practices" for global application.

### **Directions for action**

There is an urgent need for information of what has worked and what has not in terms of care and support for affected children in diverse cultural settings. Best practices need to be identified for use by communities and programme planners.



Additional research on the circumstances of orphans must be undertaken, including studies of their characteristics and circumstances and the differential impact of maternal, paternal, and double orphaning.

Policy makers should ensure policies and programmes address the different needs of girls and boys as well as adolescents versus younger children.

Governments and communities should incorporate the care and support offered by traditional institutions (religious, social and grassroots) into their overall programme planning.

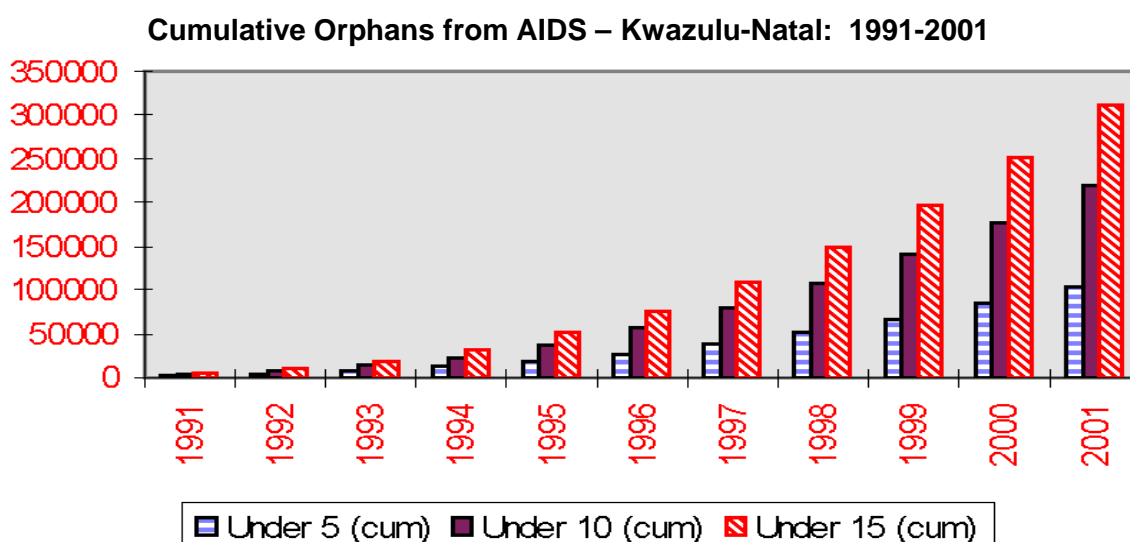
Finally, all those involved need to recognise the right of children's voices to be heard, considered and given due weight in determining their care and support needs.

### Orphans: A Looming Crisis

Already more than eight million children have been orphaned by AIDS in sub-Saharan Africa. It is projected there will be three million orphans in South Africa in the next 10 years. This issue was the focus of the *Raising the Orphan Generation Conference* held in June 1998 in Pietermaritzburg.

In this conference, a number of orphan estimates were presented. The reported number of orphaned children under 18 years of age in Tanzania was 6 percent in 1991 and 26 percent in the Rakai district in Uganda. In Manicaland Province of Zimbabwe, 6.4 percent of children under 14 years of age had been orphaned by 1991, and in Zambia, 17 percent of children under 16 had lost their mother by 1996. A 1994 survey in the KwaZulu-Natal Midlands region in South Africa showed that 6 percent of children under 16 had lost their mother (due to various causes, including AIDS).

The Children in Distress Project has prepared estimated numbers of orphans through 2001 in Kwazulu-Natal. The numbers, shown below, indicate 150 thousand cumulative orphans in 1998 and over 300 thousand by 2001 (Source: CINDI Website).



It is clear that AIDS will continue to orphan many thousands of children in KwaZulu-Natal. The state, the society, and the community are in no way prepared for the care and support which will need to be extended to these children. AZT treatment will reduce the number of paediatric AIDS cases, at an estimated cost of dollars 380 per patient, but will also serve to increase the number of orphans.

## 8. Interactions Between TB and HIV programmes

From 30 to 70 percent of young adults in developing countries are infected with *Mycobacterium tuberculosis*, most of whom will not develop disease. HIV infection is the single strongest risk factor for progression from primary as well as latent infection to active disease, so that in areas of the developing world that have a high prevalence of HIV infection, rates of TB are rising. Of the 15.3 million people estimated to be infected with HIV and *M. tuberculosis* at the end of 1997, 11.7 million (76 percent) live in sub-Saharan Africa. An estimated 7.4 million TB cases have occurred in 1996. Three countries, India, China, and Indonesia, account for half of the annual world total of TB. WHO has refined and promoted a strategy for TB control, the DOTS (Directly Observed Therapy – Short Course) strategy, which is more likely than other approaches to result in high rates of cure and avoidance of drug resistance.

Although patients with HIV-associated TB mostly have typical clinical patterns, their frequency of atypical manifestations is increased, making diagnosis more difficult. Recurrence rates may be higher than in HIV-negative persons through relapse or reinfection. Drug resistant TB has been associated with HIV, particularly in the U.S.A., where HIV-associated TB may occur in the context of other factors that decrease access to health care such as intravenous drug use and migration. Drug reactions, particularly skin eruptions, are more common in People Living With HIV/AIDS (PLWHA), notably to thiacetazone, which may lead to life threatening reactions. *M. tuberculosis* also enhances the replication of HIV, leading to higher viral levels and possibly to more rapid progression of HIV disease in PLWH who develop TB compared to those who do not. The following are the main impacts of HIV on TB control programmes:

**Increased Burden:** From 5 to 10 percent of dually infected adults will develop TB each year. If HIV seroprevalence rises as high as 10 percent of the adult population, 100 to 200 new cases of HIV-related TB can be expected per 100,000 total population. In most countries, this will represent at least a twofold increase in numbers of cases, with urban areas being most heavily impacted.

**Diagnosis:** In addition to the effect that the increased burden has on diagnosis, it is also more difficult to diagnose individual cases. Furthermore, HIV causes several other pulmonary problems that may be misdiagnosed as TB.

**Treatment:** The advent of highly active anti-retroviral therapy (HAART) may cause problems of drug interactions in the few who are able to afford this treatment; the protease inhibitors are contra-indicated while taking rifampicin. TB programmes are increasingly faced by patients with other medical problems associated with HIV in addition to TB.

**Mortality and morbidity:** Even in programmes that use the DOTS strategy, mortality in HIV-positive patients is high, mostly from other manifestations of HIV disease. This leads both to loss of the community's confidence in the programme as well as to deterioration in staff morale. Adherence to therapy and follow-up may be threatened by other medical and social problems affecting HIV-infected patients.

**Stigma:** The association of TB with HIV is widely recognized in communities bearing the brunt of the dual epidemic and HIV remains a highly stigmatizing infection. Some patients may choose not to attend health facilities through fear of being diagnosed with TB and by association with HIV. Misconceptions about TB and HIV also lead to some health care workers worrying about the risk of acquiring HIV from their patients. Other staff may discriminate against TB patients, perceiving them to be less deserving of care through association with HIV infection.

**Nosocomial and institutional transmission:** The high HIV seroprevalence among patients facilitates the spread of TB. As the HIV prevalence rises in the general population, institutional transmission also becomes a serious concern for those working in health care facilities or living in crowded surroundings in other institutions such as prisons, mines or barracks.

In summary, HIV has adversely affected TB control programmes both directly through increases in caseloads and more difficult diagnosis, but also indirectly through its effect on health-seeking behaviour and the interaction between patient and provider at the health services. The control of TB in areas with a high prevalence of HIV infection is therefore, to a considerable degree, dependant on the success of the HIV control programme.

### **Impact of TB on HIV control programmes**

Since TB is one of the most common complications of HIV infection and is eminently treatable, accurate diagnosis and effective treatment of TB should be two of the most important components of any HIV care program. As prophylaxis against opportunistic infections becomes more widely sought by HIV-infected persons in developing countries, preventive therapy for tuberculosis in HIV-infected persons will become increasingly discussed. Although preventing TB in People Living with HIV/AIDS (PLWHA) who have not yet developed active TB has been demonstrated in clinical trials, there are operational challenges to ensure that patients with active TB are not given preventive therapy when they need full treatment. Failure to exclude active disease will result in inappropriate monotherapy and lead to the development of drug resistance. TB programmes have a well-developed strategy that is integrated into provincial and district hospitals and urban and rural health centers, and which ensures delivery of care to TB patients and monitors outcome. In contrast, strategies for care of patients with HIV-related illnesses are at an earlier stage of development in most developing countries.

TB patients are also an easily identified group that has a higher prevalence of HIV infection than the general population. They are, therefore, a suitable target for interventions to reduce further transmission of HIV, and, when possible, biomedical interventions to prevent or treat other HIV-associated problems. In summary, TB diagnosis and treatment are vital components of any HIV care program.

There are, therefore, considerable opportunities for synergy between TB and HIV programmes. The decentralization and increasing autonomy for districts that health sector reform is bringing to many countries should be used as an opportunity to enhance the concerted management of the dual epidemics. Possible actions include: training; community care; IEC manuals and guidelines; advocacy; surveillance; collaboration with NGOs; and social mobilization.

### **The potential synergy of TB and HIV programmes**

Continuing expansion of the DOTS strategy is needed to control the global burden of TB. In areas of high HIV prevalence, the control of TB is, to a considerable degree, dependant on the success of the HIV control program. TB diagnosis and treatment should be vital components of the HIV care program, and HIV care must be included in TB programmes. It is also possible to prevent some cases of TB in PLWHA who have not yet developed active TB. Preventive therapy should be included in the package of care for PLWHA. Although both TB and HIV programmes are aware of the ongoing disaster, neither has taken sufficient action, largely because they are already stretched to the limit with priority activities for their specific infection. The challenge is to harness the capacity of both

programmes and their partners, the communities they serve and the NGOs involved, in order to minimize the impact of the dual epidemics. Health sector reform provides the opportunity to develop the synergies between TB and HIV activities in the delivery of services. The monitoring of the TB and HIV epidemics, combined with the monitoring of the interaction between TB and HIV programmes will show the degree to which the synergy between these two public health problems offsets—or is dominated by—the synergy between the programme aimed at controlling them.

## **9. The Global Map of Neglected Behaviours: Knowledge and Action Gaps**

As the 21<sup>st</sup> century approaches, we are discovering that the global HIV pandemic is far worse than we had thought. Furthermore, as the growth of the HIV pandemic is outpacing the mobilization of resources, prevention efforts must become more focused, more inclusive of the full spectrum of those with risk behaviour, and more efficient and effective.

This requires good behavioural information, so that resources can be directed where they will have the greatest impact and the more effective prevention alternatives chosen. Our knowledge of risk behaviours for HIV still has severe limitations in most of the countries in the world. This leaves serious questions about how to most effectively target, focus, and evaluate the responses, how to mobilise resources and efficiently use the resources that are available, and how to build political commitment.

### **Major knowledge gaps in targeting and focusing the responses**

HIV epidemics are complex in any country. They often consist of large numbers of sub-epidemics in different populations tied together through complex behavioural networks. An effective national programme must understand this complexity and develop appropriately complex solutions. Effective strategic planning for prevention creates demands for behavioural data, including consideration of the extent of risk in populations as a whole, as well as the respective size of various populations particularly vulnerable to HIV.

The levels and forms of risk behaviour must be assessed in order to understand the potential impact of widespread HIV transmission, monitor large-scale changes in behaviour, and determine the magnitude of ongoing prevention needs. The primary method for obtaining this type of population wide information has been through representative general population surveys. However, despite many efforts, including the Global Programme on AIDS Partner Relations and KABP surveys in 1989-1990 and recent sexual behaviour assessments in the Demographic and Health Surveys, knowledge of the extent of general risk behaviour remains poor in most countries. Only about 40 countries have general population surveys and few have looked at behaviour changes over time. When UNAIDS asked HIV/AIDS country programmes to provide information about the percentage of the population with non-regular partners and their condom use with those partners, less than one-third of the countries could provide information on either. Many factors contribute to the lack of behavioural data including cost; reluctance to conduct such surveys for political or religious reasons, lack of personnel or technical resources, and concerns about the reliability and validity of data that might be gathered. Using stratified sampling approaches to gather representative data, rather than insisting on a nationally representative sample, can provide a cost-effective and efficient alternative.

Without a complete picture of behavioural risk in a population it is difficult to prioritize prevention activities. Certain situations contribute disproportionately to HIV transmission, for example, sex work and injecting drug use. Yet few countries can provide estimates of the numbers of sex workers and clients or injecting drug users. Knowledge of important variations in risk behaviours within populations is rare, so prevention efforts are not necessarily focused on those with the greatest risk behaviour. Populations such as men having sex with men and sexually active youth may be missed

and other vulnerable groups such as factory workers, military, fisherman, and truckers are also likely to be overlooked.

*What is happening with youth?* In many countries it is still assumed that few youth are sexually active. Carefully collected behavioural data are required to demonstrate the need for prevention programmes among the young. Behavioural studies are also necessary to further demonstrate that sexual health education does not increase sexual activity. While many such studies have been carried out in industrialized countries, few have been done in developing countries to date.

### **Improving the local relevance and quality of behavioural data**

Locally relevant behavioural information is the best source for designing locally effective prevention programmes. Communities know their own situations best, therefore behavioural research and monitoring must actively involve communities in critically evaluating their own risk situations and contributing to the design of effective programmes. This involvement is also essential for communities to mobilise themselves to respond to the epidemic, rather than waiting for outside entities to act. In places where vulnerable populations may be severely marginalized, separate advocacy, research, and prevention efforts might be needed to supplement community-planning processes.

Behavioural research instruments need to be relevant to their locality. For example, social constructions of sexuality and gender relations vary greatly from country to country and population to population. “International standard” questions may not reflect local categorizations of sexual partners, sexual behaviour, or gender relations and questions not phrased in a relevant and understandable fashion for the interviewee will produce unreliable and invalid data which may be inappropriate to local prevention programme design. Careful formative research is needed to determine the best way to ask questions in a local context. This means that international comparison questions might need to be supplemented by locally relevant questions that contribute to overall programme design, targeting, and evaluation.

Work is also needed on methodologies for improving the reliability and validity of behavioural data. Alternative approaches such as face-to-face interviews, tape recorder administered interviews, and computer based administration should be researched critically and the approach chosen which is most effective in the local setting.

### **Efficiently utilizing resources**

As resources become more constrained, it is increasingly important to make efficient use of what limited resources are available. Our response will remain inefficient without a better understanding of what forms of prevention are most appropriate and effective with different population groups. Specific studies to compare the impact of different prevention programmes are needed in a local context, and most future behavioural and epidemiological studies are best done in the context of these programmes so that they contribute to not only knowledge of risk but to its reduction.

There is also a major gap in transferring existing knowledge on prevention between different places and into locally effective alternatives. Often we are aware of what constitutes effective prevention, but do not act on this knowledge. Approaches that we know facilitate HIV prevention, such as the development of supportive legal and social environments, are not put into practice. To do so calls for increased political will and commitment to HIV prevention. In addition, there is often insufficient sharing of behavioural and prevention experiences among developing countries, calling for an increase in the creation and support of technical resource networks and increased support for South-South collaboration.

### **Building political commitment and mobilizing resources**

Countries that have had effective responses demonstrate that high level political commitment is essential to containing or avoiding a serious HIV problem. Unfortunately, in most countries pregnant women provide one of the few epidemiological windows on the general population, and research often focuses on specific populations assumed to carry high levels of risk. These populations are often discriminated against, so that mobilizing action for them can be politically difficult. Data must be presented carefully to avoid increasing stigmatisation and discrimination, but data on the behaviours of the population as a whole and a better understanding of the behavioural linkages among various populations can help convince policymakers and community members that HIV is a serious problem.

Policymakers and the public as a whole often operate on false assumptions about sexual and other risk behaviours in society. Discomfort with discussion of sexual issues and drugs keeps many relevant issues off the public agenda. The lack of data to contradict false assumptions also contributes to the neglect of prevention needs.

There is a tendency to oversimplify the nature of epidemics. Even in countries where the epidemic has been labelled “heterosexual”, HIV transmission continues through other routes including needle sharing and sex between men. In many parts of the world, e.g., Africa and Asia, the focus on heterosexual transmission has become a barrier to looking at other forms of risk behaviour. The invisibility, illegality and stigmatization of men having sex with men and injecting drug use in many cultures contributes to this neglect. Consequently throughout much of the world, we have little solid behavioural information on changes in same-sex or needle-sharing behaviours over time. This lack of information becomes directly linked to a lack of targeted prevention programmes.

Reliable behavioural data can also help to make the importance of prevention clear and to demonstrate that prevention works. Often, however, the results of behavioural studies are not presented to policymakers and the public in a clear fashion. Policymakers should be made aware of behavioural research from the formulation stage in order to bring them into the process. Reports and recommendations resulting from behavioural data must be sensitive to the political and social constraints on policymakers’ actions. Research on the policy development process itself could help to improve the efficiency with which findings are converted into action.

### **Lack of knowledge leads to lack of action or inappropriate action**

Despite two decades of a global HIV pandemic, it is surprising how little we actually know about risk behaviours in most countries of the world. Even the simplest baseline data for evaluating widespread behaviour change in populations is often lacking. This makes it difficult to move forward and to convince people that what is being done makes a difference, especially when they see large numbers of people dying around them. A lack of accurate knowledge makes it difficult to mobilize responses, demonstrate the impact of programs, and ultimately provides one more excuse for not acting. It is essential that the necessary behavioural and epidemiological data are collected, that these data are analysed, and that the findings are understood and presented in a clear fashion. Continuing to neglect behaviours will foster continued neglect of prevention.

## 10. General Recommendations

- ❖ Combined epidemiological and behavioural research is needed to understand the most important factors contributing to variations in HIV prevalence and incidence between countries and populations, and to the rapid growth of HIV in some settings. Such understanding is essential to directing resources and mounting an early and effective response.
- ❖ Ensure that all behavioural research conducted contributes to altering policies, improving programs, or mobilizing further support for prevention and care. Establish clear links to action before any behavioural research or data collection is undertaken.
- ❖ Whenever possible, behavioural research should be conducted in the context of actual prevention and care programmes. However, the implementation of programmes should not be delayed until behavioural research is completed, but instead early action taken and the findings used to improve the programme as it proceeds.
- ❖ There is an urgent need to improve and expand behavioural assessment and surveillance to compliment other process, outcome and impact data on HIV/STD. This is essential information that will improve our capacity to monitor the trends of individual behaviours, changes in social norms and evaluate the impact of prevention efforts.
- ❖ The impact of the interaction between TB and HIV must be minimized. TB and HIV programmes must harness their capacity and the capacity of their partners and the communities which they serve in order to control the spread of these dual epidemics. The monitoring of the TB and HIV epidemics, combined with the monitoring of the interaction between TB and HIV programmes, will show the degree to which the synergy between these two public health problems offsets—or is dominated by—the synergy between the programmes aimed at controlling them.
- ❖ Data collection and analysis is needed to shape prevention and care programmes relevant to migrants, refugees and internally displaced persons. Sufficient attention must be given to the impact of gender and age differences, as well as differences in needs at different stages of the migration process.
- ❖ The number of orphans, especially those resulting from the AIDS death of the mother, is large and will continue to rise. We need to monitor the extent of care and support needs, with attention to the care and support currently being provided. Attention must be given to the documentation of best practices in community responses in different cultural settings in order to provide the best possible programmes for orphans worldwide.
- ❖ The contribution of HIV transmission in the health care setting to the spread of HIV in the general population is relatively low even in developing countries. However, for the subpopulation of health care workers in high prevalence settings, the risk of transmission may be significant. In order to reduce these infections, we need more and better data on blood safety, patient-to-patient transmission and occupational exposure. This information will enable programme managers to influence decision makers to allocate adequate resources.
- ❖ The growing needs for HIV/AIDS care and the ever-expanding array of therapies call for a focused attempt to collect and analyze data on care needs, demands, availability and use. As care is becoming strongly linked to prevention, there is a need to devise and implement monitoring systems that transcend prevention and care fields and show the degree of progress achieved in each of these fields.



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