AIDS Public Policy Training Project

Training Materials
# TABLE of CONTENTS

## I  INTRODUCTION

- Statement of Purpose: AIDS Public Policy Training Project ............................................................ 4
  - Objective ........................................................................................................................................... 4
  - Program Description .......................................................................................................................... 4
  - AIDS Public Policy Training Program Teaching Model ................................................................. 4

## II  DETERMINANTS AND IMPACTS

- Chapter 2: Economic Perspectives on HIV/AIDS ........................................................................... 9
  - Introduction to Economics of HIV/AIDS ....................................................................................... 9
  - Economic Impacts of HIV/AIDS ...................................................................................................... 10
  - Prioritizing Interventions in HIV/AIDS ......................................................................................... 12
  - Analysis of Particular Commercial Activities Relevant to HIV/AIDS ......................................... 14

- Chapter 3: Social Impacts of HIV/AIDS ......................................................................................... 16
  - Introduction to Social Impacts of HIV/AIDS .................................................................................. 16
  - The Social Impact of HIV/AIDS: Considering Impacts at the Individual, Household, and Community Levels .......................................................................................................................... 16
  - Common Social Impacts of HIV/AIDS at Different Levels ............................................................ 18
  - Orphans and their Households ......................................................................................................... 22
  - The Evidence from Viet Nam ........................................................................................................... 23

- Chapter 4: The Greater Involvement of People Living with HIV/AIDS (GIPA) in the Policy and Program Response to the Epidemic .................................................. 25
  - Introduction ........................................................................................................................................ 25
  - The GIPA Principle and the Paris AIDS Summit .......................................................................... 25
  - What Does GIPA Mean in Practice? ............................................................................................... 26
  - GIPA in Viet Nam ............................................................................................................................... 28
  - GIPA Activities .................................................................................................................................. 29
    - Peer Support ...................................................................................................................................... 29
    - Peer Education ................................................................................................................................. 29
    - Advocacy .......................................................................................................................................... 29
    - Public Education .............................................................................................................................. 29
    - Counseling ....................................................................................................................................... 30
    - Program Planning and Implementation ......................................................................................... 30
    - Policy and Legislation ...................................................................................................................... 30
    - Challenges to Implementing GIPA ............................................................................................... 30
    - Moving forward ............................................................................................................................... 31
    - Further Information and GIPA Resources ..................................................................................... 32

- Chapter 5: Gender and HIV/AIDS ................................................................................................. 35
  - Introduction ........................................................................................................................................ 35
  - The Growing Feminization of the Global AIDS Epidemic ............................................................. 35
  - Sex, Gender and Sexuality: Basic Concepts .................................................................................... 35
  - Gender and Vulnerability to HIV/AIDS ........................................................................................... 36
  - Reproductive and Sexual Health and Rights and HIV/AIDS .......................................................... 42
  - Take Home Messages and Action Points ......................................................................................... 45

- Chapter 6: HIV/AIDS, Law and Rights ........................................................................................... 47
  - Using Rights for Analysis: Vulnerability and HIV/AIDS ............................................................... 47
I INTRODUCTION

STATEMENT OF PURPOSE: AIDS PUBLIC POLICY TRAINING PROJECT

Objective
Effective national AIDS responses require the participation and collaboration of a wide range of governmental agencies and non-governmental organizations in policy making and implementation. While much global attention has focused on the need for such responses, there remain few efforts to systematically train non-health actors on the rationale for such programs and the specific sector programs and activities required. The AIDS Public Policy Training Project was created in 2003 to serve this purpose. The following materials summarize the curriculum developed collectively by the Boston-based program faculty, and are intended for use as background reading for participants in future AIDS public policy trainings.

Program Description
The AIDS Public Policy Training Project is a joint initiative between Harvard University’s Kennedy School of Government and Tsinghua University’s School of Public Policy and Management in China and between Harvard University’s Kennedy School of Government, the Ho Chi Minh National Political Academy and the Health Policy Initiative in Vietnam. The goal of the training course is to develop the capacity of government officials, including those outside the health sectors, to respond to the HIV/AIDS epidemic. It trains political leaders about the determinants and potential impacts of AIDS and about successful strategies for an effective rights-based and multi-sectoral response, including the contributions of NGOs, civil society and the private sector in responses worldwide. The course presents HIV/AIDS as a development issue requiring government leadership for multi-sectoral responses, introduces international and local best practices in HIV/AIDS prevention, treatment, and impact mitigation, reviews the main debates at the global and national levels about the HIV/AIDS response, and offers practical strategies for improving leadership and inter-sectoral and multi level collaboration and partnerships on HIV/AIDS policies and programs for a comprehensive response of linked prevention, treatment and impact mitigation.

AIDS Public Policy Training Program Teaching Model
The course curriculum has been developed by a team of Boston based faculty from Harvard University’s Department of Population and International Health and the François-Xavier Bagnoud Center for Health and Human Rights at the Harvard School of Public Health, the Taubman Center for State and Local Government and the Mossavar-Rahmani Center for Business and Government at the Kennedy School of Government, the Harvard Medical School’s Division of AIDS, Boston University’s Center for International Health and Development, and Abt Associates of Cambridge. Course instructors are drawn from the module development teams, providing a pool of potential trainers for each session. Each module team is comprised of international and in-country instructors. The course content is presented via lectures, exercises and teaching cases and includes strategic planning exercises designed to facilitate the development of multi-sectoral AIDS response plans at the local level.
Overview of the Global AIDS Epidemic

The AIDS epidemic is one of the premier development challenges of the new millennium, threatening to undermine hard-won development gains in many countries. Worldwide, over 20 million people have died from AIDS so far, an estimated 39.4 million people are living with HIV/AIDS, more than 14 million children have been orphaned, and millions of families have been impoverished by the loss of bread winners and high medical costs. In 2004, 4.9 million people, including 640,000 children, were newly infected with HIV. Countries with serious epidemics are now seeing significant reductions in life expectancy, increasing poverty, shortages of trained professionals, and weakened communities and institutions – effects that will be felt for generations. Despite substantial investments in AIDS prevention programs worldwide, by international agencies and multilateral institutions, 45 million new infections are predicted within the next eight years, with forty percent of those occurring in the Asia Pacific region. In recent years, there has been a belated recognition of the development impacts of the AIDS epidemic and subsequent acknowledgement of its potential to contribute to global instability. AIDS prevention and control can be viewed as a public good; economic growth depends on human capital, which, in turn, depends on good health and basic education.

AIDS is caused by the Human Immunodeficiency Virus (HIV), which exists as two types, HIV-1 and HIV-2. HIV-1, the more deadly version, is responsible for the current global epidemic; it has the ability to mutate quickly and has many sub-types. Despite huge investments in research, there is still no vaccine for HIV. Once infected with HIV, there is a long latency period of 5-10 years before clinical disease (AIDS) develops. AIDS is a fatal disease, but in recent years treatment has become available to prolong life, although there is still no cure. The major routes of transmission are through vaginal and anal sexual intercourse, through contaminated injections into the bloodstream through dirty needles, blood products, or through injecting drug use, and from mother to child transmission during delivery and breastfeeding.

The HIV/AIDS epidemic has been described as a long wave event. Because of the delay between infection and subsequent impacts, it has been difficult to focus attention on the urgency of needed individual and societal responses. The HIV/AIDS epidemic can be best described in four successive waves. In the first wave, a person acquires the HIV infection. In the second wave, the patient’s immune system begins to break down and other infectious diseases due to HIV, such as tuberculosis, become evident. In the third wave, AIDS illness and death occur. In the fourth wave, the impact of the deaths on individuals, families and households results in economic and social impacts for the survivors, including poverty, orphans, and social exclusion and fear due to stigma, with lasting and severe psychosocial consequences.

AIDS as a Public Policy Issue

The AIDS epidemic has been driven by social and economic inequity and vulnerability. The poor have less access to those benefits of development, such as education, which are highly correlated with HIV preventive behaviors, especially among youth. Low social status and economic need and lack of other opportunities forces women and migrants into risky work in the entertainment industries and drug trafficking. Women are especially vulnerable to HIV; because of their weaker role in the gender power dynamic, they are less able to protect themselves from infection from their male partners by refusing sex or demanding condom use. Youth, especially
young girls, are vulnerable because of lack of access to information on sexuality, safe sex and reproductive health services, and because of existing gender norms.

In the twenty-four years since the AIDS virus was first identified, the global community has learned many lessons about how to prevent and treat HIV infection and mitigate the worst social and economic impacts for individuals, families, and communities. Successful programs are halting or slowing down the rate of new infections among specific groups in some parts of the world. These programs require responses that reach beyond the health sector, and the leadership of government officials. Success stories worldwide have involved government coordination of multi-sectoral responses and inter-sectoral collaborations, political leadership, accountability and honesty about the extent of the problem, sufficient budget allocations, the collaboration and involvement of civil society, and supportive national laws and policies to protect against stigma and discrimination and to protect the blood supply. Good governance also requires a recognition of the important role of an educated and engaged media as an ally in the AIDS response. Worldwide, the media has played a crucial role in educating the public about the epidemic and how to prevent transmission, publicizing cases of successful programs and also of unfair discrimination and rights abuses, exposing cover-ups, and publicizing international agreements.

Key Debates
A number of key debates have framed the AIDS response worldwide.

Abstinence promotion vs. safe sex
Foremost among these is the debate between abstinence promotion for young people versus the provision of safe sex information and condoms for the prevention of sexual transmission of HIV. This debate occurs in every country among parents, teachers, religious leaders and youth themselves, and successful programs have usually involved a combination of both.

Law enforcement priorities vs. prevention of HIV transmission
Tensions between the requirements of law enforcement and the desires of public health officials to prevent HIV transmission among groups engaging in criminal activities such as prostitution and illegal drug use have also framed the debates worldwide. Successful programs have relied on intersectoral collaborations aimed at disease prevention and harm reduction, especially among vulnerable populations. These types of interventions are discussed further in Chapter 8.

Targeting high-risk groups vs. risk behaviors in prevention
There has also been debate about whether to focus precious resources on efforts aimed at “high risk groups” like gay men or sex workers rather than providing HIV education and prevention services to the general population. A combination of both is recommended, because it is nearly impossible to reach all members of these groups and because such targeted approaches can further stigmatize vulnerable populations, making them even more difficult to reach. Rather than focusing only on these high-risk groups, it is recommended that interventions target high-risk behaviors. Such approaches would also target the sexual partners of those engaged in high-risk behaviors.

Vertical vs. horizontal prevention services
There has also been disagreement about whether it is better to provide HIV prevention services through top-down, vertical service programs or to offer integrated, horizontal programs at local level. Again, a combination of both approaches has proved most successful with sector based programs supported at the local level by multi-sectoral collaborations and coordination.
Resource allocation for prevention vs. treatment and care
The availability since 1995 of life-saving treatment for HIV has resulted in controversies surrounding the best use of scarce resources and whether they should be devoted to more cost-effective prevention or to more costly treatment and care for those affected. Most agree that a combination of both prevention and treatment and care is essential for reasons of both rights and utility: rights of individuals to benefit from the best treatments available, even if they cannot afford them, and the important role the availability of treatment can play in reaching people with prevention messages.

Individual privacy vs. public health
The balance of priorities between individual privacy protection and public health concerns has also been debated in the AIDS response. Protecting confidentiality has been a backbone of the effort to increase the number of potentially infected persons to come forward for testing and counseling, providing an opportunity to prevent further spread. Without such protection, many persons would not be tested for fear of the stigma and discrimination that might ensue for them and their loved ones if their HIV status became known in their communities or their workplace. Confidentiality issues come up often when services are offered to young people who would not come forward for counseling if they thought their parents or teachers would be notified. Public health officials often weigh respect for individual privacy with their duty to protect the public from disease spread. For example, UNAIDS recently adjusted its policy on voluntary counseling and testing to include endorsement, in certain situations, of routine testing with the option to refuse, in an effort to increase case identification. This debate has posed a real challenge, especially where notions of individual rights are subsumed to the greater public good and must be examined with respect to the desired objectives and likely consequences to policies and programs.

Crosscutting Issues
A number of issues cut across discussions of AIDS determinants and responses.

Gender
Gender perspectives are important with respect to HIV/AIDS because women are often at greater risk of infection as a result of their lower social status and more limited economic opportunities. Lower social status plays out in numerous ways. For example, young girls are usually less educated than boys and less education and economic opportunity may force girls into higher-risk occupations. Women have little control over their husbands’ sexual behavior and may risk violence or rejection if they demand condom use. Once family members become ill with AIDS, women and girls are usually the primary caregivers. Prevention of Mother to Child Transmission (PMTCT) programs should address the mother’s health as well as that of the newborn. Finally, some of the opportunistic infections associated with AIDS in women differ from those in men.

Civil Society
In every country that has been successful in addressing the AIDS epidemic, civil society organizations and NGOs have played a critical role in mobilizing resources and responses, and in representing the interests of key stakeholders. NGOs and community-based organizations representing the legitimate interests of affected groups have raised the attention of governments and international organizations to the critical perspectives of these groups, and helped to design and carry out programs based on these perspectives. In addition, NGOs representing specific groups like youth, gay men, sex workers, and people living with HIV/AIDS (PLWA) have succeeded in carrying out peer-based programs for their communities, which have been better-received than those offered by non-representative organizations. Moreover, because
communities themselves are the most affected by AIDS, communities have played a critical role in supporting treatment and impact mitigation programs.

**Greater Involvement of People Living with HIV/AIDS**

The Greater Involvement of People with or Affected by HIV/AIDS (GIPA) is a principle that has gained wide acceptance over the last ten years. In 1994, at the Paris AIDS Summit, 42 countries declared their commitment to the GIPA Principle, stating that governments will undertake to “support a greater involvement of people living with HIV/AIDS through an initiative to strengthen the capacity and coordination of networks of people living with HIV/AIDS and community organizations.” The principle holds that personal experience of PLWA can and should be translated into helping to shape an effective response to the epidemic.

PLWA all over the world have organized to form networks and participate in forums that provide a platform for their engagement in a policy and decision-making role at the global level. Organizations of PLWA, like the Global Network of Positive People (GNP+) have been active in promoting global access to HIV/AIDS care and treatment combating stigma and discrimination, and promoting greater and more meaningful involvement of PLWA in decisions that affect their lives and the lives of their communities. PLWA also have a key role to play in preventing new infections and providing care and support to infected and affected people.

**Global Agreements**

A number of global agreements have been reached on HIV/AIDS in the last few years that oblige participating countries to include attention to AIDS in their national development plans. These include the Millennium Summit and Goals in 2000, the United Nations Special Session on AIDS (UNGASS) Declaration of Commitment in 2001, the establishment of the Global Fund to Fight AIDS, TB and Malaria to provide funding for prevention, treatment and care programs worldwide, the establishment of the AIDS Business Coalition to promote private sector involvement in the AIDS battle, and agreements and declarations at regional summits and other high level global governmental meetings like the G8 and World Economic Forum.

**Recommended Readings:**

II DETERMINANTS AND IMPACTS

CHAPTER 2: ECONOMIC PERSPECTIVES ON HIV/AIDS

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Introduction to Economics of HIV/AIDS

In the course of ravaging countries throughout the world, the AIDS epidemic is imposing huge human, social, and economic costs. This module deals with the economic aspects of the epidemic: understanding the economic determinants of HIV transmission, assessing the economic consequences, and taking stock of the guidance an economic perspective offers for effective intervention.

Responding to the epidemic will be costly. To combat HIV/AIDS, direct expenditures are (or may be) needed on public education, testing, provision of condoms, treatment and care, impact mitigation, and research. Although measures to prevent and treat HIV/AIDS are expensive, not addressing the epidemic would be even more costly. If a country mounts no effective response to the crisis, it will, in the longer run, face new expenses. Prominent among them are the burgeoning of direct costs to treat a larger number of infected individuals, the work time that is lost by sick individuals, greater difficulty in educating children as more of them are forced into the workforce because a parent cannot work or has died, and social and community stress and dysfunction. Some of these costs can be diminished if a country takes prompt action. For example, investments in treatment may reduce future medical costs for treatment of opportunistic infections, as was shown in the case of Brazil. Not taking action is likely to mean that rising costs will impose further stress on all levels of society.

The required expenditures to deal with HIV/AIDS will vary from one country to another, depending on the number of cases and basic health care costs. Indirect costs, such as lost work time, will depend heavily on the age of those who are infected. Very often, however, working-age people form the predominant group of people with AIDS, so the economic impact (stemming from these people's lost production) can be quite large.

HIV/AIDS imposes costs at various levels of society. Individuals and families are, of course, on the front line. They may try to use their own resources to seek treatment, in the course of which family savings can be quickly exhausted. The near-poor can fall into poverty, and the poor can become further impoverished. Communities suffer when the people living in them are overwhelmed with the effect that HIV/AIDS has on their lives. Social capital diminishes as people focus on their own concerns. At the sectoral level – say, for example, local industry – HIV/AIDS can debilitate enterprises when their workers (who often embody corporate memory) are no longer available or when cash-strapped consumers cut back demand for particular goods and services.

On the national level, the AIDS epidemic has the potential, in theory, to cause severe economic problems. In Vietnam at present, these problems are manageable, since they are confined to direct effects on individuals, on specific industries, and on well-defined geographical areas. However, if the epidemic grows substantially – and there are indications that it could – Vietnam could experience some broader economic impacts.
However, even if AIDS does not substantially spread to the general population within a given country, it may already be impeding poverty reduction efforts. As we will learn in this module, the poor are particularly vulnerable to AIDS. Since they are less able than others to cope with the financial pressures that AIDS can impose, those who get sick are in danger of falling into greater poverty. A downward spiral of infection-impoverishment-more infection is possible.

Prudent policy-makers need to be aware of both the potential impacts of an expanded epidemic and the actual impacts on current poverty reduction efforts. Humanitarian concerns clearly demand that resources be allocated now to those suffering from AIDS but, since government and donor investments in poverty reduction are being rendered less effective by the disease, there is an economic argument, too, for taking its effects into greater account.

A few items that are specific to Vietnam shed some light on its current efforts to combat HIV/AIDS and its ability to expand such efforts. First, Vietnam has an extremely effective family planning program that has reached every village in the country. That family planning infrastructure could be used quite effectively to speed the dissemination of HIV/AIDS messages.

Lack of access to health services by the poor, which of course means that they are unlikely to be tested or treated for HIV/AIDS, has been exacerbated in Vietnam by the increasing privatization of the country's health system. While support to the health system in Vietnam has weakened, the remaining infrastructure still offers the possibility of providing HIV/AIDS-related services to the urban and rural populations.

This module will examine the topics discussed above and will help participants understand the socioeconomic roots and consequences of the disease, including potential impacts on households and family income, the public sector (through loss of staff and strain on health and social services), firms, and the macroeconomy. Of great importance will be a focus on the elements that must comprise an effective response to the epidemic:
1) controlling and lowering the long-term incidence of the disease (prevention)
2) providing treatment and care for the sick
3) mitigating the socio-economic impacts of the epidemic.

The next session of this module will address in more detail the microeconomic and macroeconomic impacts of HIV/AIDS. After that we will study various types of interventions and methods for prioritizing government action to stop the epidemic. Finally, we will examine the specific underlying social and economic mechanisms, with a particular focus on specific commercial activities, that contribute directly to the spread of the disease.

**Economic Impacts of HIV/AIDS**
The economic impacts of HIV/AIDS fall into two categories:
- those that affect individuals and communities (the microeconomic impact);
- those that affect a country's (or a region's) economy as a whole (the macroeconomic impact).

Each of these types of impact can be quite substantial, at least in theory. Economists have done quite a lot of work to determine whether there have been impacts so far and what their magnitudes have been.

The **microeconomic impacts** can operate in five arenas:
- **Income.** When a worker progresses from HIV infection to AIDS, s/he is likely to experience a loss of income sooner or later – a loss that will typically affect a whole
family. The extent to which income falls depends on whether the person receives medical treatment that can slow (or nearly halt) the development of symptoms, how debilitated the person becomes, the type of work that the person does and whether someone who is weakened can still perform that work, policies of the employer regarding HIV-positive individuals, whether the stigma surrounding HIV/AIDS affects a worker’s employment, the person’s own efforts, and the type and amount of community and family support available. In addition, when family members who do not directly earn income (such as workers in unpaid household agriculture, or members who help in child-rearing, taking care of elderly, and doing housework) become infected, their lessened contributions can place financial strains on the family. The income losses stemming from HIV/AIDS can be truly catastrophic for a family, depleting its savings and making it more likely that a family will fall into poverty. The fact that that most of the rural population has to pay for medical expenses out of pocket means that catastrophic outcomes are not unlikely. Going beyond income per se, HIV/AIDS will likely have negative effects on pension and disability plans, and on the cost and availability of life and health insurance.

- **Savings.** One casualty of HIV/AIDS is that workers must often use whatever savings they or their family has to pay for medical care and drugs and to supplement lost income. Using up savings creates various difficulties: (1) future financial problems are much more likely; (2) other family members may be impelled to work more than they had been doing, although extra work may not be available; (3) the resulting financial uncertainties may induce considerable stress in workers and families. These extra pressures can lead family members to accept work that is less desirable (e.g., lower-paid or more dangerous).

- **Poverty/inequality.** When the loss of income by individuals with HIV/AIDS is sufficiently large, the efforts of family members to compensate by working more may be inadequate. If the loss of income is severe, a family may fall into poverty. In countries where a large portion of the population is just a little above the poverty line, many families may meet this fate. In many countries, HIV/AIDS is concentrated among the poor or the near-poor. If the income of these groups falls, while that of people who are more well-off does not, then inequality – already a significant issue in most countries – will be exacerbated.

- **Education.** Workers who contract AIDS and become unable to work will face more pressures to keep their children out of school – even if school is free – and find work for them to support the family. Some families will need to rely on their children for care in more advanced stages of the disease. In cases where families are paying for school for their children (for example, by paying the fees required by many public schools), the temptation and/or need to keep them out of school will increase. The stigma that arises from a family having someone with AIDS may cause yet more children to leave school. Finally, a young student with HIV/AIDS may be unable to continue with his or her education, both because of the current difficulties s/he faces and because the family may decide that an investment in that child’s education – even if the investment is only in the form of lost child labor – will be wasted entirely.

- **Family structure and living arrangements.** As noted above, HIV/AIDS can affect uninfected family members. The disease most often strikes people of working age. As they die, families often come to consist of grandparents and children. Surviving family members of working age may be at home less than before and often migrate to more active labor markets as they strive to make up for the lost income of those who have died. As financial difficulties mount, living arrangements may also evolve. In some cases, children must be raised by relatives or friends.
Because of the manner in which HIV/AIDS is spread, these microeconomic impacts do not hit all sectors of society equally. Particular industries and occupations, such as trucking, fishing, the military, construction, and health, are likely to be hardest hit. Commercial sex workers are particularly vulnerable. Independent of the type of work that they do or the niche that they occupy in the fabric of society, specific groups of people are also particularly vulnerable: injecting drug users, homosexual/bisexual males, migrants, the floating population, overseas contract workers, foreign business people, prisoners, and orphans. Depending on the social structure of a society, women may be more vulnerable than men. Children become vulnerable when one or both parents die. More broadly, the poor are at risk, in part because they may have less access to information about how to avoid acquiring HIV/AIDS. We return to some of these issues in Part 4.

One consequence of these vulnerabilities is that communities may undergo a precipitous decline in social capital. By this, we mean that the habits of association and the bonds of trust that link community members with one another will likely become strained. When this happens, commerce becomes more difficult, rivalries flare up, and initiative is crampd.

HIV/AIDS can also have macroeconomic impacts: the total economic activity of a country or a region within it can be dampened by the collective impact that the disease has on a large number of individuals. Such a macroeconomic impact may or may not actually come to pass. For example, in a country with high unemployment, it is possible that when someone with HIV/AIDS stops working, new workers will be ready and anxious to fill their shoes, thus eliminating or very substantially diminishing the possibility of reduced total output.

Economists have found four approaches to assess whether a country is suffering losses at the macroeconomic level due to HIV/AIDS. All of these will be covered in this session.

- **Cost of illness method.** This approach involves assessing the specific costs that HIV/AIDS imposes on individuals and society, calculated as the number of cases times the sum (per case) of direct and indirect costs. Direct costs include out-of-pocket medical expenditures by individuals or institutions, testing, education, and research. Indirect costs are the value of lost output.

- **Regression approach.** Another approach uses statistical techniques to estimate what the cost of HIV/AIDS will be. A cross-country comparison of cost per case and income levels allows researchers to reasonably project the epidemic's total cost to a country, based on its level of income.

- **Production function models.** These models build on the simple observation that an economy's overall output depends on, in part, how much capital and labor are available. Both of these, in turn, are affected by AIDS. Putting AIDS into the picture on the input side allows us to estimate its effect on output.

- **Computable general equilibrium models.** A final approach involves creating a richer, more detailed model of an entire economy in an attempt to determine the causes of shifts in economic activity. Such a model focuses on the feedbacks from one circumstance (e.g., the presence of HIV/AIDS) to other economic indicators.

**Prioritizing Interventions in HIV/AIDS**

In combating HIV/AIDS, taking effective action to slow its spread must be the highest priority of governments. But the range of actions that governments can take is quite large. What are the pros and cons of different interventions, and how can we determine which are the best ones to pursue? Weighing the relative advantages of different strategies is not straightforward. Moreover, we need to look beyond government activities and examine the private sphere to see
whether actions in that arena can make a difference. In an effort to examine the wide range of considerations that pertain to evaluating and prioritizing interventions, this session will examine the following issues:

- **Economic evaluation: cost-benefit and cost-effectiveness analysis.** Cost-benefit analysis is one of several standard methods of evaluating competing policy options when choices are constrained. We will discuss methods of assigning monetary figures to both costs and benefits, along with methods for evaluating who bears the costs and who receives the benefits. Cost-effectiveness analysis differs from cost-benefit analysis in that benefits are not given a monetary value. Instead, the costs of competing programs are compared to each other to see which gives the best results for a given expenditure, with the results typically assessed by non-monetary measures of effectiveness (such as the reduction in the number of AIDS cases).

- **Distinction between direct and indirect approaches to HIV control and AIDS care.** The direct approach to HIV control places a priority on educating the public about HIV transmission and encouraging people to practice safe sex. The direct approach to AIDS care focuses on medical interventions. But there are indirect approaches as well: strengthening health systems, improving education, and improving infrastructure (all of which promote higher incomes and people's and country's abilities to prevent and treat HIV/AIDS).

- **HIV prevention vs. AIDS treatment vs. HIV/AIDS prevention and treatment.** Heated debates have taken place between those who say that HIV prevention should take precedence over AIDS treatment, and vice versa. But are there complementarities between the two? How might an effective HIV prevention program make AIDS treatment more effective, reduce the number of cases requiring treatment, and thereby increase the resources available per treatable case? And how might effective AIDS treatment facilitate HIV prevention programs, reduce secondary transmission, and raise incentives for testing and care-seeking?

- **The public interest in HIV/AIDS and nature of alternative interventions.** HIV/AIDS has had a devastating effect on populations in many countries. With over 250,000 people now estimated to be infected in Vietnam and the threat of further rapid spread of the infection, some type of action is surely in the public interest. Should governments subsidize the provision of needles and condoms? How should they deal with commercial sex work? What about voluntary vs. mandatory testing for HIV? How does the stigmatization and social exclusion of HIV-positive individuals hinder proper identification of cases and decisions to be tested and seek care? The answers to these questions may differ depending on whether we are referring to national, provincial, or local government, since the responsibilities and resources available vary greatly among levels.

- **The role of business.** Businesses have been affected by HIV in several ways: key workers die, there is high turnover among ordinary workers, workers are less effective because they are sick, and customers have less buying power as they are impoverished by HIV/AIDS. This topic is covered elsewhere in the course, in module 10, The Business Response to HIV/AIDS.

- **National AIDS accounts.** Careful accounting of expenditures incurred on HIV/AIDS – whether on prevention or care – is an important first step in addressing the needs of a population affected by the epidemic. Such an accounting is crucial in determining the financial burden imposed by the epidemic and also helps to clarify the question of "who is bearing the cost?" Constructing national AIDS accounts would contribute greatly to informing policy making by providing the inputs needed for cost-benefit and cost-effectiveness analyses.
• The Global Fund to Fight AIDS, Tuberculosis and Malaria. Probably the most important international initiative to fight HIV/AIDS is the Global Fund, a United Nations program that is seeking to channel billions of dollars from developed countries to fight these diseases in developing countries.

• Coordination of HIV prevention and AIDS care with the national family planning program. Like HIV/AIDS, family planning is a delicate subject that has huge implications for personal, local, and national development. Since the topics addressed are closely related, it makes sense that family planning programs work closely with HIV/AIDS initiatives to ensure that, for example, community health outreach programs on both birth control and pregnancy also address HIV prevention issues.

• Design and value of clinical infrastructure for HIV surveillance. In most countries (including developed countries), the number of HIV-positive people is not known. The potential for HIV breaking out into an even larger population is ever present. Carefully designed and implemented HIV surveillance is therefore crucial. Going beyond narrow and traditional medical considerations, both academics and policymakers need to realize the significance of behavior and social factors in understanding, preventing, and treating HIV/AIDS. Data collection should therefore include these important variables.

• Targeting demographic groups (esp. adolescents and young adults). Youthful exuberance is the lifeblood of many communities, organizations, and businesses. But enthusiastic youth, like everyone else, need to take action to prevent the spread of HIV. A significant outbreak of HIV among young adults would be catastrophic for Vietnam.

Analysis of Particular Commercial Activities Relevant to HIV/AIDS
The spread of HIV/AIDS is affected in part by activities in several specific areas of economic activity. In these areas (some of which are sometimes referred to, in economic terms, as "markets") people face a range of incentives, deal with uncertain outcomes, and make decisions. The operation of several commercial sectors involves activities that affect HIV/AIDS infection rates. The constraints that people face in their daily lives, the incentives that drive them to make decisions, and the inexorable push of ordinary economic forces come together in ways that have significant implications for efforts to contain the disease. In this session we will discuss particular commercial activities in which people's actions affect, or are affected by, HIV/AIDS.

• Commercial sex. Commercial sex workers (prostitutes) throughout the world have long been subject to sexually transmitted diseases. In the past, some of these were curable, at least in cases where these workers had access to appropriate medicines. HIV/AIDS has changed the dynamic between customer and client, since AIDS is not curable. Although workers may demand that their clients use condoms, client resistance, combined with the precarious economic situation of many prostitutes, means that the commercial sex industry is a prime transmitter of HIV.

• Blood and blood products. The well-known, tragic case of HIV being transmitted by the re-injection of blood into donors in China serves as a warning to all: the economic motivations of buyers and sellers in this market can run roughshod over even minimal considerations of the health of those involved. This applies to individuals who sell their blood, who receive blood, and who are commercially involved in such enterprises.

• Condoms. Condom use is essential to the prevention of HIV infection. Public education campaigns that have focused on the need to use a condom every time (as was done in Thailand) have been extremely successful. Where the price of condoms is an obstacle to their use, governments will need to take action to make them available at lower or no cost. The economic returns to such a policy have been shown to be very high.

• Health and life insurance. The presence of HIV/AIDS in the population has made insurers wary. Why should they agree to insure someone who will have a long series of
health problems and then die? The result in many countries is that insurers are increasingly intrusive in their questioning of prospective customers. The other side of the coin is that individuals who know they are unhealthy will disproportionately seek to be insured—a phenomenon known as "adverse selection." Purely private actions on the part of insurers will not be able to resolve these problems. If the public is to be insured, public action will be needed.

- **HIV testing.** HIV testing is unattractive to individuals who do not think they will be able to get care if they are ill. Why should they risk divulging the results of an HIV test with a potentially positive result if the consequence may be social ostracism, family disarray, and job loss? Motivation to get tested is more likely to arise when there is a realistic prospect of treatment.

- **Treatment and care.** HIV-positive individuals can stave off full-blown AIDS for a long time if they have access to an appropriate drug cocktail. These cocktails are expensive, and few in developing countries can afford them. One partial solution lies in the recent steps toward allowing countries to produce, sell, and buy generic versions of these drugs. The solution is only partial, however, since millions of infected people will still not be able to afford them. If governments are to address this problem, they will have to make hard decisions about allocation of health care expenditures among competing uses.

- **Tourism.** It is theoretically possible that a country's tourist industry will suffer as potential tourists become aware of a high HIV rate in a country they would like to visit. The risk, however, arises primarily when tourists engage in unsafe behaviors with local people who may be infected. Knowing this, tourists formerly inclined toward sex tourism have become a bit wary. Overall, there is no evidence that HIV/AIDS has significantly diminished tourism to any country.

- **Migrant labor.** In Vietnam, as well as in many parts of the world, large numbers of workers migrate in search of employment. This phenomenon has repercussions in many areas of commercial activity. This session will examine the incentives facing migrant workers and the characteristics of migrant and temporary labor that are especially important to disease control.

**Recommended Readings:**

Kaufman, Joan, "Reproductive Health Policy and Programs in China: Opportunities for Responding to China's AIDS Epidemic"


CHAPTER 3: SOCIAL IMPACTS OF HIV/AIDS

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Introduction to Social Impacts of HIV/AIDS

The importance of the social impacts associated with HIV/AIDS-related illness and death cannot be overstated. These impacts vary across individuals and their households as well as over time, usually extending long after a person’s death. For an individual, the impacts will be mainly determined by his or her circumstances and access to resources and support. Because individuals exist in a web of relationships, with households at their core, the broader impacts extend far beyond the individual. Households bear the heaviest burden, but extended families, communities, work places, and formal and informal institutions are all affected by the epidemic. Unfortunately, societies generally fail to anticipate the severity and complexity of these impacts at all levels, and thus serious efforts to mitigate them tend to come slowly, and even then only after an epidemic is mature, the death rate high, and much avoidable human suffering has been felt.

In order to formulate good policies to protect their citizens from the threat of HIV/AIDS, governments must understand the full range and depth of existing and future social impacts due to HIV/AIDS across different population groups. Since the epidemic is still at an early stage in much of Asia, it is important to learn from the impacts clearly evident in other countries and to understand the potential consequences likely to unfold in the future without swift action.

The Social Impact of HIV/AIDS: Considering Impacts at the Individual, Household, and Community Levels

Why is it important to study the social impact of HIV/AIDS?

Although some social impacts are closely linked with economic impacts, such as those associated with employment, some social impacts - such as stigma, abuse, and psychosocial effects - are quite different from economic impacts. It is important to study social impacts separately for the same reason that we study other major impacts – because social impacts affect human welfare.

HIV/AIDS affects a population by increasing morbidity and mortality in people in their prime working years – precisely those ages where morbidity and mortality are typically low. This unusual age-related impact is the source of most social impacts. However, due to misunderstandings about the disease, ignorance and fear also fuel many of the worst social impacts related to HIV/AIDS. Therefore, a comprehensive approach to studying and understanding the social impacts of HIV/AIDS must recognize the links between social impacts and other impacts.

What are “social” impacts?

Social impacts are impacts that relate to the social environment and interrelationships of people in society. This includes relationships within families and households, as well as interactions between neighbors and colleagues in home and work communities. Important social impacts include stigma, employment-related issues, access to education, and physical or other forms of abuse.

Because people live in a web of relationships with others, HIV-positive people feel social impacts not just as individuals, but also as households, as economic units, as communities, and
as a nation. This means that social impacts are experienced not only by people infected by HIV, but also by the individuals, households, and communities affected by HIV. The nature of "social impact" is all about these broader consequences that extend beyond the ill person alone.

Although it may seem strange to think about social impact of HIV/AIDS at the community level, it may help to think of it as the cumulative impact at the individual and household levels. And in turn, the social impact at higher levels, such as the provincial level, is the cumulative impact of the epidemic at all lower levels.

An important concept for thinking about social impact is that of vulnerability, which relates to factors that determine the likelihood of becoming infected and, once infected, of being able to access treatment and other needed services. Thus this concept encompasses risks related to infection but also the nature and degree of social and economic impacts once an individual is infected or dies. For example, being vulnerable to infection includes individual and environmental factors such as degree of mobility, acceptance of numerous sexual partners, or high drug use. After a person is infected, vulnerability describes those features of a society or an institution that increases or decreases the degree of social impact on that person and those in his/her family, community, or workplace. Thus societies that are poor, tend to have one wage-earner, and have large families with many children will be more vulnerable to a larger negative social impact.

**The timing and visibility of social impacts**

Social impacts may be felt as immediate and severe shocks or as complex, gradual, and long-term changes. For example, the death of the main breadwinner in a household that plunges a family into poverty illustrates a sudden and strong financial impact that will likely involve household-level social impacts as well as the obvious individual impacts. This situation is not uncommon in many developing countries in which one adult, typically the father, earns a cash income while another adult, frequently the mother, is responsible for running the home, caring for children, and working in the family fields.

At the community level, high rates of HIV infection and death can dramatically affect an entire local community. Leaders in the community may not be able to effectively play their roles, resources will be diverted to take care of basic needs and to care for the ill, and new economic stresses will shake social interactions. Such short-term impacts have hit many communities in sub-Saharan Africa where the rate of HIV infection is high.

By comparison, a household in which three generations live together and two adults earn an outside income will certainly feel an impact from the loss of one income, but will be much better able to cope than the family with one wage-earner. Here, there may be serious effects on the children left behind, but they may be slower to emerge. At the community level, a high rate of infection and adult death may force surviving children to live elsewhere and fundamentally alter the nature of the community, thus representing a more complicated and long-term set of impacts.

Many household and community situations fall somewhere in between these examples. It may help to think of impacts as falling along a continuum between a sharp shock and slow but profound changes.

Unfortunately, some social impacts are difficult for researchers to measure, because individuals, households, firms, etc. may simply disappear. In communities that have been hard-hit by HIV/AIDS, vast segments of a community can “disappear” without a trace and leave no
evidence of impacts. Nevertheless, the “invisibility” does not mean that the social impacts are not real in the short and long term. Indeed, while people are going through illness and death, the entire local community will change dramatically. In the longer term, the cumulative social impacts at the community and provincial levels can profoundly change the nature of society.

Because of their impacts over time and at so many levels, the social impacts of an epidemic can change history. They end some lives, incapacitate some lives, and diminish the abilities and choices of others who care for the ill and their dependents. A sufficient incidence of illness and death can change societies at many levels by taking them in a different direction than they otherwise would have gone.

Why is it hard to study social impacts?
There are a number of reasons why social impacts are difficult to study. First, the most obvious impact of HIV/AIDS is usually on a person’s health, rather than social interactions. Therefore, health impacts have been the primary focus of research on HIV/AIDS. In addition, social impacts can be hard to separate from economic impacts, as discussed earlier.

Social impacts are also difficult to study because they can be very hard to measure and verify. People frequently do not want to tell researchers the truth (which may seem unpleasant, embarrassing, etc.) about what they are experiencing. Moreover, some of the most serious social impacts of HIV/AIDS occur at the household level and involve children and the elderly. It can be difficult to reach both groups to find out the truth of their current situation.

Some social impacts may not be observable because of the way that individuals, households, and even communities change their habits and ways of living in order to survive. By the time researchers appear to study “social impacts,” individuals and families may not be able to explain with clarity what they have experienced and lost, and how they have adapted.

There have been a number of studies on the household-level socio-economic impacts of HIV/AIDS. However, their value for Asia may be limited because most of them have been carried out in Africa. They also tend to focus on households, not on relationships between households or communities. In addition, those households most seriously affected may have already disappeared, so these studies often understate impacts.

Common Social Impacts of HIV/AIDS at Different Levels

Social Impacts at the Individual Level
Previous studies and experience working on HIV/AIDS projects indicate that HIV/AIDS affects social interactions at many different levels of society. At the individual level, due to the fact that HIV/AIDS is almost always fatal in the absence of advanced and expensive treatment (typically after 6-7 years of being non-symptomatic and a year or two of actual illness), most social impacts will be short-term rather than long-term impacts. These social impacts (broadly defined) include the following:

- **Health and nutrition** – poor health and nutrition are especially common among poor, uneducated, and isolated HIV-positive individuals. Indeed, beyond the ability to purchase health services, medicines, and nutritious food, there may be a cycle of negative impacts that fundamentally flow from social isolation, in which due to an absence of emotional and social support, a person lacks the motivation to live and eat in a healthful way, and whose health consequently deteriorates more rapidly than it would otherwise. Poor
health and nutrition can also be a serious problem for HIV-infected orphans or children whose caregivers have essentially given up hope that they will survive for an extended period.

- **Education** – education impacts, which include both attendance and performance, especially affect youths and children who would otherwise be in school. Caregivers of HIV-positive children have been known to keep these children at home and out of school because they see little value in educating children who will not live very long.

- **Psychosocial effects** – although psychosocial effects due to HIV/AIDS are often difficult to identify and measure, especially in some developing countries, they clearly play a major role in the life and health of HIV-infected individuals. Such impacts can range from a minor loss of appetite and energy to thoughts of suicide or actual suicide. Psychosocial impacts can also interact with other impacts such as social isolation and abuse in ways that make all these impacts even worse.

- **Social stigma, isolation, and harassment** – isolation and stigma, or even active harassment, due to HIV/AIDS are among the most difficult impacts to cope with because they fundamentally stem from fear and ignorance – which are very hard to overcome quickly. Such impacts can affect HIV-positive individuals at home, in the workplace, or in public places in the community. Some people have chosen to remain far from home in order to avoid stigma in their own communities.

- **Abuse and violence** – physical abuse due to HIV/AIDS is an extreme form of social stigma that appears to particularly affect women and children. In addition to abuse by strangers or community members, women may suffer physical violence at the hands of the same husbands who infected them, frequently due anger, shame, and fear. HIV-positive children, particularly those who are double orphans, have been known to experience a range of physical abuses such as beatings, burnings, etc.

- **Employment issues and unemployment** – impacts relating to employment are widespread and can include harassment on the job, losing one’s job, or being denied a job due to HIV positive status. Because employment-related impacts are so closely tied to incomes, they can easily lead to or compound health, nutrition, education, and other impacts that are related to financial resources.

- **Poverty and income impacts** – all impacts related to an individual’s financial resources, whether they stem from basic poverty that is unrelated to HIV/AIDS or from loss of a job or ability to work due to HIV/AIDS, obviously affect that person’s capacity to live in a healthy and safe environment. Typical income-related impacts include housing, education, health, and psychosocial impacts.

Two key aspects of an individual’s life determine the degree of impact (vulnerability) at the individual level. One of these has to do with personal circumstances, including physical location (i.e., degree of isolation and safety), status, education, and knowledge about care. An HIV-infected individual who is living in a secure and supportive environment, with some degree of social acceptance, education and understanding about treatment for HIV will almost certainly have a higher quality of life than someone whose circumstances are quite different.
The second aspect that bears on degree of social impact is access to resources. As explained above, access to resources can mitigate many of the negative impacts related to HIV infection, including housing, education, and health, and can mean the ability to purchase life-prolonging medicines.

Social Impacts at the Household Level
Social impacts at the household level can be both short-term or long-term, depending on the environment, degree of infection in the household, and the characteristics of the infected persons. Studies show that household-level social impacts due to HIV/AIDS include:

- **Demographic changes** – such changes include the ability to reproduce, since households with HIV+ women experience lower birth rates and higher rates of infant and child mortality. In households where one or both parents have AIDS, fewer children tend to be born and 25-30% of those who are born will die in infancy or early childhood. Over the long run, when both parents die and surviving orphans are scattered, the life ways and traditions of the family may die away completely.

- **Household composition** – the composition of households can change dramatically as a result of HIV/AIDS. Possible changes include an increased dependency ratio due to the loss of prime-age adults or due to orphans joining other households. The emergence of large numbers of orphans living in households without a parent or on their own without an adult is another clear impact, and perhaps one of the most serious long-term consequences of the epidemic. New forms of households are also emerging – elderly households with young children; large households with unrelated fostered or orphaned children; child-headed households; single-parent households; cluster foster care (where a group of children is cared for formally or informally by adults in neighboring households); children in subservient, exploited or abusive fostering relationships; itinerant, displaced, or homeless children; neglected, displaced children in groups or gangs.

- **Income-related effects** – these include the same income-related impacts discussed above for individuals, including poorer housing, reduced food consumption and access to education, etc. Research also strongly suggests that income effects within a household begin before the death of a parent, as the ill person is increasingly unable to work and spending on medical care increases. Productive assets (land, animals, equipment) are frequently sold off to pay for medicines and funeral expenses, so that a family may already be in difficult financial circumstances by the time the death occurs. Following the adult death, particularly that of the father, many families are plunged into poverty, which affects a household’s ability to pay for food, school fees, medical care, transportation, and other basic needs. Children tend to suffer malnutrition and may be withdrawn from school, especially girl children, because of an inability to pay for school fees and/or the need for the child to work outside of the home.

- **Increased workload of household members** – research on household impacts of HIV/AIDS in sub-Saharan Africa shows that the loss of an adult increases the workload on remaining members of the household. Children often must care for the ill and other younger children and therefore cannot attend school. Women and children left behind without male labor are also sometimes compelled to change to less-labor intensive (and less nutritious) crops, which can worsen the nutrition impacts resulting from lower incomes.
The degree of impact at the household level is determined by several important factors. These include the number of cases of HIV in the household, characteristics of the deceased (age, gender, income), and previous family income and assets. Clearly, households with more wage-earners and higher incomes will be better able to cope with the death of a household member. In addition, access to assistance can be critical in mitigating some of the worst income-related impacts.

**Social Impacts at the Community Level**

Social impacts at the community level can also be both short-term and long-term. Some of the major impacts include:

- **Demographic shift** – clearly, the biggest potential impact of HIV/AIDS is on the demography of the community. Because HIV infection leads to the deaths of members of society who are in the most productive years of their lives, communities can lose parents, teachers, bankers, health workers, doctors and other skilled professionals in all sectors of society. The “hollowing out” of the middle section of society also imposes huge burdens on the young and older members of the extended households in the communities. Most tragically, children lose their parents, and grandparents may have to fill in the role of the parents. However, the grandparents may be in need of assistance themselves and may not be able to adequately provide for the children. In addition, demographic impacts can lead to health and education impacts.

- **Broad health and education impacts** – due to the deaths of parents and young adults, the health of both the youngest and oldest members of the communities may suffer because they are unable to care for themselves without the middle generation of adults. Moreover, grandparents and other relatives (often having meager resources) frequently have the added responsibility of caring for the orphaned children, making all such households particularly vulnerable, including an increased risk for illness, which can impact the community further. Because of the increased demand on their time from home activities, the school attendance and academic performance of affected children will decline, with differential impacts on boys and girls.

- **Impacts on medical infrastructure and personnel** – the deaths of doctors and health workers can lead to unfilled vacancies in the staffing levels of the public health sector and this in turn can lead to deterioration in the provision of public health services. In the short term, it may not be easy to replace experienced professional workers.

- **Increased poverty and homelessness** – some of the most immediate and powerful effects in communities heavily affected by HIV/AIDS result from increased poverty and homelessness at the household level. These impacts are directly related to a loss of income from the deaths of many of the most productive members of the community. Increased poverty can also spur higher rates of HIV incidence of HIV (susceptibility).

- **Increased inequalities** – increases in poverty among affected households can clearly lead to an increase in the level of inequality in the broader community. There is also a gender bias in inequality since households headed by women or the elderly are more likely to be severely impacted (vulnerability).

- **Increased crime and social instability** – reports suggest that increased homelessness due to rising HIV infections and AIDS orphans magnify social stresses. Relative poverty and widening inequalities have a tendency to undermine short-term social stability at various levels.
In the longer term, all the above impacts can be exacerbated, and lead to a reduced quality of human and social capital as well as a reduced capacity for economic growth and development. At the same time, however, communities can adapt in order to survive and there are examples in sub-Saharan Africa of communities forming groups or organizations to help assist families in need. Over the long-term, communities or regions may change cultural practices, such as funeral rites and wife inheritance, in order to reduce the long-term social impacts of HIV/AIDS.

**Orphans and their Households**

*Introduction: The Face of AIDS-related Orphanhood*

One of the most serious and long-term impacts of HIV/AIDS is the emergence of a generation of orphans. Here, an orphan is defined as a child below the age of 18 years who has lost one or both parents. Such children are vulnerable to a range of problems including reduced health and education, psychosocial issues, homelessness, and abuse. But most fundamentally, these orphans are at risk of growing up outside of a nurturing environment, without the socialization necessary to become healthy and productive members of society. Although orphans themselves perceive many of their problems, when a group of orphans in Uganda were asked what they needed the most, one girl answered, “we need someone to love us.”

Perhaps the best way to begin to understand the impact of AIDS on children is to see, through photos or a film, the way they live after they have lost a parent to HIV/AIDS. This session thus begins with a film on AIDS orphans.

*The Situation of Orphans – Numbers and Impacts*

As of the end of 2003, the cumulative number of children estimated to have been orphaned by AIDS by age 18 in sub-Saharan Africa was 12.3 million. In 2003, orphans (including orphans whose parents died from causes other than AIDS) accounted for 12.3% of all children in sub-Saharan Africa. Looking ahead to 2010, there are expected to be 18.4 million orphans in sub-Saharan Africa;9 orphans are expected to represent 15-25% of children in 12 sub-Saharan African countries.

Parental death from HIV/AIDS has a particularly powerful effect on a child, though the impact generally begins long before a parent actually dies. With HIV/AIDS, there is likely to be a long period of parental illness prior to death, during which time there is usually a significant socio-economic impact on all members of the family, due to the combined effects of lost adult labor, a decline in income, and increasing medical costs. Families often face difficulties providing for the most basic of needs and children generally must shoulder new and major responsibilities as a result. They may be removed from school to work in the fields or the home, pursue outside employment to earn cash income, or help care for the ill. They suffer immeasurable emotional and psychological stress watching a parent die a lengthy and painful death, particularly as family resources dwindle. Uncertainties about the future, including the health status of remaining family members, future care for surviving dependents, and inheritance of land and property, combined with the continued stigma and shame attached to HIV/AIDS, can traumatize young and older children alike, leading to anger, depression, and even serious mental health problems. The tendency for adults in many cultures to avoid discussing and preparing for a future death due to cultural taboos tends to exacerbate the strain on children during the period of impending orphanhood.

By the time a parent dies, the combined effects of lost labor and income, increased health care and funeral expenses, and emotional stress and uncertainty have affected surviving children in a variety of ways, most frequently by being removed from school and suffering a decline in health and nutritional status. But the period of psycho-social-economic limbo is typically far from
over. Decisions must be made about whether children remain in the family home or are sent off to live with relatives, and under what sorts of circumstances. These difficulties impact children and families in a variety of ways, largely depending on the economic strength of a family and surrounding community. But given the very high poverty levels in so many developing countries heavily affected by HIV/AIDS, most families clearly suffer tremendous hardships as a parent dies and the family struggles to set up a new way of surviving and caring for children. The direct impact on girl orphans, as opposed to their brothers, is also usually greater as they are likely to be the first children taken out of school, typically have more work responsibilities within the home, and are more likely to suffer sexual and other abuse.

Previous studies that have been done in sub-Saharan African suggest that the most serious impacts on orphans include: reduced nutritional status, poorer school attendance, psychosocial impacts including depression and fears about the future, homelessness, and child labor and prostitution.

While Africa is proportionally the region hardest hit by HIV/AIDS, the total number of orphans is largest in Asia. Although the number of orphans in Asia has dropped by almost 10 percent since 1990, and despite lower HIV prevalence rates, Asia had twice as many orphans due to all causes than sub-Saharan Africa in 2003. This is due to much larger populations in Asia, which has almost four times more children (1.2 billion) than sub-Saharan Africa (350 million). There are three countries in Asia where 10 or more percent of children are orphaned: Afghanistan, Lao PDR, and the Democratic People’s Republic of Korea. 6% of children in China and 7% of children in Viet Nam are orphans.

Although there are few specific studies that focus on children in Asia who were orphaned due to HIV/AIDS, most experts agree that the socio-economic problems related to these children may be significant because of a lack of institutions to care for them. It is still early in the epidemic in countries such as China and Viet Nam, but household economic losses stemming from adult AIDS deaths has already had a noticeable impact on children, including in the form of reduced schooling. With time, it is reasonable to expect that the HIV/AIDS epidemic will continue to produce rising numbers of orphans in these countries who will suffer a similar range of impacts observed in countries that are already at a mature stage of the epidemic.

The Evidence from Viet Nam

A 2005 report by UNDP provides relevant information on the socio-economic impacts of HIV/AIDS in Viet Nam.1 HIV prevalence in Viet Nam is particularly high among very young people, with about 80% of infected Vietnamese between 20-39 years of age. Because these are prime working years, the epidemic has led to reduced working capacity, income, and savings. According to the report, 50% of employed HIV-positive Vietnamese lose their jobs because of their illness. These impacts, in turn, have affected poverty levels. In 2004 alone, it is estimated that 126,000 persons in Viet Nam became poor or poorer as a direct result of HIV/AIDS. In 2015, it is expected that over 400,000 Vietnamese will fall below the poverty line, with 36% newly poor or poorer due to HIV/AIDS.

This same report includes data on the total cost of care and treatment, including anti-retroviral therapy (ART), in Viet Nam. It claims that an estimated 497.6 billion VN dong (US$ 33.2 million) was spent on care and treatment in 2004, with this cost rising to 550 billion VN dong (US$ 40 million) in 2005. Due to the falling cost of ART medications, this total was projected to fall to 253 billion VN dong (US$ 16.8 million) in 2007.

Data on caregivers of HIV-positive Vietnamese indicates that there has been a significant increase in the burden on caregivers within households. Since approximately 74% of caregivers of HIV-positive Vietnamese are mothers, wives, or sisters of infected persons, a disproportionate share of this care giving burden falls on women in Viet Nam, as is true in other countries. Survey data suggests that the time needed to care for one HIV-positive person in Viet Nam is about 5 hours per day.²

Additional information indicates the range of responses at the household level when a family member is HIV-positive. These are listed below, along with the % of households with HIV-positive members that indicated the response:³

- Borrow money from friends and family (36.0%)
- Reduce spending on food (28.8%)
- Borrow money at high interest rates (27.2%)
- Reduce spending on health care for other family members (25.6%)
- Sell non-permanent assets (TV, bikes, etc.) (20.8%)
- Send elderly family members out to work (17.6%)
- Sell permanent assets (land, house, etc.) (5.6%)
- Keep children out of school (3.2%)
- Send children out to work (2.4%)

Survey information provided by Viet Nam’s Ministry of Health (MOH) and Save the Children in 2003 indicate some of the impacts experienced by children infected and affected by HIV/AIDS. According to these figures, roughly 50% of HIV-positive children and 50% of children in a home with a HIV-positive person live in poor households. Not surprisingly, these children often must work to help support themselves and their families. The MOH data indicate that 58% of HIV-infected children and another 42% of children affected by HIV/AIDS work for wages. As in most countries in the world, HIV/AIDS has affected the ability of children to attend school. More than four in five (81.3%) of HIV-positive children and two in five (39%) children living in a family with an HIV-positive member do not attend out of school.

Recommended Readings:


² UNDP (2005).
³ UNDP (2005).
CHAPTER 4: THE GREATER INVOLVEMENT OF PEOPLE LIVING WITH HIV/AIDS (GIPA) IN THE POLICY AND PROGRAM RESPONSE TO THE EPIDEMIC

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Introduction
There are an estimated 40 million people living with HIV/AIDS (PLHA) in the world. In Viet Nam the figure is between 250,000 and 300,000 by current estimates. While these numbers represent the enormity of the epidemic, behind the figures are individuals, people who can and do make a critical contribution to fighting against HIV/AIDS.

The greater involvement of people living with HIV/AIDS in the policy and program response to the epidemic, or GIPA, is a term that is used to describe, recognize and promote the important contribution people living with HIV/AIDS, and others affected by HIV/AIDS, provide in all areas of HIV/AIDS prevention, care and treatment. The principle of PLHA involvement has been evident wherever the epidemic has taken hold. PLHA and vulnerable communities have been at the center of developing and implementing some of the most effective HIV/AIDS measures. The rationale underlying GIPA stems from this experience. Involvement promotes the human rights of those most affected by bringing them into the foreground of the policy and program response and adding their voices and experiences to the broader response, this in turn creates a more effective public health response.

This session brief provides information on the international background to GIPA and on the development of GIPA in Viet Nam.

The GIPA Principle and the Paris AIDS Summit
The term GIPA gained international recognition and support at the Paris AIDS Summit in 1994. The summit brought together 42 heads of state to renew their political commitment to the fight against AIDS by signing the Paris Summit Declaration.

This document, which was signed by all 42 participants in the Summit, reaffirms the need for "political leaders to make the fight against HIV/AIDS a priority" by undertaking in their national policies to "make available necessary resources to better combat the pandemic, including adequate support for people infected with HIV/AIDS, nongovernmental organizations (NGOs) and community based organizations (CBOs) working with vulnerable populations."

Many countries, including Viet Nam sent official delegations. The relevant text from the declaration calls on governments to:

Support a greater involvement of people living with HIV/AIDS through an initiative to strengthen the capacity and co-ordination of networks of people living with HIV/AIDS and community-based organizations. By ensuring their full involvement in our common response to the pandemic at all -national, regional and global- levels, this initiative will, in particular stimulate the creation of supportive political, legal and social environments."
The GIPA principle has since been reaffirmed by numerous international conferences and meetings including UNGASS (199 and 2006)

GIPA represents a global movement that has a history longer than the 12 years since the statement was made and in many senses its origins are in changes in public health and civil society which go back much further than the epidemic. In a broad sense the movement for GIPA lies in the changes in which health and the role of the patient have re-conceptualized over time. In basic terms GIPA is a part of a this challenge which involves broader and more holistic definitions of the meaning of health, the role of the patient and the ways in which illness is defined.

More specifically it is important to recognize that the work of PLHA has a long and honorable history. It is not a history that is in the foreground of accounts of the epidemic; however, it is the foundation for the things that work. PLHA have been the architects of the most innovative and important responses in HIV/AIDS care, treatment and prevention, and a driving force for policy change. These include the concept of safe sex, the pioneering of harm reduction, the value of peer education, policy setting, the undocumented caring, insight into treatment, tireless work on prevention education, the creation of organizations and groups often in extremely hostile environments and the human rights campaigning and sacrifices of many people living with HIV/AIDS.

Crucially, they help to bring home the message that HIV and AIDS can affect anyone from any background, any country, any education level or position. People living with HIV understand each other’s situation better than anyone and are often best placed to counsel and advise one another and to represent their needs in decision – and policy making forums.

**What Does GIPA Mean in Practice?**

As the above diagram suggests involvement is GIPA is not a project or program. GIPA is a principle that will facilitate more successful local, national and global responses to HIV/AIDS. The GIPA Principle means involving positive people at every level of the response.

**GIPA does not mean that there is an imperative for all positive people to reveal their status in public, although it is clear that those who do, make a major impact on public perception and the more people who are open, the**
greater the potential for a reduction in AIDS-related discrimination. UNAIDS has
described a pyramid of possible levels of involvement of people diagnosed with HIV. At the
first level, positive people are recipients of services and can provide feedback to those
planning and implementing these services. Many positive people move to the next level of
the pyramid, as contributors to prevention programs and as public speakers. Fewer
progress higher to become implementers of programs, for example as outreach workers or
peer educators. A few are recognised as experts on a level with other public health
professionals. At the peak of the involvement pyramid, positive people are decision-makers
in policy and project design.

For positive people to be involved as equals, it is crucial that they possess the skills appropriate
to the level of involvement. Although many positive people have the will and capability, they may
lack education, and the process of HIV diagnosis often results in a severe reduction of self-
estee. Positive people must be provided with training to develop appropriate skills. Self-
estee must be improved so that they feel equal with others to whom they must relate. Also,
those with whom positive people work need to be made aware of the consequences that can
rise from breaches of confidentiality, and be taught to respect the limits to which individuals may
wish to reveal their status or become involved. This can only come about within a supportive
environment.

People affected by HIV/AIDS also have a crucial part to play in the response to the epidemic.
This group of people includes the partners or parents of positive people. Apart from their
support role, many older affected people are more ‘respected’ and often find it easier to
communicate, so they can have a strong impact on policy makers.
GIPA in Viet Nam

GIPA is relatively new in Viet Nam. Prior to 2003 PLHA involvement in HIV/AIDS activities was limited. Stigma and discrimination against PLHA was a big challenge, creating pressure on many people to remain isolated. HIV information and education was insufficient and many IEC messages created fear and increased stigma. The HIV policy environment was also limited, providing little guidance on how to support or involve PLHA.

While the extent of stigma and discrimination against PLHA has decreased, it remains a major barrier to greater involvement. However, PLHA are responding to the challenges of living with HIV/AIDS by providing critical support and services, as well as much needed input into HIV/AIDS policy and program design. In 2003 the self help group “Bright Futures” was established in Hanoi with 11 members. Since 2003 Bright Futures has worked to support PLHA providing care and support, prevention education, hospital referrals, counseling and treatment information to thousands of people in over in the North of Viet Nam and the network has expanded to cover over 12 provinces.

In Ho Chi Minh City the “Friend-Help-Friend” model also developed rapidly, and many PLHA began to set up their own self help groups. These groups have been linked in a city wide network which provides support and care to PLHA in the City.

In addition the PLHA self help movement there are a number of other initiatives supporting GIPA in Viet Nam. The Viet Nam Women’s Union is providing support for a GIPA project that places United Nations Volunteers (UNV), many of whom are living with HIV in government agencies to help create a greater awareness and understanding of involvement.

The HIV/AIDS law and policy environment has also improved and now provides a framework which is supportive of the involvement of PLHA at the policy and the program level. The national Strategy on HIV/AIDS which came into force in 2004 provides for the protection of the rights of PLHA and calls for the development and support for involvement of PLHA self help and support groups. Article 3.4 of the new HIV/AIDS law states PLHA involvement is a principle of HIV/AIDS prevention and control. This is further elaborated in;

‘Article 20 Participation of HIV infected people in HIV/AIDS prevention and control

1. HIV-infected people shall be entitled to participate in HIV/AIDS prevention and control activities.

2. The State encourages and facilitates HIV-infected people to participate in:
   a) peer education groups, clubs and other forms of activities organized by HIV-infected people in accordance with the provisions of the law;
   b) Propaganda activities and harm reduction intervention measures to prevent HIV/AIDS transmission;
   c) Activities of supporting and caring for HIV-infected people;
   d) Contributing ideas for the formulation of programs, policies and laws concerning HIV/AIDS;
   e) Other HIV/AIDS prevention and control activities.’
The rapid scale up of ARV treatment in Viet Nam also provides the potential for increasing PLHA involvement. A significant barrier to GIPA is illness, as ARVs become more available greater numbers of people will remain well and be able to make a contribution.

GIPA Activities

Peer Support
The first step towards empowerment of positive people is enabling them to meet other people living with the virus - peers. Such meetings allow sharing of feelings and information, and provide mutual support. Meeting peers facilitates acceptance of one’s status and enables people to realise that they are not alone. It can also assist in disclosure to family or loved ones, where ultimately positive people may get more support than they at first anticipate. Development of peer support groups (including groups of infected and affected people) is an essential element of GIPA.

Peer Education
Living with HIV can be very complex. Difficult questions frequently arise, such as dealing with personal relationships, having children or choosing treatment regimen options, and health care workers are frequently poorly informed or out-of-date. Many positive people find it is important for peace of mind to become expert on the many aspects of living with the virus. They are then in a prime position to pass this expertise on to peers in ways that are more appropriate to those who have limited education. They can be trained to become treatments' educators, training their peers on the appropriate use of antiretroviral medication, treatment regimes, adherence issues, and side effects.

Advocacy
Positive people can be very persuasive as advocates. They can lobby for improved treatment and care on an individual or group level, as well as raise awareness of issues at policy-making level. Elected officials are sometimes more willing to support people who benefit directly from their actions (such as approving budgets for treatment and care) rather than those who benefit less directly (via targets of prevention programs).

Public Education
Positive people who speak out openly and put a human face to HIV break the silence that surrounds HIV and AIDS. Most people untouched by the epidemic assume that HIV is nothing to do with them, and therefore pass by opportunities to learn more about it. Positive people can also make a major impact on health care workers. There are many examples in Viet nam of PLHA who speak openly about living with HIV and break the silence surrounding the disease. Pham Thi Hue was among the first PLHA to speak publicly about living with HIV in Viet Nam.
She started a peer support group in Hai Phong which has promoted care and support for PLHA. In 2004 she was awarded the title of ‘Asian Hero’ by Time magazine for her outstanding contribution to HIV/AIDS.

Counseling
Positive people can also be trained as counselors. They make very sensitive counselors and are perceived to be much more empathetic to their peers than people who are untested or HIV-negative. Effective peer counseling alleviates the fear most people face on diagnosis. With the increased pressure of governments to test more people for HIV, the need for quality counseling is at a premium.

Program Planning and Implementation
Positive people have expertise outside the fields of peer support and treatment and it is crucial that this is used to improve programs. For example, prevention messages frequently add to AIDS-related stigma and discrimination.

Policy and Legislation
At the peak of the GIPA pyramid is involvement in decision making related to AIDS policy and laws, at provincial and national levels. In several cases, such involvement has avoided potentially harmful actions and resulted in better policies. In Vietnam PLHA have made important contributions to the law and national strategy as well as on operational policy, for example the national treatment and care guidelines.

Challenges to Implementing GIPA
There are many challenges to implementing the GIPA principle, and implementation takes many forms – GIPA is not merely a project, an initiative, or an activity. It is a principle that is followed through from concept, design, implementation and evaluation.

Despite the positive changes that occurring in Viet Nam, HIV/AIDS related stigma and discrimination remain a significant barrier to increasing the involvement of PLHA. Prejudice at the community level creates a serious disincentive to access services and support which provide the gateways for involvement. GIPA is a relatively new concept and its application in the response to HIV/AIDS is still a work in progress. This means that few programs or policy initiatives are developed to incorporate GIPA. In many cases this may arise from a lack of understanding of how to do this, however it can also be an outcome of a reluctance to involve PLHA, due to stigma and a belief that they are unable to make a contribution.

PLHA require basic knowledge and awareness of the impact and effect of HIV/AIDS at both personal and policy levels before gaining policy negotiation skills and a level of familiarity with the national HIV/AIDS response. Understanding and being able to articulate the personal experience of HIV/AIDS is a prerequisite to coming to terms with the more technical knowledge domains that dominate policy development.

International research on GIPA strongly suggests that effective involvement is contingent on the development of PLHA organizations and structures that can fairly represent the interests and needs of the widest range of PLHA. This is particularly important at the policy level where network structures can convey the views of diverse constituencies and support more informed policy development. The absence of representative structures creates a significant barrier.
There is also a lack of PLHA groups in central Viet Nam; this represents a significant gap in coverage and also major barrier to effective commoditization of GIPA.

GIPA is a crucial policy and program tool but remains, at this stage of the epidemic, a blunt one. The stigma of injecting drug use, sex work, and non-normative sexuality underlie and compound the stigma of HIV/AIDS epidemic. The question for policymakers and people with HIV/AIDS is how to develop GIPA to address these issues without adding to already virulent institutional and community-based stigma and discrimination. Achieving the meaningful involvement of people living with HIV/AIDS who are also sex workers, men who have sex with men, or injection drug users requires a related set of activities that build a supportive environment.

### Moving forward

The recommendations below have been synthesized from GIPA information gathered from research carried out by the health Policy Initiative, Care international, and a series of PLHA meetings in Viet Nam.

- Help people living with HIV/AIDS build the skills and confidence required to speak and act as partners in the response to HIV/AIDS – this is particularly a problem with highly marginalized groups, and also for women for whom joining groups and becoming openly involved in the public sphere may be very alien;

- Create access to effective treatments including anti-retroviral drugs, so people are well enough to take part in activities and care for themselves and their families;

- Reduce stigma and discrimination through the promotion of positive and productive images of PLHA;

- Provide training and support for people working with PLHA;

- Increase knowledge and skills among senior programmers and policy makers (especially non-health sector personnel) on how to meaningfully involve PLHA and create links between PLHA, policy-makers and services providers;

- Increase the knowledge of health workers to help them improve their physical and psychological care of PLHA;

- Develop GIPA policies and budgetary guidelines for all sectors;

- Develop poverty alleviation strategies (i.e. employment & income generation) for PLHA;

- Create self-help groups linked to civil society and permit the formation of a national PLHA network in Viet Nam;

- Strengthen and enforce anti-discrimination laws;

- Increase the knowledge of PLHA about their rights;

- Coordinate activities between donors in their support of PLHA groups;
• Encourage and highlight positive statements by high level government and party members as well as by high profile and well known public personalities.

Further information and GIPA Resources

• A guide to PLHIV Involvement in Country Coordinating mechanism, available in English and Vietnamese from Health Policy Initiative, (04) 9331 4188, email policy@fpt.vn
• From Principle to Practice” (UNAIDS 1999), available from the UNAIDS website http://www.unaids.org.vn/

CONTACT LIST

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9. VNMTS Sơn La :
10. VNMTS Thái Bình : Thành 2, Vụ Tây, Kiên Xương, Thái Bình, 0902030126
11. VNMTS Thái Nguyên I : Số 11, ngõ 723 Lương Ngọc Quý, Tp Thái Nguyên, Thái Nguyên, 0915663703
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18. H’ Long t–i ®Np : Tàe 47, khu 3 B, ph-ýn yÕt kí pu, tp H’ long - Quãng Nhinh, 090223604
19. Tình b’n : Nhà số 8, tổ 2 khu 5 B, phường Hà Lâm Tp Hạ Long, QN, 033.614929
20. Bnh Minh : Tổ 5, khu 01, phường Trần Hưng Đạo, Tp Hạ Long, QN, 0904082789
21. Ục m’ xanh Quan L’n :
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23. Cố lộc bé Hoa Hìng Đặng QN: CLB Hoa h-ìng d-àng h' long, phế Trị t'n H-ìng S' o, 41 Đ-àng Trị H'ngh S' o, L.p H' long, QN, 0913369265
24. Hoa phong truyền Hố Phìng: 68, H' Lý, quận Hạng Bừng Lp Hà Phìng, 031.842747
25. Tính biến: 1 B, 59 phố Tiên Đức, phường Trại Chuối, tp. Hải Phòng, 031.599059
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28. Hoa Sen: TrDIM xe An L-§, Thuû Nguyªn, Hố phìng, 031.774572 (090.974839)
29. Phô nò tù lục: Sè 35, Lã §¹i Hµnh- Hố phìng, 031.777903
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31. iéc mò xanh Hµ Néi: Số 1 / Ngõ 224, phố Nam Du, quận Hoàng Mai, Hà Nội, 04.6432889
32. Hoa sá: 46 Lương Sử B, Quốc Từ Giám, quận Đông Da - Hà Nội, 04.7322472
33. Cố lộc bé Hoa Hìng Đặng: CLB Hoa Hướng Đã, hố chư thâp tp. Đô, số 5 ngõ 180, Nguyªn Lương Bằng, Hà Nội, 04.8513683
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35. CLB Hoa Xanh: CLB Hoa Xanh, hố thâp tp. Đô, số 5 ngõ 180, Nguyªn Lương Bằng, Hà Nội, 04.6961332
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38. CLB Chìa HiÓn Quang: Thôn Trung, x- Đ-àng Hố, huyOn Gia Lộm, Hố Néi, 04.6961332
39. Mai Khái HCMC: 44, Tổ X-ìng, quEn 3, T.p HCM. 43/5 Ph'm V'n Chiþu, quEn G8 VÈp, HCM, 08.9322637
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**Formatted:** Swedish (Sweden)
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15. DKT: Phòng 504-tầng 5, 30 Nguyễn Du - Hà Nội, 04-9437363/9437370
16. PATH Canada: 15-16 ngõ 232-Tôn Đức Thắng -Đống Đa-Hà Nội, 04-5119904/5119905
17. Tổ chức thủy ngân pháp (MSF): 830/24 Sư Vạn Hạnh -Phường 13, quận 10 - T.p Hóc Môn, 08-2650597/2650596
Introduction

The gender and HIV/AIDS module provides an overview of gender power dynamics, sexuality and the behavioral and structural determinants of HIV vulnerability among women, men, and young people. The module begins with an introduction to the concepts of gender and sexuality and discusses how gender, sexuality, masculinity and femininity are constructs shaped by social, economic and cultural factors. The epidemiology of HIV in women and men worldwide is reviewed with a focus on the feminization of AIDS. The module explores the biological, social, economic and programmatic vulnerability of women vis-à-vis men. Gender-based violence as a factor in HIV transmission is discussed in the context of biological, economic and social vulnerability. In addition, the module introduces the concepts of and relationship between sexual and reproductive health and rights and HIV/AIDS. Through a gender perspective, the module analyzes the benefits and negative consequences of targeting “high risk groups” versus a more comprehensive approach that addresses vulnerability and determinants of behavior in HIV prevention, treatment and impact mitigation. The module highlights HIV/AIDS strategies, programs and policies that integrate gender equity and healthy sexuality for a more effective response.

By the end of this module, participants should understand:
- the importance of and relationship between gender and HIV/AIDS
- the differences in vulnerability to and impact of HIV/AIDS on men and women
- gender and sexual behavior dynamics as important determinants of vulnerability
- reproductive and sexual rights in relation to HIV/AIDS
- the benefits of a comprehensive response over a targeted approach alone, and
- strategies to integrate a gender perspective into HIV/AIDS programs and policies.

The Growing Feminization of the Global AIDS Epidemic

Over the last twenty years the world has witnessed a growing feminization of the AIDS pandemic. Worldwide, women currently account for nearly half of all people aged 15-49 living with HIV/AIDS (17.6 million women and 19.6 million men). Since 1985, the percentage of women among adults living with HIV has risen from 35% to 48%. What is particularly alarming is that young women make up 60% of 15-24 year olds living with HIV. The majority (57%) of all people living with HIV in Sub-Saharan Africa are women. In Asia, women are increasingly becoming infected. From 1996 to 2004, the percentage of women living with HIV/AIDS in Asia increased from 12% to nearly 30%.

Sex, Gender and Sexuality: Basic Concepts

In order to understand this epidemiological phenomenon, it is important to understand the basic concepts of sex, gender and sexuality and their implications for vulnerability to HIV. Sex is a biological construct. Differences between male and female sexes are physical and behavioral, distinguishing individuals according to their reproductive functions. Gender, on the other hand, is a social construct that defines and differentiates the roles, responsibilities, expectations and power of men and women in a given society. Because societies are different, gender roles,
responsibilities, and power of men and women vary from culture to culture. These gender roles, responsibilities and power dynamics often change over a person’s lifecycle.

Like gender, sexuality is socially constructed and is influenced by gender norms and expectations, type of sexual relationship, sexual orientation, partner(s), age and stage in the lifecycle. Sexuality involves pleasure, desire, pain, power and reproduction. The World Health Organizations notes, “Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, ethical, legal, historical and religious and spiritual factors.”

**Gender and Vulnerability to HIV/AIDS**

Differences in biology and gender power dynamics, roles and expectations are linked to differences between men and women in vulnerability to HIV. This module reviews the following five types of vulnerability to HIV/AIDS:

- Biological: physiological factors that render men and women differentially vulnerable to HIV.
- Socio-cultural: factors that define and determine individual behavior, beliefs, norms and expectations in relation to gender, sexuality, ethnicity and class.
- Economic: factors that determine access or lack of access to resources/assets, economic dependence or independence and/or safe or risky financial transactions
- Programmatic: the effect of HIV/AIDS programs on women’s and men’s ability to protect themselves from HIV, access affordable and effective treatment and mitigate the impact of HIV/AIDS on their lives.
- Structural: the larger legal, institutional and policy environment that reinforces social and cultural norms and influences HIV/AIDS programs and policies.

**Biological Vulnerability**

Women are more biologically vulnerable to HIV than men. Research has demonstrated that women are more than twice as likely as men to be infected in a single act of vaginal intercourse.\(^4\)\(^5\)\(^6\) Female genital tracts are more vulnerable to trauma, and women have a larger area of exposure to the virus than men. For these reasons, transmission of HIV and other sexually transmitted infections is more efficient from men to women than from women to men. The presence of a sexually transmitted infection (STI) facilitates the transmission of HIV.\(^7\)

Women, however, are less likely than men to show symptoms if they have an STI and therefore less likely to seek and obtain effective treatment. Women and men are equally vulnerable to infection through receptive anal intercourse.

**Social and Cultural Vulnerability**

Sexual and drug use behavior are shaped by cultural gender norms and expectations. Men and women are expected to think and act differently with regard to sex. Most cultures associate

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\(^5\) Public Health Seattle and King County. 2002. HIV Infogram: Update on Sexual Transmission of HIV. March
masculinity with earlier sexual activity, many sexual partners/experiences, virility, and pleasure. Men are also seen as and encouraged to be actors and initiators of sexual activity. Men are also encouraged to take greater risks in general which may result in negative behavior such as risky sex, violence or drug use. Femininity, on the other hand, is often associated with passivity in sexual matters, virginity, chastity and fidelity to one’s spouse. In many cultures the most important role for women is to have children. Women are often portrayed as objects of desire rather than individuals who experience or should experience pleasure in sex. Social institutions such as families, community and civic organizations, schools, workplaces, political systems and religious institutions create and reinforce these gender roles and expectations. Those who do not conform to these gender and sexuality norms (e.g. women with multiple partners, men who have never been sexually active, homosexual and transgendered people) are often socially ostracized, stigmatized and discriminated against.

These gender roles and expectations lead to differences between men and women in vulnerability to HIV infection. Men are more likely to make the decisions about sexual behavior: when, where, and how to have sex and whether to use a condom. Male condoms are the only widely available method for prevention of sexual transmission in heterosexual and homosexual encounters. Women have little or no control over condom use and sexual decision-making in their own relationships or in their partners’ relationships with others.

Research does confirm that individual sexual behavior is likely to change over the life cycle and may differ from relationship to relationship, depending on the level of trust, power, and commitment perceived in those relationships. Men are much more likely to use condoms with sex workers than they are with casual and marital partners. Condom use in casual relationships is ambiguous, and negotiating condom use may be perceived by the partner as a sign of lack of trust and commitment. Female sex workers are much more likely to use condoms with their non-regular clients, less so with their regular clients, and rarely with their husbands or partners. Unfortunately, few programs address the contexts, meanings, and vulnerability associated with different types of sexual relationships.

Women are also vulnerable to HIV infection through injecting drug use. There is tremendous denial in some countries that women injecting drug users exist or, if they do, it is within the context of sex work. In fact, data show that most women begin using drugs first and then may turn to sex work to support their addiction. Women IDUs are often in sexual relationships with men IDUs. Their relationships with their male drug using partners render women vulnerable through both unprotected sex and by sharing injecting equipment. Research has shown that men do not often use condoms in these relationships. Women are also more likely to be the receptive needle sharing partner – her male partner will use the syringe/needle first and then pass it to her. This receptive sharing leaves women highly vulnerable to infection.

Gender-based violence and the link to HIV transmission

Another critical but little addressed issue is violence against women, a phenomenon that occurs in all countries throughout the world and reinforces male dominance and discrimination against

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women. Violence against women is a human rights violation and a significant public health and law enforcement problem worldwide. Sexual violence and abuse includes intimate partner violence or by someone known to the woman or girl; violence in conflict situations; violence against sex workers; and trafficking.

Research has shown that violence against women puts them at greater risk of HIV infection due to biological, psychological, economic and cultural factors. Physical trauma leads to lesions in genital/anal tract and greater biological vulnerability to HIV. Long-term effects of sexual violence in a woman’s past include increased sexual risk taking including greater numbers of sexual partners, casual partners, transactional sex, and lower condom use. Research suggests that violence or the fear of violence limits women's ability to negotiate condom use. Women fear abandonment, loss of economic support and loss of children if they seek divorce as a result of violence or refusal to have sex. Violence or fear of violence also keeps women from disclosing their HIV status to their partners, seeking voluntary counseling and testing (VCT) and obtaining HIV/AIDS care and treatment. For men, violence against women is linked to their own sexual risk taking including extra-marital sex and having an STI.

Economic Vulnerability and Economic Impact

Women tend to be poorer and more economically dependent on male family members (fathers, brothers, husbands, and sons). They are less likely than men to have access to and control over resources/assets such as income, land, property, housing, and food; and are less likely to inherit assets upon their husband’s death. Further, women are more likely to be employed in the informal sector with its lower wages, fewer benefits, and job insecurity. If they do work in the formal sector, women earn lower wages compared to their male peers. And women on average are less likely to be as educated as men.

All of the above render women more economically vulnerable to HIV. Research has shown that lower incomes and less education are associated with lower condom use. Women's employment options are often limited due to their lower educational levels and inherent discrimination against hiring women for living wage positions. As a result of economic

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14 Ahmed, Saifuluddin; Lutalo, Tom a; Waver, Maria b; Serwadda, David c; Sewankambo, Nelson K. c; Nalugoda, Fred a; Makumbi, Fred a; Wabwire-Mangen, Fred c; Kiwanuka, Noah a; Kigozi, Godfrey a; Kiddugavu, Mohamed a; Gray, Ron. AIDS. 15(16):2171-2179, November 9, 2001. HIV incidence and sexually transmitted disease prevalence associated with condom use: a population study in Rakai, Uganda.
insecurity, some women may engage in formal and/or informal sex work in exchange for food, shelter, goods and physical security. Sex work is associated with greater numbers of sexual partners and partners who are older, more powerful, and more sexually experienced. In economically dependent relationships women also lack leverage to negotiate condom use or fidelity by their partners. Labor migration to urban areas also leaves both men and women vulnerable to HIV. Away from home men and women may engage in extra-marital relationships (sometimes in a commercial sex context).

Research has also shown that AIDS has a greater economic impact on women and girls than on men and boys. For example, families are more likely to remove girls from school to help with care and housework in the event of a family member living with HIV/AIDS. Women also have a greater economic burden as traditional caregivers for sick. To care for sick relatives, women must often limit or stop income generating activities. HIV positive women are more likely than HIV positive men to be divorced by their spouse. Positive women are less likely than men to access services and treatment due to the lack of money, time, or transportation and are also less likely to have necessary financial resources when infected or affected by HIV resulting in greater likelihood of economic hardship and deepening poverty.

**Men's Vulnerability**

Like women, men are vulnerable to HIV because of prevailing gender norms and expectations. These norms and expectations often encourage risky behavior in men. For example, men are more likely than women to experience pressure to be sexually active before and outside of marriage. Men are more likely to have more sexual partners than women. Men are more likely to be injecting drug users than women. Men who have sex with other men, especially the receptive partners, are highly vulnerable to HIV infection. Men are also less likely than women to have access to sexual and reproductive health services and are therefore less likely to receive appropriate treatment for STIs. If a man is a victim of sexual violence, he is much less likely to report the violence and receive appropriate care. All of these factors render men vulnerable to HIV infection.

**Programmatic vulnerability: a gender analysis of AIDS programs**

While HIV/AIDS programs seek to provide the best services to their clients, the content of these programs will vary from place to place, culture to culture. Because they are designed within specific cultural and social contexts by individuals raised in those contexts, AIDS programs generally reflect prevailing gender norms, values and expectations of that particular society. Depending on the extent to which men and women are viewed as equals in society, these AIDS programs can either reduce or increase vulnerability to HIV. While in many countries women have equal legal rights, the prevailing culture may perpetuate beliefs that women are physically, emotionally and intellectually inferior.

Early in the epidemic most AIDS programs target “high risk groups” such as female sex workers and injecting drug users in HIV prevention efforts. There are many benefits to the targeted approach. Targeted programs have proven effective at limiting the spread of HIV by quickly getting the means of prevention (condoms and clean needles and syringes) to those known to engage in risky behavior. Often these are the only social services available to these highly marginalized, stigmatized and difficult-to-reach populations. These programs can also serve as entrée points for other important services such as drug rehabilitation. Where funding is limited, these programs focus valuable resources on the most vulnerable.
While targeted approaches are necessary and an essential component of an effective comprehensive response, targeted approaches alone are not sufficient to control the epidemic. The reasons for this failure include the following:

1) Targeted programs can create a false sense of security in those who do not self-identify as being members of a “high risk group.” While an individual may engage in high risk behavior (e.g. unprotected sex with many partners, occasional drug use), s/he may not be a sex worker or addicted or habitual drug user, may not consider her/himself at risk and therefore may not practice safe behaviors.

2) Many HIV/AIDS programs do not recognize the importance of extra- and pre-marital sexual behavior outside the commercial sex context to the spread of the epidemic, despite substantial evidence that such behavior exists. Unfortunately, the emphasis on preventing sexual transmission in the context of sex work has not addressed the growing numbers of people infected in other sexual relationships including casual relationships and within marriage, where most unprotected sex takes place and where condom use is uncommon, uncomfortable and often shameful and taboo. Furthermore, many AIDS programs have been slow to recognize and address the vulnerability of men who have sex with other men. Unfortunately, because of the efficiency of HIV transmission during anal sex, many men who have sex with other men are highly vulnerable to HIV.

3) Many women have been infected with HIV through sex with their husbands or long-term partners. Research has demonstrated the vulnerability of women within the context of marriage and other committed sexual relationships. Within these types of relationships, condom use is extremely rare and women’s ability to discuss and enforce condom use by their husbands inside or outside of marriage is very limited. As a result, in many settings where men engage in extramarital sexual relationships, monogamously married women are at risk. For men, their dislike of condoms and their reluctance to broach the subject of condom use with their partners also leaves them vulnerable to infection, especially in casual relationships in which the subject of condom use is unclear and uncomfortable to broach.

4) There remain large gaps in addressing prevention, treatment and impact mitigation needs for most women. Women lack access to preventive methods that they are able to control without the knowledge or consent of their partners. In most settings, the availability of women-controlled methods for HIV prevention is extremely limited. While the female condom is becoming increasingly available, it still remains expensive compared to the male condom even when reuse is taken into consideration. It is also a method that is difficult to use without the knowledge of a sexual partner. Microbicides, chemical barriers to HIV infection, are advantageous for several reasons including the ability to use them without a male partner’s knowledge. But they remain in the clinical trial stage and it could be several years before they are ready for widespread use. Many women who do not engage in sex work or drug use discover their HIV status only after testing positive during pregnancy. Most of these women are not targeted in prevention efforts as they are not considered members of a high risk group. The

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only AIDS program services available to them might be preventing transmission to their children through Prevention of Mother to Child Transmission (PMTCT) programs. While their children may benefit from PMTCT, women’s access to treatment for themselves is often limited.

5) Targeted AIDS programs can inadvertently cause stigma and discrimination because they associate HIV transmission with illegal and socially-defined immoral behavior. Many governments link HIV transmission with the already marginalized populations of sex workers and drug users. As a result, many people living with HIV/AIDS face tremendous stigma and discrimination. Because of prevailing gender norms and values, women living with HIV/AIDS often face even greater stigma and discrimination than men. In many societies, people will assume that HIV positive status in women is because of sex work and/or drug use, a more stigmatizing association for women than for men.

6) Targeted programs often perpetuate already existing gender biases particularly the false dichotomy of women into “bad” women (usually unmarried and sexually active) and “good” women (unmarried virgins and married women who have sex only within marriage). AIDS prevention programs tend to focus on female sex workers as vectors of disease with little acknowledgement of their vulnerability to HIV positive male clients. These programs also tend to implicitly blame sex workers and fail to recognize clients, the market, or larger socio-economic conditions that determine the HIV vulnerability of these women. Mothers and wives, on the other hand, are seen as innocent victims of their male partners’ sexual behavior with sex workers. Because of this gender bias, AIDS programs may perpetuate naiveté in “good” women and girls about sex, condoms or other preventive measures at the same time ignoring women’s pleasure, power and responsibility. Meanwhile, AIDS programs often accept risky male behavior (“boys will be boys”), but deny men’s vulnerability.

7) The response to HIV is most often led by health care providers who have little or no knowledge of gender, sexuality and rights. As a consequence, HIV/AIDS programs have primarily viewed sexuality through a clinical or disease lens. Often these programs do not address other sexualities including homosexuality, bisexuality or the needs of transgendered people. Public health programs that address sexuality often focus on the negative consequences of sexual behavior, including STIs/HIV, unwanted pregnancies, and abortion. The concept of healthy sexuality—sex that is pleasurable, equitable, and free of coercion, infection, and unwanted pregnancy—is a fairly new concept in sex education and in HIV and sexual and reproductive health programs. Innovative sexual health programs for youth have taken this approach with great success. While abstinence education for youth is an important component of youth sex education programs, provision of information on contraception and safe sex with condoms further reduces vulnerability to sexual health problems including STIs/HIV and unwanted pregnancy.

8) Many AIDS programs ignore the link between women, injecting drug use and sexual vulnerability to HIV. While many countries with widespread injecting drug use epidemics have implemented successful risk reduction programs, the focus of these prevention efforts has been primarily on male IDUs. Few programs reach women IDUs in terms of their injecting or sexual vulnerability within their relationships with their male drug using partners. Women IDUs may be targeted in prevention efforts but the focus is on access to and use of condoms within the commercial sex context rather than clean injecting equipment and condoms in their regular partner relationships.

9) AIDS programs often place the responsibility of prevention on already marginalized populations (female sex workers and IDUs) with no legal protection or their control over access
to condoms and clean needles and syringes. While sex workers and IDUs are often blamed for the spread of HIV, they are not often empowered to design and implement AIDS programs. Research has shown that when these groups are empowered to do so, their work is often more effective than if the program is run by the health sector alone. Peer education programs worldwide have proven highly successful at reaching these groups. This is because vulnerable people usually know more than AIDS program managers about their situations and abilities to protect themselves.

Reproductive and Sexual Health and Rights and HIV/AIDS

Reproductive and sexual health and rights are important components to HIV/AIDS programs. Reproductive and sexual health and rights are defined in a number of international documents including the platforms of action from the United Nations General Assembly’s Special Session on HIV/AIDS (UNGASS), the International Conference on Population and Development in Cairo in 1994 and the Beijing Women’s Conference in 1995. Reproductive and sexual rights include the right of all persons, free of coercion, discrimination and violence, to:

- the highest attainable standard of health in relation to sexuality, including access to sexual and reproductive health care services;
- seek, receive and impart information in relation to sexuality;
- sexuality education;
- respect for bodily integrity;
- choose one’s partner;
- decide to be sexually active or not;
- consensual sexual relations;
- consensual marriage;
- decide if and when to have children; and
- pursue a satisfying, safe and pleasurable sexual life.

The above rights are equally important for men and women; yet there is greater likelihood that the sexual and reproductive rights of women are violated because their contact with reproductive health programs is much greater. (For a more detailed list of rights, please see Women and AIDS: the Barcelona Bill of Rights, approved at the XIV International AIDS Conference in Barcelona, Spain in 2002).¹⁷

Many women discover they are HIV positive within reproductive health settings as a result of antenatal testing, often without their knowledge or consent. In addition to testing without consent, other rights abuses have occurred, including coerced abortion and sterilization of women who are HIV positive.¹⁸ ¹⁹

While antenatal HIV testing is often conducted to enroll women in Prevention of Mother to Child Transmission (PMTCT) programs, in some cases where treatment for HIV-positive people is not yet offered by the health care system, testing is sometimes performed to allay health care worker safety concerns rather than for providing care and support to HIV positive patients. This rationale for testing is flawed because a person may test negative for HIV but still carry the virus, particularly during the “window” period between initial infection with HIV and production of HIV anti-body. Yet, testing may not be uniformly conducted on all patients. For example, while women may be routinely tested during antenatal visits, other patients undergoing surgery or other treatment may not be tested unless the physician “suspects” the patient of drug use or sex work. Instead, health care settings should routinely employ universal precaution measures to ensure that patients and providers are protected. Universal precautions are internationally accepted procedures for handling patients in health care settings and in other settings in which workers may be exposed to blood and other bodily fluids (i.e. prisons). These procedures assume that all patients may be infected with HIV and other blood-borne pathogens. By employing universal precaution procedures health care settings ensure equal treatment to all patients and reduce the likelihood of stigma while at the same time addressing a very real concern of health care workers.

PMTCT programs seek to avert the births of HIV-positive children. In these programs, women are provided anti-retroviral therapy to prevent transmission of the virus to their children at birth. However, most women in PMTCT programs do not have access to antiretroviral therapy for themselves after they deliver their children. Prevention of HIV among newborns is a critical component of a comprehensive AIDS response; however, medical ethics as well as the right to the highest attainable standard of health demand that women have the same access to life-prolonging drugs in their own right. Fortunately, “PMTCT Plus” programs are being implemented in selected countries throughout the world. These programs provide ARV therapy to mothers and often to fathers and other members of the household who are HIV positive. This enables families to live healthy lives with HIV for as long as possible and to enable parents to care for their children.

Fortunately HIV positive people with access to anti-retroviral therapy (ART) are living longer reproductive and sexual lives and HIV is becoming a chronic disease managed by lifelong medication. Unfortunately, most AIDS programs ignore or may sometimes deny the right of positive people to a healthy sex life. Many programs instruct people living with HIV not to have sex at all. It is critical that programs and policies recognize and adapt to meet the growing reproductive and sexual health needs and rights of positive people. Comprehensive programs can provide HIV positive women and men with counseling and services that promote their right to healthy, safe, and pleasurable sexuality, their right to choose whether or not to have children, and the means to have them without transmitting the virus. However, with increased access to ART people living with HIV will have increased need for voluntary counseling and testing services and reproductive health care including contraception, safe abortion, infection prevention, fertility, safe conception, and PMTCT Plus.

Strategies to integrate a gender perspective into HIV/AIDS programs

In order to increase the effectiveness of HIV/AIDS prevention, treatment and impact mitigation programs, many policy makers are beginning to integrate a gender perspective. The International Center for Research on Women (ICRW) recently reviewed efforts in policymaking, program implementation and research to highlight ways in which HIV/AIDS programs can better address gender, sexuality and rights and therefore be more effective. The result is a continuum of effective interventions from the most minimal to the most engaged on issues related to gender power dynamics and addressing the determinants of vulnerability.22

Stage One: At the first stage on the continuum, the main principle is to “do no harm.” This stage eliminates gender stereotypes that reinforce vulnerability and damage men’s and women’s ability to benefit from the program. Examples of interventions at this stage include:

- Sex education programs that remove gender stereotypes and scripts that depict and reinforce women and girls as passive sexual victims and men and boys as sexual aggressors.
- HIV treatment programs ensure that women and men have equal access (including opportunity, resources, etc) to anti-retroviral therapy programs.
- HIV/AIDS programs that ensure reproductive rights of women and men are protected.

Stage Two: The next stage along the continuum incorporates gender sensitivity into HIV/AIDS programs. This stage requires that HIV/AIDS programs recognize that prevention, care, and treatment needs of men and women are often different due to physiology and socially constructed gender roles. Examples of these types of interventions include:

- Development of female controlled methods such as the female condom and microbicides;
- Integration of STI diagnosis and treatment into reproductive health services; and
- Programs that address men’s vulnerability.

Stage Three: In the third stage of the continuum, interventions transform social and cultural values about gender. These programs work with men and women to redefine gender norms and encourage healthy behavior. Examples of interventions at this stage include:

- Programs that work with women and men to examine gender, sexuality and sexual behavior and their impact on sexual health as well as programs that foster gender-equitable masculinity and femininity. Most often the focus of these interventions is the couple rather than the individual alone. Some of these programs are addressing gender-based violence.
- Youth healthy sexuality programs that promote sexual behavior and sexuality that is pleasurable, equitable and free of coercion, infection and unwanted pregnancy.

Stage Four: Interventions in the fourth stage of the continuum address structural factors to create an enabling environment through empowerment. These interventions equalize the balance of power between men and women within an overall context of social and economic development. Examples of these interventions include programs that enable women and men to access:

- information, education and services;

- resources and assets; sources of credit; property inheritance; formal sector employment with equal pay for equal work;
- political and social capital; leadership at community and social levels; and
- protection and fulfillment of human rights.

**Take Home Messages and Action Points**

Imbalances of power between men and women lead to differences in vulnerability to HIV and the ability to access effective prevention, care, treatment and impact mitigation programs. On the whole, women and girls are more vulnerable to HIV/AIDS. Understanding sexual behavior and gender power dynamics is essential to effectively addressing the epidemic.

Gender power dynamics influence the ways in which programs are designed and implemented. Yet, there remain critical gaps in the AIDS response. These include gaps in prevention for women and men not engaged in sex work or drug use, gaps in access to treatment, lack of protection of reproductive and sexual rights, especially for positive people and the lack of comprehensive sex education and services for young people.

**Action Points:** Various sectors can take action to ensure that gender is addressed and thereby increase the effectiveness of HIV/AIDS programs. These actions include the following:

- All HIV/AIDS programs and policies must take into consideration gender issues and gender differences and plan accordingly in the short, medium and long-term. It is important to ensure gender equity is a major component of AIDS programs and integrate gender perspectives into all programs and policies. Specific interventions should be implemented to address gender power dynamics in sexual relationships, particularly regarding safe sex, condom use, healthy sexuality and decision-making in sexual matters.
- In order to do the above, AIDS programs need to learn more about gender and sexual behavior dynamics in specific cultural contexts through high quality social science research. Research should be designed to inform policy makers about these issues and to provide concrete recommendations for addressing them in programs and policies.
- There is an urgent need to integrate HIV/AIDS and reproductive and sexual health services for women, men and youth, including the need to offer safe sex counseling, contraception, abortion, fertility assistance and referral to PMTCT services.
- AIDS programs need to understand and address the needs and rights of HIV positive people by ensuring participation in AIDS program and policy development, implementation and evaluation, reducing stigma and discrimination, enabling reproductive and sexual health choices, and increasing access to anti-retroviral drugs.
- Much more should be done to support men’s efforts to address their own sexual vulnerability in positive and affirming ways, develop sexual health services for men, address their responsibility in acts of violence against women, and promote a positive approach among men to women’s empowerment.

- AIDS programs targeting injecting drug use must recognize the special needs of women injecting drug users in terms of both their injecting and sexual vulnerability through programs that employ women as peer educators and that provide clean needles and syringes, condoms and sexual and reproductive health care. At the same time, these programs need to work with male IDUs to reduce both their and their sexual partners’ vulnerability.
Finally, all of the above must take place within an enabling social, cultural, economic and political environment that supports the ability of individuals to engage in healthy sexuality that is pleasurable, equitable and free of infection, coercion and violence; equitable access to resources and assets; and engagement in decision-making, political participation and leadership. This is especially important for women, girls and marginalized groups whose historic participation in such processes has been weak or non-existent.
III Strategies for Formulating a Multi-Sectoral Response to HIV/AIDS

CHAPTER 6: HIV/AIDS, LAW AND RIGHTS

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Using Rights for Analysis: Vulnerability and HIV/AIDS

The purpose of this session is to introduce the concept of vulnerability and its links to HIV/AIDS and human rights. The vulnerability concept has been key to the work of UNAIDS and its partners, because unless stigma, discrimination and human rights are understood in the context of HIV programs, no matter what services and resources are available, behaviors will remain unchanged and services will be underutilized.

From a public health perspective, vulnerability links to notions of risk and to the individual and collective factors that determine the likelihood of being exposed to HIV through risk-taking behaviors or risk-generating situations, and once infected, to the probability of being denied appropriate care, support and treatment. Paying attention to vulnerability in the context of prevention means linking risk and vulnerability to the factors that influence risk, at the individual, programmatic and societal level.

A vulnerability analysis means recognizing that in addition to risk behaviors, a person’s likelihood of becoming HIV-infected is influenced by individual, programmatic and societal factors, all of which affect the way people can access services, or make free and informed decisions about their lives. Which leads to human rights, and means recognizing that individually and collectively, the individual, programmatic and societal factors that are relevant to vulnerability and to a person’s likelihood of becoming infected with HIV and once infected, of receiving adequate care, support and treatment are influenced by economic, social, cultural and political factors. Therefore, all rights: civil, political, economic, social and cultural, and how they are respected, protected and fulfilled, is relevant to who gets infected, and what is done about it.

Controlling and mitigating the impact of HIV requires traditional risk-reduction strategies such as condom promotion, but also policies and programs that consciously set out to reduce vulnerability to help ensure that if condoms are made available they will be utilized.

Therefore, we must look not only at traditional public health markers like information, education, and services, but also civil, political, economic, social and cultural factors like gender relations, religious beliefs, homophobia, racism, and their impact on the extent to which individuals are able to access services or make and effectuate free and informed decisions about their lives and therefore on their vulnerability to becoming infected. The idea is then to connect vulnerability to discrimination and to the other human rights dimensions, both as a method of analysis and a framework for action.
HIV/AIDS, Health and Rights: Core Concepts, Documents, and Institutions

Human rights concern the relationship between the government and people as individuals or groups within its jurisdiction. Governments usually have prime responsibility for public health. In serving their goals, therefore, countries need to combine sound public health practice with the fulfillment of their obligations towards human rights.

The overall objective in integrating human rights & health is to reach a "win-win" situation: to foster the strongest mutually reinforcing interaction between the promotion & protection of health and the promotion & protection of human rights.

This process of "optimizing the balance" requires skill-building, analytical tools and guides. All work in HIV/AIDS policies and programs should recognize the synergy and ability to make more effective HIV/AIDS programs through their work.

The two basic ways in which HIV/AIDS and human rights relate are:
1) The impact that HIV/AIDS policies, programs, legislation and practices have on human rights.
2) The impact that the neglect or violation of human rights has on vulnerability to becoming infected, and once infected, on ability to access needed care and support.

A rights-based approach to HIV/AIDS refers to the processes of a) using human rights as a framework for policy and program development, b) assessing and addressing the human rights implications of HIV/AIDS policies, programs and legislation and c) making human rights an integral dimension of the design, implementation, monitoring and evaluation of HIV/AIDS related policies and programs.

What are the practical implications of integrating human rights into HIV/AIDS-related work?

First, since human rights norms and standards have been generated by the governments of the world, through a consensus-building process, they provide an authoritative standard against which to assess national level HIV/AIDS policy and practice. Second, human rights provide an analytical framework to identify the societal determinants of risk and vulnerability to becoming infected with HIV/AIDS (e.g. discrimination against various population groups). Third, since human rights include the obligations of all sectors of government, this facilitates engagement with a range of partners within government including the Ministry of Health, the Ministry of Justice, the Ministry of Education, Women's Affairs, etc, as well as civil society.

Countries have found benefits in using human rights as a tool for work in public health. They are the first responsibility of governments, and encompass civil, cultural, economic, political, and social dimensions. They thus provide an inter-sectoral framework to address HIV/AIDS across a wide range of health and social determinants.

Note that in this course the focus is not on rights for advocacy purposes or to identify violations, but on human rights as they have been effective in strengthening the work of governments to respond to HIV/AIDS.

HIV/AIDS impacts peoples' lives in three ways: 1) People are infected with HIV; 2) People are affected by the impact of HIV/AIDS on their families and communities; and 3) People are vulnerable to the risk of becoming infected and, once infected, of accessing needed care and support.
HIV/AIDS strategies must therefore include attention to: prevention, care and treatment, and impact mitigation. All three of these elements must be included. The balance will vary by country and community, but each is necessary for a comprehensive response to HIV/AIDS.

Human rights have been understood as fundamental to the response to the epidemic since the beginning. Human rights have been integrated into HIV/AIDS work since the initial WHO global response to HIV/AIDS not only because human rights are the legal obligations of governments but also because they are critical to effective HIV/AIDS programming.

Human rights are used in a number of different ways by different actors: as grounds for making policy and program decisions; to analyze what a government is or is not doing, and as an advocacy tool. Given these differences, it is always important to be clear how rights language is being used and for what purpose. In our work together, we will focus on how human rights can be a tool to help government do their job better.

*What are Human Rights?* International human rights law defines what governments can do to us, cannot do to us, and should do for us. Human rights law is meant to be equally applicable to everyone, everywhere in the world, across all borders and across all cultures and religions.

Human rights are universal, interrelated and indivisible. Human rights are primarily about the relationship between the individual and the state, and international human rights law consists of the obligations that governments have agreed they have in order to be effective in promoting and protecting our rights.

*Key Documents.* The International Guidelines on HIV/AIDS and Human Rights are the product of the Second International Consultation on HIV/AIDS and Human Rights, organized jointly by the United Nations Office of the High Commissioner for Human Rights and the Joint United Nations Programme on HIV/AIDS (UNAIDS). They provide an important means for supporting both human rights and public health, emphasizing the synergy between these two areas. These guidelines offer concrete measures that could be taken to protect human rights and health where HIV/AIDS is concerned. The measures in the guidelines follow three broad and interconnected approaches:

1) improvement of governmental capacity for acknowledging the government's responsibility for multisectoral coordination and accountability;
2) widespread reform of laws and legal support services, with a focus on anti-discrimination, protection of public health, and improvement of the status of women, children and marginalized groups; and
3) support for increased private sector and community participation in the response to HIV/AIDS, including building the capacity and responsibility of civil society to respond ethically and effectively.

The United Nations Declaration of Commitment on HIV/AIDS is a key policy document for work in HIV/AIDS. China and Vietnam, along with other governments of the world, have committed to report periodically as to how it is advancing its work in prevention, care and treatment, and impact mitigation according to the indicators agreed to. It is a useful document for highlighting the many facets that need to be considered in effectively responding to HIV/AIDS.
Human Rights Obligations. The obligations of governments with respect to human rights include three components:

1) To respect a right means not to directly violate it.
2) To protect a right means enacting laws and setting up mechanisms to prevent violation of the right by non-state actors and to provide redress if the right is violated.
3) To fulfill the right means to take active steps to put in place laws, policies, resources, institutions and procedures that will enable people to enjoy the right.

The human rights machinery recognizes that resource and other constraints can make it impossible for a government to fulfill all rights immediately and completely. Therefore, realization of rights is generally understood to be a matter of “progressive realization” of making steady progress towards a goal. In practical terms, a commitment to rights in the context of HIV/AIDS requires more than passing good laws. It will require financial resources, trained personnel, facilities, and, more than anything else, a sustainable infrastructure. Governments are encouraged to set their own benchmarks and targets in this regard.

Restrictions on Rights. Rights are not absolute and they may be limited. Public health is a valid justification for restricting most rights. For example, interference with freedom of movement when instituting quarantine or isolation for a serious communicable disease is a restriction on rights that may be necessary for the public good, and therefore could be considered legitimate under international human rights law. The basic steps that must be considered before rights can be legitimately restricted are spelled out in the ‘Siracusa Principles’.

The principle of non-discrimination. Non-discrimination is a key concept in human rights. It means treating all people with dignity and respect but it does not mean treating all people the same. It can exist in law or practice, but key is that discriminating against people on the basis of their difference is strictly prohibited.

The Application of Human Rights to Health Policies and Programs
In order to enable them to design and implement more effective policies and programs, policymakers must be able to recognize the ways in which rights are relevant to HIV/AIDS policies and programs.

The following methodology attempts to maximize both the public health and human rights quality of HIV/AIDS policies and programs. The methodology includes four steps:

1) consideration of the extent to which a policy or program represents good public health.
2) consideration of the extent to which it is respectful of and promotes rights.
3) consideration of how to get the best balance between public health goals and rights.
4) assessment of whether once the balance is established this is the best approach for dealing with the public health goal it seeks to address.

The assumption is that generally a program or policy, which is respectful of rights, while still achieving its public health goal, is going to be better than one that limits or restricts rights. First, consider the extent to which the policy promotes and is good for public health. The list should include such elements as effectiveness, coverage, feasibility, cost, community involvement, etc. Consider the public health problem being addressed; the goal of the proposed action; the public health quality of this intervention. Is it good public health?
Second, consider the rights aspect of the policy. Determining the human rights value of a policy or program can be done by considering each of the rights in the Universal Declaration of Human Rights and determining for each right if it is positively or negatively impacted, or irrelevant. Consider the following: How serious is the public health problem? Is the proposed response likely to be effective? What is the severity, scope, and duration of the burdens on human rights resulting from the program? To what extent is the program restrictive and intrusive? Is it over-inclusive (too broad) or under-inclusive (too narrow)? What would you propose to reduce the burden on human rights? How would you improve its human rights quality?

Third, consider again the public health quality of the policy. How would you improve that? What does improving the human rights aspects of the policy do to the public health? Improve it or worsen it?

Policies and programs which respect rights are actually better and more effective. Human rights and public health concerns are not incompatible. Considering human rights in the design, implementation or evaluation of HIV/AIDS policies and programs is useful for determining if policies and programs promote or violate rights, and for judging their effectiveness. Public health decisions are often made for political expediency, without consideration of their effects on human rights, and even to some degree their effect on public health. People working in public health have a responsibility to look at whether human rights are promoted, neglected or violated by actions taken in the name of public health.

Links to government that exist for anyone working in public health, whether as an agent of the state or because they receive government funding, impose a dual obligation to promote and protect health, as well as to promote and protect human rights. People working in public health have the power to decide to restrict rights, so this responsibility has to be taken seriously.

Evidence has shown that there are negative long-term consequences of policies or programs that violate rights, in that they make it harder for people and communities to trust the value of HIV/AIDS policies or programs more generally.

**Recommended Readings:**


Strategic Management and Leadership

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The multi-faceted nature of the HIV/AIDS problem means that diverse professions and organizations must collaborate if response is to be effective. No single organization is in charge of the full range of functions involved; these are lodged in agencies and organizations of many types and at several levels – national, provincial, and local. Building and improving programs to prevent, treat, and mitigate HIV/AIDS therefore requires skillful leadership and management of institutions in efforts that reach across organizational boundaries.

Strategic Management

Leaders who wish to take action effectively on HIV/AIDS must first think strategically about what they wish to accomplish (value); what resources, authority, and backing they can develop (support); and what their own organization and its partners are able to accomplish (capacity).

The “strategic triangle” is a conceptual framework used to organize thinking about how a specific policy “actor” or “player” can pursue a policy objective from a particular institutional location. For example, one might analyze the strategic position as seen from the perspective of a provincial health department leader, or a national minister, or a local public security official. This vantage point may be higher or lower in the hierarchy of government, or it may look across government functions from a particular functional vantage point.

No matter what perspective is adopted, the components of the analysis are similar. One assesses value, support, and capacity.

• By value, we mean the set of purposes or impacts that programs and policies are striving to achieve. In the HIV/AIDS case, these might include (but not be limited to) health impacts (e.g., by prevention of the spread of the disease and treatment to care for those stricken); mitigation of harmful impacts (on the health care system or on children or other dependents of infected people); avoidance of future budget obligations (for HIV/AIDS prevention, treatment, or mitigation); avoidance of negative economic impacts (e.g., death or disability of skilled workers or damaged reputations of a community or province); etc.

These values may or may not be consistent with each other, perhaps requiring tradeoffs. Different values, moreover, may be more or less important (or wholly irrelevant) to some stakeholders; and various stakeholders are likely to prioritize the set of values in different ways. Therefore, strategic positioning may involve sorting out, prioritizing, and reconciling the set of values involved.

• By support, we mean the positive or negative orientations of important stakeholder groups toward the values (see above) involved. Critical to appraising the level of support are (1) the perceived legitimacy of a given program or policy (whether stakeholders regard it as appropriate and desirable) and (2) the willingness of stakeholders to supply needed resources (e.g., legal authority, funds, expertise, political backing) to make action possible.

Assessing support requires disaggregating the set of key stakeholders (which, depending on one’s purposes, may be conceptualized as either organizations or key people) and probing their
attitudes and motivations in relation to the policy or programs in question. In this realm, as well as in the value area, stakeholders may be in conflict or have inconsistent priorities, or they may agree.

• By capacity, we mean the mobilization of operational resources that are available to take action on the policy or program. This capacity may reside in a single organization (e.g., a health department), but in many circumstances the necessary capacity is located in more than one agency or mass organization, perhaps even at more than one level of the system.

Therefore, assessing capacity may require looking at networks of organizations to see whether they have adequate personnel, funds, expertise, and overall operational ability to carry out necessary activities to achieve program or policy purposes. When networks of organizations are involved, analysis of capacity importantly must focus on the linkages between organizations as well as their internal capabilities.

Strategic Alignment or “Fit.” In assessing strategy, it is not enough to assess value, support, and capacity independently. They are dynamically linked and interdependent.

The Strategic Triangle:

- **Value**: What can be produced that will be socially useful?
- **Support**: What will stakeholders approve and provide resources for?
- **Capacity**: What resources can be used to produce value?

A first step toward assessing this interdependence is to analyze whether each element is compatible with the others. To achieve a specified set of program purposes or value, is there enough support from stakeholders to sustain action? (Support does not have to be unanimous, merely sufficient to accomplish desired purposes.) For the same purposes or value, is operational capacity (within a single organization or a network of organizations) sufficient?

When all elements of the triangle are compatible, we can say that these elements are aligned or fit together. Said another way, an aligned strategy represents a program or policy that is SIMULTANEOUSLY:

- Substantively valuable (value)
- Politically feasible and sustainable (support)
- Administratively and operationally feasible (capacity)

Often a strategy is NOT aligned, however. One or more elements of the triangle may be incompatible with others. For example, a desired policy may be well defined in its goals and have ample support but still not be viable because of inadequate capacity to carry it out. Or an organization may have sufficient capacity to carry out a policy but not have agreement from key stakeholders that it is a legitimate action to take.
When the strategic triangle for a particular policy or program is misaligned, the situation creates pressure for one or more element to change. For example, inadequate budget support to sustain the capacity to run a program will create pressure either to increase the budget or to cut back program purposes to the point that existing capacity and support allow effective performance. Change may occur in one direction or another, but the situation is not strategically stable if the triangle is misaligned or lacks fit.

**Change Over Time.** Even when a program or policy is strategically aligned at one point in time, change in one element of the strategic triangle or another may affect its future stability. This change may be generated by internal factors – e.g., a change in public attitudes or the departure of key personnel – or it may be caused by external factors – e.g., fiscal stringency or the emergence of a new infectious disease like HIV/AIDS.

The value of the strategic triangle as a conceptual framework is that analysts can think about whether the elements of program success are present and, if they are not, assess what kinds of changes must be sought to create strategic alignment. This assessment can be applied to a current time period (how well is strategy aligned today?) or to a time in the future (will conditions five years from now result in misalignment?). Assessment of **WHY** a strategy is misaligned, moreover, leads naturally to consideration of **HOW** the situation might be adjusted to create a better fit.

**Case Study Analysis.** To illustrate the utility of this conceptual framework, class discussion will apply it to the problem of HIV/AIDS policy in a county government in China, as described in the case study that will be assigned.

**Stakeholder Analysis**

Stakeholder analysis is a fundamental tool used to identify and "map" the system of organizational and key individual "players" who are important in a given policy development or implementation situation. It allows the analyst to develop methods to assess these players' motivations, resources, likelihood of participation, and influence in this situation – and to identify the particular "action pathways" in which they are involved.

**Case Study Analysis.** Stakeholder analysis will be applied to the case study described above. In class discussion, we will identify:

- The set of individual and organizational actors who are key players in HIV/AIDS policy,
- What interests and attitudes they bring to this policy arena and therefore how they are likely to act,
- Why their orientations matter in HIV/AIDS policy – i.e., what resources and power they bring to bear, and
- The action pathways – i.e., the decision-making or operational spheres – in which they participate.

The relationships identified will then be "mapped" graphically to provide a heuristic device for more sharply focusing and considering political and institutional relationships in HIV/AIDS policy and program implementation.
Change Management

Given a particular strategic position and configuration of stakeholders (as explained in the parts above), a leader must develop a plan of action for purposeful change. Change is not always positive in social systems; but in the HIV/AiDS policy systems in China and Vietnam, for example, it is essential to alter the status quo in new directions of policy and program effort. How can the process of change be understood? How can leaders take effective action?

A conceptual framework identifying the stages of organizational change will be introduced and discussed in the context of the case study (described above). This framework sees change generated initially by exogenous events or social trends that are perceived by a key leader in an organization or policy system who thereby sees the need for adopting new goals or practices. (Strategically, this may be perceived as a need to modify the value being pursued, increase or reconstitute support, or build new operational capacity – or some combination of these elements.) But that change orientation is likely to encounter resistance along two dimensions: (1) organizational and (2) personal.

Organizational resistance may be of three main types: technical, political, or cultural.

• Technical resistance is connected to proposed new organizational processes – that go counter to established methods of carrying out operations – and/or to the introduction of new technology.

• Political resistance stems from change in decision-making, allocation of resources, and the balance of organizational power among individuals or occupation/professional groups.

• Cultural resistance stems from alterations in organizational values, accepted orientations toward stakeholder groups, or internal threats to the prestige of individuals and groups.

In addition, individuals may exhibit personal resistance that comes from psychological commitments to past ways of conceptualizing a policy problem, their own values, or their concerns about being able to adapt to a future that has been altered from past practice.

How then can a leader drive change in the organization? Three stages of change are identified at the organizational level, with parallel personal/psychological changes occurring in individuals:

• Creation of a vision of a desired future state. A leader cannot simply request or demand support for change. Instead, s/he must articulate a coherent picture of what a changed organization would look like so that members of the organization and its stakeholders will be motivated to commit their efforts to achieving that vision. This vision does not have to be extremely precise – and can it be elaborated over time; but it does have to provide motivation on each of the dimensions that can engender resistance. Organizationally, this vision must be sketched out so that its technical, political, and cultural implications are well understood. At a personal level, members of the organization must begin to give up past expectations and commitments and become ready to form new ones.

• Mobilization of commitment. Once a vision of the future is presented, a leader must take steps to transform the motivation of organizational members into action to implement that vision. Mobilization of effort must also occur and personal.

• Institutionalization. No change is complete until it has become firmly rooted in the organization’s practices and orientation. The process of institutionalization involves embedding the new programs or practices in the daily work and attitudes of the organization. Again this must occur along the organizational dimensions that can
engender resistance – technical, political, and cultural – as well as engender strong psychological commitments to the new orientation by those engaged.

**Recommended Readings:**

Leonard, Herman B. “A Short Note on Public Sector Strategy-Building” (Cambridge: Kennedy School of Government, Harvard University, 2004(?)).

Mark Moore, *Creating Public Value* (Cambridge: Harvard University Press, 1995), Ch. 3.

CHAPTER 8: THE BUSINESS RESPONSE TO HIV/AIDS

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Background
The private sector has a unique role to play in global and local responses to HIV/AIDS by bringing to bear its unique assets and competencies. There are substantial risks posed to businesses by HIV/AIDS and ethical and financial motivations for businesses to proactively respond. This module outlines international guidelines for workplace policies and international and local best practices in workplace HIV/AIDS interventions, including prevention, education, and awareness activities, voluntary counseling and testing, and care, support and treatment. Opportunities for businesses to intervene beyond the workplace include activities directed at the larger communities to which their employees belong, encouraging and incentivizing proactive responses to HIV/AIDS among suppliers and distributors, and participating in collective activities of regional business coalitions or industry-specific efforts. There are advantages and opportunities for public private partnerships in responding to AIDS that can contribute substantially to improved global and national level AIDS programs.

Risks posed to business by HIV/AIDS
HIV/AIDS is a threat not only to households and firms, but also to national and regional economic growth and development. In high-prevalence countries, the loss of skilled and experienced workers due to illness and death can cause productivity to fall just as business costs are rising due to increased retraining and hiring costs. The loss of skilled workers and managers may not only undermine short-term productivity but threaten the longer-term ability of nations to deliver essential goods and services. UNAIDS predicts that the size of the labor force in high-prevalence countries will be 10–30% smaller by 2020 than it would have been without HIV/AIDS.

Tax revenue and foreign investment may be undermined—potentially disastrous setbacks for economic development in many high-prevalence countries.
HIV/AIDS has a disastrous impact on the household level: the disease threatens the livelihoods (and therefore the savings and consumption) of workers and those who depend on them.

Workers in the informal economy—the main source of employment in many developing countries, and in most parts of the Asia-Pacific region—are particularly vulnerable to the epidemic’s impact due to the precarious nature of informal employment, the lack of social protection and limited access to health services.

The Global Business Council on AIDS and the Futures Group have developed a modeling tool to provide a preliminary assessment of the costs from HIV/AIDS to companies operating in heavily affected regions (available at www.businessfightsaids.org).

Risks to businesses from HIV/AIDS will depend on:
• existing levels of HIV/AIDS within the workforce and surrounding communities

23 Action against AIDS in the workplace. Asia Pacific Region, UNAIDS.
• costs to the company of HIV/AIDS-related employee absence and death (absenteeism, recruitment, training, reduced productivity etc.)
• costs to the company resulting from hospitalization, home care and any existing prevention activities

The Business Case for Responding to AIDS
Even for low-cost companies, investments in HIV/AIDS prevention and treatment can have positive financial returns. HIV/AIDS interventions are a core investment in human capital. They will have positive financial, social, and ethical returns for many (perhaps most) companies. These returns include:
• retaining workforce skill and experience
• reducing impacts on morale and cohesion
• maintaining social stability in the surrounding community.

A study of six South African companies used an analytical framework that broke the costs of HIV/AIDS into four categories: the direct and indirect costs to individuals, and the direct and indirect costs to organizations. The study found the aggregate cost of infections in skilled workers reaching nearly 12% of total annual wages and salaries. Results of this study strongly support the case for companies to invest in a response to HIV/AIDS, because it showed that the net present value of the return on such investments is much higher than the cost of those investments.24

The same study found even greater returns to the company of investing in prevention.

Workplace Responses

A. Workplace Policies
A workplace policy on HIV/AIDS is the first step in a company’s HIV/AIDS response.

Workplace HIV/AIDS policy typically addresses the following areas: (i) non-discrimination; (ii) confidentiality and disclosure; (iii) benefits; and (iv) hiring and firing. Most policies include some form of the following key statements:
• Employees will not be dismissed because of HIV status.
• Company will not conduct pre and/or post employment HIV testing.
• Employees are not required to disclose status.
• If status is disclosed it cannot be disclosed to others without prior consent of the employee.
• HIV/AIDS employees are entitled to the same privileges and benefits afforded to all other employers

B. Workplace Programs
Companies may also mount workplace programs for prevention and treatment.

24 Corporate Responsibility in a World of AIDS: The Economic Case for Investing Now, presentation by Lora Sabin, BU CIHD, 5 Nov 2003
1. Prevention, Education, Awareness

Workplace HIV/AIDS prevention programs for workers are mainly focused on the provision of information about risks and risk reduction behaviors, making voluntary testing available either at the workplace or through referral to outside testing locations, and the provision of condoms.25

Prevention, education and awareness workshops and training programs typically cover the following themes and issues:

1. basic medical facts about HIV/AIDS (ie. dispelling myths and misunderstandings)
2. modes of HIV transmission
3. risk reduction behaviors (ie. abstinence, monogamy, condom use, STI diagnosis and treatment)
4. company policy regarding HIV/AIDS
5. how to access support and treatment (ie. on-site and community resources)

In some places, prevention activities can be more acceptable if linked to a wider range of health and prevention issues. This was true for Coca-Cola in Egypt where the conservative society was more receptive to a campaign which included other contagious diseases.

Accra Brewery started a program where condoms are included in monthly employee pay packs. Managers had observed that embarrassment obtaining condoms directly from the company and from vending machines led employees to avoid using condoms. By giving workers each an equal allowance of condoms, Accra was able to increase condom use while helping employees to retain anonymity.

2. Workplace HIV Testing

VCT, or “voluntary counseling and testing”, typically includes pre-test counseling, HIV testing; and post-test counseling. The International Labour Organisation’s Code of Practice on HIV/AIDS and the world of work advocates that HIV/AIDS screening should never be compulsory for workers or job applicants. Instead of mandating HIV testing, companies should encourage workers to access VCT provided through workplace programs or at off site VCT facilities. Most company VCT programs offer free VCT for employees, either through on-site VCT resources or through referral to off site testing facilities, both covered by the company medical scheme. On site VCT centers can be located in hospitals, clinics, and medical stations and are often staffed by counselors and medical staff trained by the company. Off site testing may be more attractive to employees who desire anonymity. If on site testing is provided, there must be assurance of confidentiality.

3. Care, Support, Treatment

Care and treatment programs can be provided for workers and their families and their communities. Programs can include antiretroviral therapy (ART), treatment of opportunistic infections, palliative care, home-based care, psychosocial support, and nutritional and lifestyle counseling:

Other possible care and support provisions include:

- Paid time-off for health-related appointments.

25 Bloom et al.
• Assurance of continued employment
• Financial and insurance assistance
• Short and long-term leave
• Reassignment to a less physically demanding position or change from full-time to part-time employment (e.g. job sharing)
• Making condoms available (partnership with the government and/or NGOs) for secondary prevention on HIV infected workers.

Some examples of workplace AIDS treatment and care programs offered by companies include:

BarloWorld, a company operating in Durban, South Africa, offers a medical aid scheme for its HIV positive workers. The program includes a care program for employees and their dependents, consisting of primary health care, counseling and vitamin boosters. The availability of these services helps to encourage employees to undergo testing and reveal their HIV status.

DaimlerChrysler’s South Africa operations has allocated funds to support medical care for HIV-infected employees and their family with the help of a grant from GTZ, the German bi-lateral development aid program.

Rohm Apollo Electronics in Thailand financially supports HIV-positive employees who become ill and allows them to change to other positions in the company to facilitate their ability to continue working for as long as possible.

The Role of Business Beyond the Workplace
Some companies have extended their prevention, treatment and support programs beyond the workplace, to the communities they work in or to the home communities of their workers.

Some companies have extended their education and awareness activities to the communities in which they do business, making prevention information available in local bank branches (Old Mutual) and gas stations (BP?), or by using company billboards or buses to promote prevention messages. Some companies have identified a specific need in their local community and directed their resources to addressing that need, sometimes in partnership with an NGO, local organization, or local government. Examples include sponsored training/awareness programs for local teachers and school children, as a way of preventing the future spread of HIV in the communities in which their customers and employees live. Chevron-Texaco partnered with the local public health system to modernize blood bank facilities, in an effort to augment the public sector’s capacity to eliminate this mode of transmission, a major infection route in the community where they were located. Larsen and Toubro, an Indian engineering firm used advertisements on the company’s fleet of buses and ran newspaper articles to raise AIDS awareness among employees families in the community where it worked. Later, in an effort to extend their response beyond their own workplace and workers, the company then invited other businesses in the region to an HIV/AIDS roundtable.

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26 Company Actions on HIV/AIDS in the Durban Metropolitan Area, HEARD www.und.ac.za/und/heard
A. Supply/Demand Chains:

Some large companies with global supply networks and distributors have extended HIV/AIDS programs to their business networks. The Body Shop developed its own HIV/AIDS policy and awareness training for employees in the 1980’s. As part of the company’s promotion of fair trade practices to its network of suppliers it also saw the need to address HIV/AIDS in high prevalence countries. Get Paper in Nepal and Teddy Exports in India are two resulting programs. Each has gone beyond the usual level of business involvement in HIV prevention, treatment and care in their communities, resulting in the creation of independent Trusts that raise funds and deliver services that would not otherwise be available in their regions.

Metropolitan and AIA, two life insurance companies pioneered integrated product development and innovative marketing to place life insurance coverage within reach of PLWHA and to advocate HIV/AIDS treatment as a crucial part of a corporation’s HIV/AIDS response. They rewarded customers (companies) who complied with specific HIV/AIDS workplace standards by giving them a bonus on insurance rates.

B. Coalitions/Industries:

Business Coalitions and trade unions can also play an important role in supporting and promoting a proactive business response to HIV/AIDS. For example, the Asian Business Coalition on AIDS is an alliance of corporations that promotes the development of workplace policies on HIV/AIDS, education and prevention programs, and access to health care and support facilities for affected employees. The Vietnam Chamber of Commerce and Industry has developed guidelines on HIV/AIDS prevention and care for both foreign and domestic companies operating in the country. The Chinese Business Coalition on AIDS is promoting the development of workplace policies and programs among multi national companies working in China and trying to extend its influence to Chinese companies as well. The Philippines Trade Union Congress created a network of health centers to provide members with counseling, testing and treatment associated with reproductive health, including HIV/AIDS.27

At a global level, the International Organization of Employers (IOE) and the International Confederation of Free Trade Unions (ICFTU) have developed policies and training materials for their members. The Global Business Coalition on HIV/AIDS and the Global Health Initiative of the World Economic Forum promote and support action by companies against the epidemic. The International Labour Organisation consulted widely with governments, employers, and workers, to develop a Code of Practice on HIV/AIDS and the world of work. It identifies the following key principles:

1. Recognition of HIV/AIDS as a workplace issue
2. Non-discrimination
3. Gender equality
4. Healthy work environment
5. Social dialogue
6. Prohibitions against screening for purposes of exclusion from employment or work processes
7. Confidentiality
8. Continuation of employment relationship
9. Prevention
10. Care and support

27 Action against AIDS in the workplace. Asia Pacific Region. UNAIDS.
This document provides practical guidance for developing national and workplace policies and programs to combat the spread of HIV and mitigate its impact; it informed the development of the Malaysian Code of Practice on the Prevention and Management of HIV/AIDS and the Thai Code of Practice on the Prevention and Management of HIV/AIDS, among others.  

Public-Private Partnerships

Many companies decide that partnering with other organizations is their best course of action, rather than building extensive new internal capacity to carry out workplace or community based AIDS programs. Such an approach allows companies to leverage expertise and experience of other organizations.

Examples of successful partnerships between businesses and outside organizations in the fight against HIV/AIDS include:

1. **Business + Government + Foundation.** One example of a public-private partnership formed to address HIV/AIDS is the African Comprehensive HIV/AIDS Partnerships. ACHAP was established in 2000 by the Government of Botswana, The Merck Company Foundation/Merck & Co., Inc. and the Bill & Melinda Gates Foundation to support and enhance Botswana's response to the HIV/AIDS epidemic through a comprehensive approach to prevention, care, treatment and support. The Merck Company Foundation and the Gates Foundation each committed $50 million to the initiative. In addition, Merck is donating its antiretroviral (ARV) medicines to Botswana's national ARV therapy program for the partnership's duration.

2. **Business + NGO.** Yahoo! partnered with an NGO to develop public awareness of the need for an AIDS vaccine, supporting a campaign by the International AIDS Vaccine Initiative, IAVI. Through banner ads and emails the campaign sought signatures from the public for a Global Call to Action petition. The online campaign grew through the involvement of other companies willing to carry the message on their internet pages and services. Another example of a business + NGO partnership was the 1995 Youth Career Development Programme launched in Thailand as a collaboration between the Pan Pacific Hotel Bangkok and UNICEF’s Thailand Programme for Children in Especially Difficult Circumstances. This training program was designed to prevent commercial sexual exploitation of young girls. Through a variety of empowering activities, it focuses on providing career skills in hotel hospitality for at-risk adolescent girls from Thailand’s North and Northeast regions.

3. **Business + Government.** In the Ivory Coast, the Ministry of Health partnered with Compagnie Ivorienne d’Electricite (CIE) to provide centralized HIV testing and ART treatment for company employees, bulk buying of drugs, and use of government laboratory facilities for monitoring drug resistance.

Summary

There are progressive levels of involvement for companies in the AIDS response. All companies should develop clear workplace policies aimed at preventing discrimination against HIV infected persons and protecting their confidentiality and employment rights. Companies may also decide to mount workplace programs ranging from awareness raising to risk reduction education and services to HIV testing to HIV treatment or financial or other support and services to employees. Companies may also extend these programs into the communities where they
work or to the families of employees. Finally, companies can reach beyond their own workforce
to engage in CSR activities in partnership with governments, foundations, or NGOs to play an
active role in the global, national, or local response to HIV/AIDS.
Strategies to Prevent HIV/AIDS in the General Population

Early HIV/AIDS prevention efforts mistakenly focused HIV/AIDS prevention only to “high-risk groups” like commercial sex workers, intravenous drug users, and gay men. While members these populations may engage in especially high-risk behaviors and may well be core transmitters of HIV, prevention efforts must extend beyond these groups into the general population, especially where the AIDS epidemic is well established. Because “high-risk groups” are often socially stigmatized and hidden, it is often hard to reach them with HIV prevention information and services. Most importantly, efforts focusing only on groups like sex workers and drug users further stigmatize these groups, make them even harder to reach, and lead to the dangerous and false complacency that others in the general population are not at risk. For these reasons, targeted prevention interventions are best focused on high risk behaviors rather than the groups themselves.

In addition to problems related to stigma and misperception, there are practical problems related to the accuracy of targeting high-risk groups rather than high-risk behaviors. For example, clients of sex workers and sexual partners of drug users, who are important “bridges” from between “high-risk groups” and the “general population” because they are involved in the “high-risk” activity of commercial sex, would not be reached through efforts that target only FSWs and IDUs, members of the “high-risk group”. Similarly, rather than targeting prevention efforts only towards gay or homosexual men, it is more effective to focus on the risk behavior itself, and try to reach men who have sex with men (MSM), who may or may not consider themselves gay, with HIV prevention information.

However, many of the prevention strategies shown to reduce HIV risk in the general population can not be implemented without supporting laws and policies and their enforcement, and guarantees on the protection of confidentiality. Such policies are essential to provide protection, and the incentive, to individuals who are or may be infected, to self-identify and come forward for counseling and treatment.

A number of proven prevention strategies, used in combination, should therefore be promoted as part of a behavior change-oriented HIV prevention strategy for all populations. These include:

- sexual behavior risk reduction through delayed initiation of sexual activity,
- reductions in numbers of sexual partners,
- correct condom use during sexual intercourse,
- efforts to reduce sexual violence and nonconsensual sex, and
- skill-building for negotiating condom use by both partners.
Condom promotion and availability is an important part of an HIV prevention strategy for the general public because, to date, condoms (when used properly) are the best available mechanical method of HIV prevention.

Prompt diagnosis and treatment of sexually transmitted diseases is also a critical prevention strategy, since untreated STDs substantially increase the risk of HIV transmission. Therefore, HIV prevention efforts must concentrate on raising the awareness of the STD/HIV link and increasing service-seeking for STDs at appropriate facilities, assuring the quality of STD service and treatments provided by health workers, and providing accurate counseling to STD patients both on HIV and to prevent further transmission of their STD, and to advise their sexual partners to obtain treatment.

For all potentially infected persons, voluntary counseling and testing (VCT) should be available and encouraged. VCT is the main gateway for HIV counseling to prevent acquisition (for the uninfected) and further spread (for the infected) of the virus, and to access treatment and care services. VCT has been shown to be more effective in reducing reported risk behaviors than simple provision of health information to the general public. But without guarantee of anonymity, access to treatment, and enforcement of non discrimination policies for HIV infected persons and their families, few persons who suspect they may be infected will come forward for testing and counseling, for fear of stigmatization and discrimination. The experience of recent years has shown that in many settings, the availability of VCT does not generate identification of enough cases of HIV to effectively stem incidence of infection. Therefore, UNAIDS now endorses the use of routine testing in certain settings with the option to refuse. In these settings, it will be extremely important that confidentiality and the ability to refuse testing are protected.

Testing is especially important for pregnant women in order to prevent maternal to child transmission of HIV. Pregnant HIV positive women can prevent transmission of the HIV virus to their offspring through use of a single dose of nevirapine at the time of delivery. Prevention of HIV transmission in medical settings requires testing and insuring the safety of the blood supply, elimination of paid blood donation, universal precautions involving protective gear such as latex gloves, proper disposal of medical waste by health care workers, using only single use syringe and needles, and sterile injection practices to prevent cross contamination.

For injecting drug users, the combination of prevention strategies that promote demand reduction, supply reduction and harm reduction have been successful in many settings in reducing HIV transmission. These programs require close collaboration between police and health authorities in order to reach drug users with prevention messages aimed at eliminating needle sharing and the provision of clean needles.

Finally, public education about HIV, supported by an educated media, is crucial for mobilizing public support and understanding of HIV prevention efforts. First, every citizen should understand the basic transmission routes of HIV so they can assess their own and their families’ risk of infection and can take appropriate prevention measures. Second, public education and the media play a critical role in creating public support for laws and policies that protect against stigma and discrimination of infected persons. HIV education for in-school youths and outreach to out of school youths are crucial for the primary prevention of HIV among vulnerable youth, and their parents must be educated and mobilized as well. Edu-entertainment through soap operas, radio shows, comic books, and other forms of entertainment have been very successful in a number of countries in helping to shape public opinion and educate the public about HIV/AIDS. Finally prevention messages are often best communicated to specific groups like youth, gay men, sex workers, drug users, and HIV positive persons by “peers”. Thus, it is
crucial to work with and through civil society organizations constituted by these communities themselves who have the legitimacy among their members to communicate sensitive information and promote behavior change strategies.

HIV/AIDS Prevention among Youths

Primary Prevention
Worldwide, youth have been disproportionately affected by the HIV/AIDS epidemic. Young people, aged 15-24, have the highest rate of new HIV infections in every country and region where the epidemic has taken hold and many AIDS sufferers acquired the infection during their youth. They account for nearly half of new HIV infections worldwide.2 Youth are particularly vulnerable to infection because of their sexual inexperience, restricted access to information and services, peer pressures, and poor comprehension of risk. Young girls have the highest incidence of HIV infection in sub-Saharan Africa, where economic need, gender inequity and consequent disadvantage in the “gender power dynamic” of sexual relations, sexual violence and abuse, unequal gender role expectations for girls and boys, and lack of information combine to increase risk of HIV infection disproportionately. Over the last twenty years, a number of strategies have been demonstrated as effective in preventing HIV transmission in youth.

However, in almost every place in the world, the backdrop to the provision of HIV risk reduction information and services to youth is the debate over abstinence-only education versus the provision of safe sex information and services. Often spearheaded by conservative religious leaders and supported by cultural norms in most countries that discourage pre-marital sex, abstinence-only education has been a mainstay of sex education curriculum around the globe. Abstinence-only education posits that education about the health and psychological risks of early and non-monogamous sexual relationships will succeed in convincing youths to delay sexual debut and limit their number of sexual partners.

However, most evaluations of abstinence-only education programs have found that they fail. Based on this evidence, the approach to sex education for youths supported by WHO is a curriculum that promotes delay in sexual debut and limitation in number of sexual partners, but also provides youth, especially young girls, with safe sex information; intervenes early to help shape appropriate gender role norms around masculinity and femininity, consensual sex, and the sexual gender power dynamic to support safe sex and condom use; and utilizes peer-education and support mechanisms (clubs, newspapers, chat lines, etc) to change youth norms and behaviors. Recent research and successful programs have also demonstrated that parent and teacher education classes are crucial for reinforcing values and behaviors for young persons. It is important that the design of prevention education programs be informed by the specific cultural context of the region or population in which they will be used; the most appropriate approach may vary, according to specific risk factors and social norms.

Secondary Prevention
Most HIV prevention efforts directed at youth are aimed at primary prevention of HIV. Unfortunately, in many parts of the world, a significant proportion of youth are already infected with HIV. These youths, often unmarried and increasingly able to obtain life-prolonging treatment, are unlikely to refrain from sex. Many hope to marry and have children. This population must be the focus of secondary prevention efforts, the aim of which is to prevent transmission of the virus to sexual partners and offspring. This population also poses a major challenge to efforts to prevent drug-resistant strains of HIV. Secondary prevention in this population will be greatly facilitated by the development non-spermicidal microbicides for HIV prevention.
HIV/AIDS Prevention for Women

Background

HIV prevention efforts for the general population involve public education on HIV risks from untreated STDs and reproductive tract infections as well as integration of services to provide HIV testing and counseling and to screen and treat STI/RTIs with other existing health services, including STD services, routine gynecological services for women, family planning services, and maternal and child health services.

Women and girls in many countries are among the most vulnerable populations for HIV infection, especially in those places where double standards exist for women and men’s sexual behavior. These women, often in monogamous relationships with boyfriends or husbands, are at risk of HIV infection from partners who may visit commercial sex workers. Even if aware of their partners’ sexual practices, most women are unwilling or unable to insist on condom use, either because they wish to become pregnant (an important requirement of their status in the household) or because it would be perceived as an indication of distrust or inappropriate knowledge and result in violence against them. In places where homosexuality is socially stigmatized and hidden, gay men may be married and their wives may be at risk for infections acquired from their partners’ other sexual relationships. Moreover, general population education and knowledge of transmission routes and risks of infection are important for individuals to assess their own, their sexual partner’s, and their families’ behavioral risks so as to minimize transmission from injections and blood donation, intravenous drug use, and unprotected sex with non monogamous partners.

Sexually transmitted diseases are major risk factors for HIV transmission. Some STDs, especially those that cause ulceration (like syphilis, genital herpes, condyloma, HPV) can increase the efficiency of HIV transmission during unprotected sex four fold. Therefore, prompt diagnosis and effective treatment of sexually transmitted diseases in men and women is extremely important as a first line of defense against HIV transmission. Unfortunately, STD diagnosis and treatment quality have been difficult to assure. Because of the embarrassment and stigma associated with STDs, individuals will often seek confidential care at poorly standardized private clinics where the treatments may be ineffective and where “partner notification” does not occur, thus their sexual partners will often go untreated and continue to transmit the infection and re-infect their partner. Drug resistance caused by incomplete regimens have created problems in many regions of the world, especially southeast Asia, so that drugs available are no longer effective in eradicating the infections; counseling and follow-up to insure compliance with drug regimens is an important part of programs.

The development and use of diagnostic algorithms for STDs has been useful for diagnosing on the basis of symptoms, and treating STDs in men in places where laboratory diagnosis of infections is limited. Unfortunately, these syndromic approaches do not work well for women, in whom the STDs are often without symptoms or where symptoms may exist in the absence of any infection. However, for women, the consequences of untreated STD infections are much more serious than for men, increasing women’s vulnerability not only to HIV, but also to adverse outcomes of pregnancy and risks of severe acute pelvic infection, especially in conjunction with contraceptive use and abortion.

Most women do not seek care for STDs at STD clinics. For women in developing countries, often their main exposure to health services occurs because of reproductive issues: either associated with the use of family planning services or in conjunction with pregnancy and child
delivery. Therefore, integrating HIV prevention services into family planning, routine
gynecological, and maternal and child health services is important for reaching women at risk
with STD diagnosis, diagnosis of other non sexually transmitted reproductive tract infections
which can also increase the risk of HIV transmission, and providing condoms, counseling and
information HIV prevention and safe sex. These clinic based services must be supplemented by
outreach to the community in places where use of both prenatal care and attended delivery and
family planning services is low.

In recent years it has been demonstrated that it is possible to significantly reduce the
transmission of HIV from a pregnant woman to her offspring by administering an anti-retroviral
(ARV) drug to the mother shortly before birth and to the child shortly after. Therefore HIV-
infected pregnant women must be identified in order to administer this inexpensive and highly
effective HIV prevention method for their child, either through efforts to diagnose HIV infection at
prenatal clinics, or through educational outreach to the community. To be effective and ethical,
these programs must also provide services and care to the women themselves. Also, continued
research is necessary to determine the best approach to preventing mother to child
transmission (MTCT), taking into account resource constraints, as well as the potential for
development of drug-resistance in women as a result of the use of ARVs to prevent MTCT.

Targeted Strategies for Vulnerable Groups Engaging in High-Risk Behavior

Harm Reduction Strategies for Injecting Drug Users

Background
The urgent need for expanded and improved HIV/AIDS prevention programs for injecting drug
users (IDUs) in Vietnam arises in the context of the intertwined global epidemics of drug use
and blood-borne infectious disease, particularly HIV/AIDS and hepatitis C. As of 1999, 134
countries around the world were home to IDUs and 114 of these had reported cases of HIV
infection among IDUs. The HIV epidemic in Vietnam probably began among IDUs in the early 1980s. As elsewhere in Asia, the appearance and spread of HIV infection in Vietnam
represented the natural culmination of a chain of circumstances beginning with a shift to
production of heroin in regions hitherto involved only in opium cultivation, to establishment of
heroin trans-shipment routes passing through northern Vietnam, to the supplanting of traditional
opium smoking by heroin use along these routes, to the transition from smoking and inhaling
heroin to injecting the drug, to widespread sharing of injection equipment. Since first appearing,
HIV infection among drug users has subsequently been identified in many other Vietnamese
provinces. Prevalence of HIV among IDUs in Vietnam is about 33% overall and has reached 60-
80% in some places, including Quang Ninh and Haiphong. Once established, HIV epidemics
among IDUs can expand with astonishing speed. Moreover, as HIV spreads among IDUs there
is increasing likelihood of infection bridging to sex workers, IDUs’ sexual partners, and other
parts of the larger community. HIV prevalence among antenatal women has already passed 1%,
the UNAIDS definition of a generalized epidemic, in several Vietnamese provinces. Experience
from many parts of the world, including Asia, demonstrates that HIV epidemics among IDUs can
be prevented in the first instance or at least brought under control once they take root.

The Basics of Harm Reduction Strategies
There are three approaches to reducing HIV/AIDS among IDU populations.

- Supply reduction – crop eradication and substitution, border control, crackdowns on
  trafficking: extremely difficult; little evidence of success; often results in shifting
  patterns of drug trafficking and using.
Demand reduction – education, social/economic development, rehabilitation and treatment of users: works only in the long-term if at all.

Harm reduction – does not condone drug use but assumes that it does and will continue to occur despite efforts to reduce supply and demand. Rather, seeks to reduce the harms associated with drug use, among them HIV infection. Harm reduction is entirely compatible with and should be adopted in the context of an integrated program also incorporating reduction of supply and demand.

Harm reduction programs have common philosophical elements. They:

- Emphasize short-term, practical, achievable goals over long-term, idealistic goals.
- Offer a hierarchy of risk reduction methods from most desirable (but most difficult to achieve) to least desirable and still beneficial (but easiest to achieve).
- Actively involve drug users in the development and delivery of programs.
- Advocate for and design programs based on sound research and evidence.

Strategies that should be included in a comprehensive harm reduction program:

- **Information/education** regarding drug use and HIV risks, including practical risk reduction techniques. Straight education is unlikely to achieve much real risk reduction, particularly if it is presented in simple slogans and superficial and overly idealistic goals. In particular, educational messages based on fear and stigmatization of drug use and drug users are bound to fail – e.g. DARE programs in U.S.
- **Drug treatment and substitution** programs that are voluntary, flexible, understanding, and supportive of the needs of drug users. Drug users subjected to mandatory detoxification, particularly those in punitive settings, have extremely high relapse rates. Methadone maintenance for opiate addicts has been proven to be safe, to reduce death and criminal activity, and to reduce HIV risk. Buprenorphine shows promise and has the added advantage of requiring less frequent dosing.
- **Community outreach and peer programs** to deliver HIV education and prevention messages and teach risk reduction practices to IDUs. Peer educators, usually current or recovering users, have built-in credibility, acceptance, and trust in the IDU community, particularly compared with government officials, and can achieve much if properly trained and supervised. Successful programs exist worldwide, employing varying models, including in Vietnam, India, and China.
- **Needle/syringe distribution and disposal**, particularly needle/syringe exchange programs (NSEP) have been implemented in >40 countries and have demonstrated success in reducing HIV transmission while not increasing frequency of injection or recruiting new users. NSEPs have also been shown to be extremely cost-effective. Collection and safe disposal of used needles/syringes also has a broader public health benefit. A successful peer education and needle/syringe distribution program has been implemented in the northern Vietnam provinces of Lang Son and Ha Giang and across the border in Guangxi Province, China.
- **Pharmacy sale of needles/syringes**, completely legal in Vietnam and other Asian countries, offers another method to increase IDUs’ ready access to sterile injection equipment. Needles/syringes are generally cheap in pharmacies but even the low cost sometimes precludes purchase by IDUs who are generally very poor and unemployed. Also, some pharmacists may be hostile to IDUs and unwilling to sell them needles/syringes. A pharmacy voucher component of the Cross-Border project addresses the cost issue and has successfully recruited pharmacists.
- **Voluntary HIV counseling and testing (VCT)**. Peer outreach, NSEPs, drug treatment programs can refer IDUs to VCT in the community, if it is available. Maintaining
confidentiality of HIV test results is critical to the success of VCT programs in attracting IDUs and other stigmatized populations.

• **Incorporation of strong sexual risk reduction components** in harm reduction programs for IDUs. Contrary to widely prevailing myth, IDUs are sexually active and often engage in unprotected intercourse with sex workers, regular and casual partners. Successful delivery of sexual risk reduction programs requires training and attention to the sensitivity of sexual issues.

• Special attention to reaching women IDUs and sex workers, many of whom also inject drugs, and who represent particularly stigmatized and often deeply hidden populations. e.g. Drop-in center in Can Tho, Vietnam

• Reaching and addressing the needs of special populations, such as prisoners, residents of drug rehabilitation or reeducation camps, migrants, and members of ethnic minority groups. These groups may be at particularly high risk but also suffer particularly from discrimination and thus be very hard to reach.

Harm reduction programs, by their very nature, require the collaboration and coordination of multiple government and non-government stakeholders. Some of the key elements to effective harm reduction programs include:

• **Gain and maintain multi-sectoral collaboration.** Many government agencies, mass organizations, NGOs, pharmacies have stakes in harm reduction programs. If their concerns are addressed and their capabilities understood, they can all make significant contributions to the successful implementation of harm reduction programs.

• **Addressing stigma and fear.** It is extremely important to combat ostracism and marginalization of IDUs and their conceptualization as “them” with the general community as “us.” Drug users are part of the community – family members, neighbors, and colleagues. Communities and programs should put a human face on drug addiction and present users as suffering from an insidious disease the recovery from which and the reduction of harms associated with which call for understanding, sensitivity and support. In such a context, IDUs may overcome their fears and their isolation and be willing to participate fully in harm reduction programs.

• Gain and maintain the **support of the police.** Police and other law enforcement agencies are in critical position to support and facilitate many harm reduction programs or thwart them. Police must be brought in very early and actively involved in the development and implementation of programs. Their legitimate concerns must be met. Specialized training for police may be extremely helpful – for instance, the China -UK project training manual for police.

• Gain and maintain the **support of families, neighbors, and the larger community.** A common and very persistent myth about harm reduction programs is that they encourage or facilitate drug use. There is strong evidence to refute this, but communities need constant education and re-education in the principles and true objectives of harm reduction (i.e. reduction of disease transmission, protection of the public health).

**Harmonizing law, policy, and practice**

Currently in Vietnam, there is a somewhat fragmented and inconsistent approach to IDUs and HIV/AIDS. The criminalization of drug use and repression of drug users makes the arrest of IDUs for possession of needles/syringes common, although laws do not prohibit this. Persons apprehended in possession of drugs are committed to drug rehabilitation centers (06 Centers) even though harm reduction strategies have been recognized and made a part of the
Prevention Strategies for Sex Workers

In almost all countries of the world, female sex workers (FSW) are a highly stigmatized group, which are both criminalized and morally looked down upon. Yet commercial sex work exists in almost every society and is driven in most cases by the economic pressures for women to earn livelihoods in economies where women’s employment opportunities are limited. In many places, direct and indirect sex work exists. Direct sex workers are those working at brothels, on the street, or as “call girls”. Indirect sex work, by far the most common, includes women who work in formal jobs in places such as bars, cafes, tea houses, restaurants, beauty parlors, massage parlors, but who are also available for sexual services. Some sex workers were trafficked as young girls and remained in sex work out of fear and shame. These young girls often come from societies where discussion of sexual matters by girls and women is considered shameful, so they know little about HIV or safe sex, are too inhibited to demand condom use if they do, and are extremely vulnerable. As marginalized and stigmatized women in society, they are doubly powerless, with little protection from violence.

Yet FSWs are often the first targets of HIV prevention efforts, either through arrest and incarceration or, if they can be located, through educational outreach and mandatory STD, including HIV testing, and licensing. Clients of sex workers, even harder to identify, are not routinely included in HIV prevention efforts. Sex workers will often engage in unsafe sex (without a condom) when pressured by a client to do so, especially when extra money is paid. And while they may use condoms for “work”, they may not use them with husbands or boyfriends. Therefore, the most successful HIV prevention efforts for FSWs have involved both primary and secondary prevention. Primary prevention of sex work includes education and the provision of economic alternatives to young rural women before they enter prostitution, economic alternatives to sex workers, and rescue for young girls involuntarily forced into prostitution. Secondary prevention involves safe sex education for FSWs that includes appreciation for issues of personal safety from violence, fear of incarceration by the police, economic need, and skills for negotiating condom use and safe sex.

FSWs will be greatly aided by the availability of female-controlled methods like microbicides. Female condoms, where available, have been well-received by some groups of sex workers.

Because commercial sex work is illegal in most countries, sex workers are often a difficult to reach population. They move from place to place to avoid arrest. Therefore, HIV prevention programs for sex workers must be undertaken in collaboration with law enforcement authorities and be done on the basis of “harm reduction” approach. The police must agree not to arrest sex workers identified through HIV prevention program. Also, because sex workers are often highly stigmatized and looked down upon in society, they are frequently not considered innocent victims of the HIV/AIDS epidemic nor worthy therefore of efforts to save them. But as noted above, most sex workers are young and poorly educated and don’t fully comprehend the risks of sex work. They are engaged in sex work because of economic need and many regard sex work as a temporary occupation. The same factors which make sex workers vulnerable to HIV also make them vulnerable to STDs, which facilitate the transmission of HIV, so one crucial
intervention for sex workers is the diagnosis and treatment of STDS and education of the importance of refraining from sex work until the STD is cured. The main behavioral intervention for sex workers is the promotion of safe sexual practices: demanding consistent condom use during sexual intercourse and substituting alternative non penetrative safe sexual practices, skill and confidence in negotiating condom use. Successful primary prevention programs have reached out to young women before or after they enter sex work to either keep them in school or provide economic alternatives to sex work. Peer approaches whereby sex workers educate other sex workers and provide condoms and peer support for safe sexual practices and protection of personal safety have also been successful in some settings.

Fear of violence and personal safety contributes to risk taking by commercial sex workers who may fear that demanding condom use may result in violence, either from a client or their regular sexual partners. Thus protection of personal safety is often an important contextual determinant of safe sexual practices among commercial sex workers. For sex workers who work in establishments like hotels, bars, massage parlors, and entertainment venues, it is important to directly involve intermediaries such as bar owners, mamas, and others involved. Their involvement in and support for programs will be key to success. 100% condom use programs have been successful in reducing HIV prevalence among sex workers and onward transmission to clients in a number of locations, such as Thailand and Cambodia, but these programs must also protect the rights of the sex workers as well. Finally, programs need to reach out to the potential and actual clients of sex workers in entertainment venues, hotels, massage parlors and among migrant workers and mobile populations, making safe sex information and condoms available and educating these potential clients about risks.

Prevention Strategies for Mobile Populations
There are substantial mobile populations in Vietnam. These comprise people who are voluntarily mobile because of occupation (e.g. truckers, seafarers, and freelance sex workers), people whose mobility is legally required (e.g. soldiers, deportees), and people whose movement is coerced (e.g. political refugees, trafficked sex workers, and war-related displaced persons). In these populations, poverty, various forms of vulnerability and lifestyle changes may lead to increased risk of HIV or sexually transmitted diseases.

Because of their heightened vulnerability and risk, mobile populations need access to a full range of HIV prevention and treatment services. These services should be offered in the languages used by these populations and should be focused in border regions. According to a UN Regional Task Force, effective HIV prevention programs for mobile populations require an enabling environment of non-discriminatory policies and access to prevention supplies (e.g. condoms, sterile needles/syringes, and IEC materials). Such programs should also be people-centered and community-based and should be developed and implemented through multi-sectoral partnerships.

Prevention Strategies for Men who have Sex with Men
Introduction: MSM Versus Male Homosexual
Homosexuality has existed in all cultures and societies since ancient times and is well documented in historical records and classical literature, including those of ancient China. Experts estimate that there are approximately 20-30 million male homosexuals in China today, of which 8 million reside in major urban centers. However, this group is highly stigmatized and misunderstood in China and poses a serious threat as a major transmission mode in the spread of AIDS.
The concept of Men who have Sex with Men (MSM) is different from that of male homosexuality. MSM is based upon sexual behaviour rather than sexual orientation. For instance, an MSM could be (1) a male sexworker who is heterosexual by orientation but engages in sexual behaviour with male clients due to special needs; (2) a man who is married but also has anonymous sex with multiple male sex partners; and (3) a man who has sex with other men in an all male setting, such as prison and army. MSM may or may not be homosexual by orientation.

HIV Prevalence: How Serious is the Problem
Compared with transmissions via drug injection and , MSM is not the main mode of HIV transmission in Vietnam. However, sexual transmission (both heterosexual and homosexual) will be the “next big wave” and MSM may play a major role in this development. There may be 140,000-400,000 MSM in eight major cities in Vietnam, many with high rates of risky sexual behaviour, including involvement in sex work, and low levels of HIV/AIDS knowledge. HIV prevalence among MSM in Vietnam is thought to be 6-8%.

Unique Aspects of MSM: Why Do MSM Need Special Attention?
Although groups such as commercial sex workers and injecting drug users are recognized as high risk groups in Vietnam the context of HIV/AIDS prevention, MSM has yet to receive such recognition. The following factors make MSM unique in AIDS prevention, and therefore require special attention:

- Difficulty to reach out to MSM due to stigma and fear of discrimination;
- Constant police harassment make health outreach to MSM more difficult;
- Lack of knowledge, particularly on risk level of various behaviours;
- Higher degree of bisexual behaviour compared to the West;
- Increase of MSM in sex work industry;
- Accessibility and affordability of condoms and lubricants;
- Anal intercourse is higher risk of HIV transmission than other forms of sexual intercourse.

Therefore, in order to succeed in AIDS prevention among MSM, generic prevention programs would not be effective, and specifically designed programs are required.

Effective prevention programs for MSM require developing programs that recognize and address specific needs, though some developments in the overall strategies are similar to those targeting other high risk groups.

- Programs should be non judgemental and accept MSM for who they are;
- Outreach should not evoke fear and stigmatization;
- HIV prevention is the sole goal, and should not be mingled with other agendas, such as convincing sex workers to stop sex work or convincing homosexual to become heterosexuals;
- Programs should be community based. For example, actively involving MSM in the development and delivery of programs, because they know what they need, and what would work;
- Community outreach and peer education programs are effective methods to deliver the prevention message;
- Community building and empowerment among MSM not to promote homosexuality, but to promote social harmony and anti-discrimination;
- Programs should involve multiple stakeholders, such as the policy and other law enforcement agencies, owners and managers of MSM venues, and managers of male sex workers. They are crucial in supporting AIDS prevention programs.
There is a delicate balance between the need for MSM specific programs and the further stigmatization of MSM that may result. MSM programs therefore need to go hand in hand with prevention programs in other populations.

**Recommended Readings:**

**General Population**


**Injecting Drug Users**


**Sex Workers**


CHAPTER 10: HIV/AIDS CARE AND TREATMENT

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HIV as a Medical Disease

Nearly twenty-five years of experience with HIV has led doctors and health workers to a clear understanding of how HIV is transmitted from person to person, the progression of HIV disease from an asymptomatic phase to end-stage AIDS, and the impact that treatment can have on the disease, particularly the use of antiretroviral (ARV) medications. At its heart, although the HIV/AIDS epidemic has widespread social and economic impacts, its toll is felt one infected individual at a time.

HIV is a virus. Like most viruses, it cannot survive for long outside of its host. Unlike many other viruses, HIV cannot be transmitted by casual contact, or through the air. There are three major routes by which HIV is spread from an infected person to an uninfected person. Most commonly, HIV is transmitted sexually. The virus lives in high concentrations in an infected man’s semen or an infected woman’s cervical secretions. During sexual intercourse, the virus can be passed as these fluids are exchanged, establishing a new infection in a previously uninfected person. A second mechanism by which HIV can be spread is through infected blood. The virus lives in high concentrations in the circulating blood. Previously uninfected people who are exposed to the blood of an infected person—through blood transfusions, needle-sharing between intravenous drug users, or an accidental needle injury to a health care worker—can contract the virus this way. Because HIV infection is transmitted by blood, health care workers are advised to use universal precautions. This principle requires health workers to assume that all blood is potentially infectious, and to use the appropriate safeguards: glove use, care with needles, and proper disposal of blood and contaminated waste. Finally, the third route by which HIV can be transmitted is by pregnant women, who can pass HIV to their newborn child. This can occur during pregnancy, at the time of delivery, or through breastfeeding.

Once a person has become infected with HIV, the disease follows a fairly predictable, prolonged course, which can be broken down into four phases: acute HIV infection; asymptomatic HIV infection; symptomatic HIV infection; and AIDS, which represents the final stage of the disease.

Acute HIV disease occurs within the first one or two months after the infection. Most commonly, about two weeks after contracting HIV, a newly infected person will develop fevers, swollen lymph nodes (“glands”), a sore throat, headache and a rash. These symptoms are nearly identical to many other common illnesses, such as influenza or malaria. Typically, symptoms will last for two or three weeks. Like influenza, the symptoms will disappear on their own, without treatment. Despite the symptoms of acute HIV, newly-infected patients may or may not seek health care, and may dismiss the illness, attributing it to influenza or some other benign illness. From this time forward, however, they are infected with HIV, can transmit the infection to others, and will remain infected for life.
At this point, HIV-infected people enter an *asymptomatic* phase. They can feel completely healthy, and unless they seek HIV testing, will be unaware that they are infected with HIV. The duration of this phase of HIV infection can vary significantly from person to person, but in general lasts between 5 and 10 years. Although HIV-infected people may feel healthy, the virus is taking its toll every day, slowly destroying their immune system and their ability to fight off infections. During this time, particularly if they are unaware of their infection, asymptomatic people can transmit HIV to uninfected people.

Towards the end of the asymptomatic phase, HIV-infected people begin to notice poor health. They may have frequent infections, such as pneumonias. They may develop frequent rashes, lose weight, and become fatigued easily. At this point, they have entered the phase of *symptomatic* HIV infection. One important marker of this is a decrease in a blood test known as a CD4 count, which measures how much damage the immune system has suffered. Healthy, HIV-negative people have a normal CD4 count of approximately 800 cells/mL of blood. In patients with longstanding HIV disease who have developed symptoms, CD4 counts have generally fallen by 50% or more, to between 200 and 500 cells/mL.

Finally, in patients who have been infected with HIV for an average of 8 to 10 years, AIDS develops. AIDS represents the end stage of HIV infection, and reflects the destruction of the immune system by the virus. It is characterized by the development of severe “opportunistic” infections of the lung, brain, eyes, gastrointestinal tract, liver or other organs. In most countries, tuberculosis is extremely common. These infections are often life-threatening, and can be extremely difficult to treat. Patients may also develop unusual cancers, especially of the skin and brain. People whose CD4 count has dropped below 200 cells/mL are also considered to have progressed to AIDS, regardless of the presence of an opportunistic infection, because of their extremely high risk of contracting one of these opportunistic infections. It is useful to remember that, as a general rule, HIV does not cause death directly—rather, it is other types of infections, which healthy people who have an intact immune system would normally fight off, that lead to death in most HIV-infected people. In addition to these life-threatening infections, people with AIDS frequently suffer from severe diarrhea, malnutrition, decreased mental function, and often cannot care for themselves.

Until 1995, there was little that could be done to reverse or even slow the inexorable progression of HIV infection, and nearly all HIV-infected patients progressed to AIDS and death. The most significant medical intervention was the use of “prophylactic” antibiotics in patients with advanced HIV disease, which could provide some help to a patient’s failing immune system to ward off infection. Two of the most common opportunistic infections in AIDS—*Pneumocystis carinii* pneumonia, a severe lung infection, and *Toxoplasma gondii*, a severe infection of the brain—can be prevented by an inexpensive antibiotic, trimethoprim-sulfamethoxazole, taken every day. In countries where it is made available, all HIV-infected patients begin taking this antibiotic when their CD4 count has dropped below 200 cells/mL, or when they have developed signs of AIDS. Similarly, most HIV-infected patients at risk for TB should take prophylaxis with isoniazid (INH) to prevent active tuberculosis.

In 1995, research studies showed for the first time that a combination of three anti-HIV medications—if taken regularly, and for life—could stop the progression of HIV disease and prevent AIDS. This major advance in the fight against AIDS has been the most significant development to date. There are now 19 medications available to treat HIV, and a number of different combinations are extremely effective. Their impact has been enormous. Patients who are near death with advanced AIDS can take these medications, and within six months most will recover to good health, and will remain in good health for as long as they continue to take all of
their medications. The amount of virus circulating in the blood will usually drop to near zero. While these drugs are not a cure, they effectively transform HIV from a terminal disease, like cancer, to a chronic illness, like diabetes—so long as the medications continue to be taken regularly.

The use of these medications is not entirely straightforward. Many of the medications have significant side effects. Most importantly, the need to take every dose without interruption is critical. Failure to do so can lead to high levels of drug resistance which, as with tuberculosis, creates new, more difficult problems. Drug-resistant virus can be spread to others, making many people difficult to treat and requiring more expensive medications. Proper use of HIV medications also requires a comprehensive program, usually with frequent laboratory tests to monitor the effectiveness of the drugs and to identify the first signs of drug resistance, or drug toxicity.

This module will examine the topics discussed above and will help participants understand the natural history of HIV infection in individual patients, the role of antibiotics in preventing infection in HIV patients, and the use of anti-HIV medications to prevent the complications of HIV infection: AIDS and death.

The next session of this module will address in more detail the essential components of HIV care and treatment, including the various types of programs that have been used to both stop the spread of HIV infection to uninfected people, and to reduce the impact of HIV disease through appropriate treatments.

Elements of an HIV Care and Treatment Package
The care and treatment of HIV can be broken down into a small number of discrete services ad programs:

- Testing and entry (commonly referred to as Voluntary Counseling and Testing, or ‘VCT’)
- Staging and Clinical Assessment
- Prevention and Treatment of Opportunistic Infections
- Antiretroviral Treatment
- Adherence Support
- Palliative Care
- Prevention of Mother-to-Child Transmission (or ‘PMTCT’)
- Laboratory Services

Each of these programs can exist as a distinct program within a hospital, health district, or centralized health system. However, experience in many countries around the world has indicated that the various aspects of HIV care and treatment can be more effective when they are integrated into a comprehensive program. Careful integration can avoid unnecessary duplication of effort, as well as the failure of one program due to lack of support from another program. This integrated approach has been increasingly used to maximize the health outcomes of HIV interventions, particularly as ARV treatment becomes more affordable.

Each of these programs will be briefly described below.

- **Testing and Entry.** The majority of HIV-infected people are unaware of their HIV status. Typically, 5 to 10 years can elapse from the time of infection to the time when the first symptoms of HIV infection develop. During this time, HIV-infected people may transmit to virus to others, and may not reduce risk behaviors if they are unaware of the presence of HIV infection. Experience has also shown that even when HIV testing is
free and widely available, many people at risk choose not to be tested, unless treatment and care services are available. A number of strategies have been developed to make services available and increase the number of people who choose to be tested.

Diagnosis of HIV infection is relatively straightforward, according to standard testing protocols devised by the World Health Organization. These tests are more than 99.9% reliable. Over the past few years, the testing process has been simplified by the use of rapid tests, which are relatively inexpensive ($1 to $2 each) and can provide results within 30 to 60 minutes. In many countries, these tests are now performed by trained counselors at voluntary counseling and testing (VCT) centers. These VCT sites may be associated with a clinic, district hospital or other health facility, or they may be free-standing, run by social service agencies or NGOs. Most important is the integration of VCT sites with clinics and other sites of care, as VCT sites will represent the point of entry into the health care system for most HIV-infected patients.

- **Staging and Clinical Assessment.** Because the natural history of HIV infection takes place over ten years or more, the majority of HIV-infected patients at any point in time are asymptomatic, relatively healthy, and require few additional treatments or interventions. In order to ascertain at what stage an HIV-infected person is in their disease, a careful clinical assessment is necessary. This assessment generally requires the use of the CD4 count, a laboratory test to measure the amount of damage to the immune system. Once an initial assessment is done with a CD4 count and clinical evaluation, the expected course of an individual HIV-infected person’s disease can be predicted with some accuracy. Patients who are early in the course of HIV disease—in other words, those that have been infected within the past one or two years, and have a high CD4 count—can be monitored less frequently than patients late in their disease, and may require no medications. This staging process can help identify from the outset those patients who need close follow-up, and those who need to begin prophylactic antibiotics or anti-HIV drugs. A second, more expensive laboratory test form HIV RNA ("viral load") measures how much virus is circulating in the blood, and is also useful.

The ability to monitor patients through the several years of their HIV disease is facilitated by the use of standardized medical records, either computerized or written, that can be updated regularly during contacts with the health system, including clinic visits, laboratory visits, prescriptions and hospitalizations. Ideally, medical records can be standardized across health districts, and can follow a patient across district and provincial borders as they move for employment or other reasons.

- **Prevention and Treatment of Opportunistic Infections.** Many HIV-infected patients are first diagnosed with HIV when they present with a serious infection such as tuberculosis or toxoplasmosis. In countries with severe epidemics, these cases of serious infection have frequently overwhelmed hospital wards. Treatment of these infections can be difficult and expensive, but may be an essential part of care for HIV patients.

Because of the high rates of opportunistic infections in HIV patients, several interventions that can prevent these infections have proven to be extremely effective clinically, as well as cost-effective. The most well established of these is the use of trimethoprim-sulfamethoxazole for patients with advanced disease. In addition, treatment of latent TB infection is considered to be an important part of preventing infection in HIV patients, given the extremely high rate of TB.
Antiretroviral Treatment. The use of the HIV drug ‘cocktail’—a combination of three antiretroviral (ARV) medications—has had the most significant impact in the fight against AIDS. Although treatment with ARVs is fairly straightforward in most patients, several issues around cost, security, training of health workers, and monitoring of side effects and adherence have led many low- and middle-income countries to implement ARV programs only at central and district health care facilities. These facilities are generally staffed with more highly trained doctors, nurses, pharmacists and laboratories. Most patients who begin ARVs receive intensive follow-up at a local health facility during the first few months of treatment, when complications such as side effects are most common. Over time, patients are seen less frequently, but still receive the type of close supervision that patients taking TB treatment would receive. Specialized training in the use of ARVs and the clinical care of HIV patients is considered essential to establishing effective programs.

In addition to establishing the appropriate infrastructure and trained human resources, ARV programs require a significant budgetary allocation. In many countries, the initial implementation of ARV treatment is being supported by the Global Fund to Fight AIDS, TB and Malaria, the U.S. President’s Emergency Fund for AIDS Relief, or other donors.

Until recently, the price of ARVs was prohibitively expensive. Fortunately, the price of ARVs has dropped considerably in recent years, decreasing from $12,000 per patient year in 1998 to as little as $140 per patient per year for approved generic versions of the drugs. Establishing careful and sustainable mechanisms for drug procurement, drug distribution, security, and safety monitoring can also be as important as budgeting for drug purchasing.

Adherence Support. Unlike many treatments for other diseases, two factors make ARV treatment somewhat unique. First, in order to be effective, the medications need to be taken every day, reliably, without missing a dose. Studies have shown that missing as few as two doses per month can lead to failure of treatment. More critically, missed doses also lead to the development of drug resistance, which has become a major problem in the west and has significantly increased the difficulty of treating HIV patients, as well as significantly increased the cost. The medications for drug-resistant virus are much more expensive and difficult to take than the drugs used to treat patients initially.

Second, ARVs must be taken for life. Unlike the treatment for TB, there is no ability for patients to take HIV medications for a few months, or even a few years, and then stop. The medications do not cure the disease; they merely help control it and allow the immune system to recover. Combined with the high risk of drug resistance, this factor makes ARV treatment a challenge for health programs everywhere. One of the most effective and successful strategies has been the use of ‘adherence counselors’—community health workers, family members or others who work closely with HIV-infected patients to make sure they are taking all of their medications appropriately. Particularly in poor countries like Haiti, where the use of community health workers has been studied, this strategy has proven effective in keeping HIV patients on therapy and preventing the development of drug resistance.

Adherence support should also be considered as part of a broader provision of social supports, including counseling, mental health and other social services.
• **Palliative care.** As patients progress to AIDS, and as the epidemic matures in societies, the need for palliative and end-of-life care expands considerably. As described earlier, end-stage AIDS is extremely debilitating, and is associated with severe diarrhea, wasting, mental deterioration and frequent infections. AIDS patients who are unable to recover through ARV medications can impose a significant burden on hospital systems, families and friends. The role of specialized palliative care centers and hospices has been essential in many HIV care programs.

• **Prevention of mother-to-child transmission (PMTCT).** One of the first HIV interventions to be introduced in many countries is a program to use antiretrovirals during the last phase of pregnancy, in order to prevent transmission of the virus from mothers to newborn children. A number of different protocols have been studied and shown to be effective, although there is currently no clear consensus on which is the best to use in the long run. There are a number of concerns around PMTCT programs, including the best way to test pregnant women and enroll them in PMTCT, the best medications to use, and the role of breastfeeding vs. infant formula. In many countries, however, PMTCT programs have represented the first HIV program established on a provincial or national level, and have become major sites for testing and entry into care.

• **Nutrition.** The interplay between nutrition and HIV infection is complex, but, as with many other infections, inadequate nutrition can predispose people to more rapid disease progression, and HIV infection can exacerbate existing nutritional deficiencies. Food security and adequate nutrition may be important to effective HIV care and treatment services.

• **Traditional and complementary medicine.** In many settings, traditional healers and traditional medicine play a large role in health care. Many HIV-infected people seek treatment from traditional healers as they become symptomatic from HIV disease. Integrating these healers and complementary and herbal medicines into HIV services is an important consideration for HIV treatment programs.

• **Laboratory services.** Unlike other diseases such as TB, HIV care and treatment involves frequent use of laboratory tests, some of which are essential to the delivery of effective care. As the cost of ARV medications has dropped significantly, laboratory services have become the most expensive component in many programs. While the tests themselves can be expensive, they also require a significant investment in laboratory infrastructure, and careful logistical planning. Most programs make use of centralized laboratory services, so that equipment expenditures are minimized. This approach, however, requires investment in specimen preparation and specimen transport capacity at more peripheral sites of care, as well as a laboratory information system for reporting results.

**Operationalizing HIV Services**

No matter how limited the resources of any HIV care and treatment program, success requires that each patient access the above services—from initial testing and entry, to clinical staging and laboratories, to ARV treatment and adherence counseling. The challenge for most programs around the world is to develop an operational plan that can make these services available in a manner that **builds on existing health programs and infrastructure**, and is both **affordable** and **sustainable**.

**What is necessary to operationalize HIV treatment services?**
First and foremost, a detailed plan that incorporates the various elements and is responsive to the interests and needs of all stakeholders is essential—as with any public health program. The specifics will vary according to the scope of the plan and the unique characteristics of the local site, province or country in which the program is developed. At a minimum, the following operations will be included:

- Establishing a model of care
- Selecting and approving sites for HIV care
- Developing human resources
- Training health care workers
- Drug procurement
- Drug distribution
- Laboratory services
- Adherence counseling
- Drug resistance monitoring
- Outcomes measurement
- Community mobilization

### Challenges of Operationalizing HIV Treatment Services

- Equity of access to treatment
- Human resource capacity
- Sustainability
- Donor coordination

In this module, we have reviewed the elements of HIV care and treatment, and introduced the issue of how these elements can be operationalized to create a program that provides ARVs and other services to HIV-infected people in an effective way, and the factors which may make this operationalization challenging. In the next module, we will examine the different models for operationalizing HIV care that exist around the world, with an emphasis on how a few countries have addressed the epidemic.

### Operational Aspects of HIV/AIDS Care and Treatment

In many countries, successful ‘pilot’ program have been established in small clinics or large hospitals. In order to scale up these efforts, however, detailed operational aspects must be taken into consideration, as outlined in the previous module. A number of critical efforts must be coordinated in order to implement successful HIV care and treatment on a large scale at the district, province, or national level. This coordination can take place along any of a number of different models, which will be reviewed in this module.

### Pilot HIV treatment programs

From 1995 to 2000, when effective three-drug ARV therapy was still relatively new, a number of pilot treatment programs developed in settings around the world. These pilot programs generally had three aims: 1) to demonstrate the effectiveness of these new regimens; 2) to save the lives of HIV-infected patients who had progressed to AIDS; and 3) to develop local expertise in the use of ARVs and the care of HIV-infected patients. These pilot treatment programs were often supported by funding from international agencies and NGOs, and typically provide treatment for between 20 and 200 HIV-infected people.

Over the past few years, the emphasis has shifted from pilot programs to the goal of “scale-up”: extending the availability and impact of ARV treatment to hundreds, thousands, and millions of HIV-infected people. Several factors have been implicit in these scale-up efforts: that ARV
treatment is effective, affordable, and sustainable, and can be operationalized alongside HIV prevention and other public health programs.

Models
In different settings, several models have developed by which HIV care and treatment has been scaled up to reach larger numbers of people. In general, models have developed according to local resources and pre-existing health care systems and infrastructure. Not all of the models have been equally successful in all settings, and as the scale-up of HIV care and treatment is still in the earliest phases, the optimal approach to delivering HIV care and treatment to hundreds of thousands of people in one system remains unknown. The distinct models will be reviewed briefly below. Keep in mind that a combination of two or more models may be most appropriate for a given setting.

Public Health Model – Vertical Programs – In some settings, the various elements of HIV care and treatment described earlier have been developed into distinct programs along traditional public health lines. The first of these programs to be introduced in this manner were the Voluntary Counseling and Testing (VCT) programs. While the utility and impact of VCT extend beyond care and treatment, encompassing prevention and other public health efforts, VCT is also essential to HIV care and treatment. More recently, programs targeting the prevention of mother-to-child transmission (PMTCT) have been established in several countries. In these programs, ARVs are made available to pregnant women late in their pregnancy, in order to prevent HIV infection to newborn babies. "PMTCT Plus" programs extend access to ARVs to mothers and families after birth to prevent orphanhood.

In general, the key features of programs developed along the public health model are that specific groups of HIV-infected or at risk people are identified and targeted for interventions, including care and treatment. While this has been successful in some settings, the need for comprehensiveness in HIV care has limited the ability to scale up these programs to large numbers of people.

Primary Care Model – Integrated Programs – In some settings, the various elements of HIV care and treatment described earlier have been incorporated into primary health care. In effect, HIV is considered and approached just as any other disease would be—diabetes, hepatitis B, malaria—and care and treatment is offered in the context of existing primary care programs. All health care providers are trained in the provision of HIV care, and ARVs are (when resources permit) made available in widespread settings.

In general, the key features of programs developed along the primary care model are that the extensive resources necessary for successful treatment are not readily available. The lack of centralization to coordinate care and provide expertise can lead to poor implementation and limited uptake of care and treatment services.

Tuberculosis Care Model – In some settings, the similarities in HIV care and TB care have led to the incorporation of HIV care and treatment efforts into existing TB treatment programs. Both diseases require effective recognition, diagnosis and staging of infection, central procurement and distribution of a limited number of drugs, close monitoring of treatment and monitoring of drug resistance. Because of the similarities in training and infrastructure requirements, HIV treatment has been absorbed into TB treatment programs in a few settings. These efforts are more recent, and limited data are available to evaluate their success.
**NGO Model** – Many pilot programs were established under the auspices of non-governmental organizations (NGOs). Depending on the nature of the NGO, these programs focused on different elements of HIV care and treatment—testing vs. ARV use vs. palliative care, for instance. As programs grew, they incorporated more elements of HIV care and treatment, and several NGO-based efforts now provide comprehensive HIV care to a large number of people. The largest of these is run by Medecins sans Frontieres (MSF), an international NGO based in France.

The strength of the NGO model is in its flexibility and ability to reach people most in need. To date, however, the decentralized nature of most NGO programs, their variability in focus and implementation, and resource limitations have limited the number of HIV-infected that can be reached.

**Private Sector Model** – In many areas where the impact of HIV has been felt the most, private companies have recognized that their supply of labor—young, healthy adults—is in jeopardy. Particularly in middle-income countries (such as Botswana and South Africa) private companies, often multinationals, have established their own, internal HIV care programs. These programs tend to follow traditional private models of care with corporate health insurance schemes paying for basic services aimed at keeping a healthy labor force. Largely because of the availability of resources and the use of established disease management programs, these efforts have been extended to reach several thousand HIV-infected people in southern Africa.

**Cases studies of individual countries**

**Haiti**—Haiti’s experience with HIV has been especially informative. Haiti has the lowest per capita GNP in the western hemisphere, and was one of the earliest countries where the HIV epidemic emerged. Because of the political instability and extreme limitations on resources, HIV care and treatment through a national public sector program has been impossible, as even basic services—food, water, electricity, primary health care—are unavailable to many Haitian citizens. Nonetheless, Haiti has one of the most successful HIV treatment programs in the world. More than one thousand Haitians are enrolled into care, and more than 1,700 are receiving ARVS, many of whom began treatment as long ago as 1996. This care and treatment effort incorporated two models—the NGO model and the TB model—using pre-existing TB treatment services developed by an NGO, Partners in Health, to provide successful HIV care.

**Thailand**—Thailand has faced an HIV epidemic longer than many countries, as the first cases were recognized in 1984. The virus spread rapidly from high-risk populations of intravenous drug users and commercial sex workers, into the heterosexual community. At the end of 2001, Thailand’s adult HIV prevalence was 1.8%. Relative to many other countries, Thailand developed a comprehensive strategy to combat HIV that has proven quite effective. Although prevention activities have been a strong component, HIV care and treatment has been available in Thailand for longer than most other countries as well. VCT programs are widespread and highly utilized, and PMTCT programs are among the most mature in the world, implemented nationally since 2000. More recently, Thailand has embarked on a national comprehensive treatment program, and the Thai government has become directly engaged in the manufacture of ARV medications for domestic use.

**Brazil**—Recognizing the threat posed by HIV early in the epidemic, the government of Brazil passed legislation in 1996 authorizing universal access to HIV treatment for all Brazilian citizens. Through both negotiations and public pressure, the government was also able to obtain lower prices for ARVs than most countries, making universal treatment affordable and
sustainable for the government budget. By 2002, 125,000 of Brazil's 600,000 HIV-infected citizens were receiving free care and treatment with ARVs. The impact has been enormous: 80% reductions in mortality from HIV, stable seroprevalence rates, large reductions in tuberculosis rates, and an overall cost savings to the health system calculated at US $2.2 billion.

South Africa- South Africa, with a population of 44.8 million people and more than 5 million living with HIV infection, has the largest number of HIV infections of any country in the world. Unlike Thailand, the South African government was initially slow to adopt a comprehensive approach to HIV care and treatment. More recently, however, the government has adopted a comprehensive program that includes all elements of HIV care and treatment, and will be made available to all HIV-infected citizens equally across the country. As of December 2004, an estimated 37,000-62,000 people were on ARVs in South Africa. As treatment rolls out on a massive scale, the South African experience with ARVs will provide information critical to the success of other programs in Africa and throughout the world.

Recommended Readings:


CHAPTER 11: IMPACT MITIGATION STRATEGIES FOR HIV/AIDS

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Background and goals

The primary goals of the social impact mitigation module are to understand the importance of the meaning of “impact mitigation” in response to HIV/AIDS, to present successful examples of impact mitigation at different levels and for different target populations in a variety of countries, including Vietnam, and to highlight concrete ways to mitigate some of the social impacts related to HIV/AIDS. For this module, we begin by reviewing the ways in which HIV/AIDS impacts on individuals and other groups in society - families, workplaces, communities – and even nations as a whole. The module brings out relevant evidence from other countries, with a focus on mitigating the impacts of large numbers of orphans – sometimes described as the “third wave” of the epidemic (following high rates of illness, and then death, among adults), which indicates that rising orphanhood is one of the most difficult and complex consequences of HIV/AIDS.

Vietnam is still at a relatively young stage in the epidemic, and has not yet experienced the high rate of AIDS-related orphanhood already evident in some communities in China and other countries. Fortunately, the myriad ways in which families, communities, local and international NGOs, and even national governments around the world have responded to the challenge of raising AIDS orphans offer a range of program and policy models.

The first part of the module introduces the concept of HIV/AIDS as an illness that begins in an individual, but that can quickly spread beyond that individual through a series of “ripple effects”. When a person is HIV infected or dies, a wave of impacts is created – in areas that affect the entire community, not just the infected population. These impacts include loss of income; lower rates of education attainment; and lower rates of productivity that result in decreased earning, spending, saving, and often increased poverty.

The underlying message is that impacts may be enormous, not only on individuals, but also on families and communities. However, with appropriate programs and adequate resources, many of these impacts can be significantly mitigated. Numerous relevant examples from around the world indicate that it is possible to introduce interventions that reduce suffering and improve the chances of achieving larger development goals, like reducing poverty and child mortality.

What Is Impact Mitigation?

The second part of the module focuses on defining impact mitigation and its focus – reducing the negative impacts of the third wave associated with the HIV/AIDS epidemic. Impact mitigation should ideally focus on individuals, families, and communities, as well as other social groupings. Such interventions may be combined with prevention and treatment projects, but assistance must be tailored to specific circumstances.
It is important to bear in mind that impact mitigation is a key component of a comprehensive strategy of fighting the HIV/AIDS epidemic at every level: local, regional, and national. While prevention of infection reduces future infections, death, and suffering, and care and treatment provides critical assistance to those currently infected, impact mitigation helps those both infected and affected by HIV/AIDS. All three types of programs are necessary for a truly comprehensive and effective response to the HIV/AIDS crisis.

**Best Practices from Around the World**

UNAIDS has defined “best practice” as meaning accumulating and applying knowledge from different situations and contexts about what is working, and what is not working, in the response to the HIV/AIDS pandemic. This means that although nothing that works in one place is guaranteed to work in another place, we can still learn lessons from others’ experiences, offer feedback, and adapt these experiences to other circumstances. “Best practices” stresses that we should share our cumulative experiences, successes and failures, so that we don’t always “invent the wheel” in our efforts to respond to HIV/AIDS.

What best practice experience can mean for Viet Nam is that there are concrete steps that can be taken that will achieve real results. This means steps that can reduce suffering and improving the quality of life of those infected and affected by HIV/AIDS, reduce short – term and long – term socio-economic costs, and contribute to related national and local objectives, such as the achieving the Millennium Development Goals. Providing a range of these best practices is the focus of this part of the module.

It is important to remember that there is no single model for providing assistance for impact mitigation. A variety of different types of institutions provide support for HIV/AIDS infected individuals and their affected communities – local and international organizations such as NGOs (including those of People Living with HIV/AIDS), government agencies, and private companies. Support may be comprehensive or focused, and may target different groups and levels of individuals and groups throughout communities, regions, or nations.

I. Support for HIV-positive individuals

Support for people living with HIV/AIDS (PLWHA) themselves is key to effective impact mitigation. Care and treatment, including ART, prolongs life, is cost-effective, and reduces household impacts by keeping adults alive and families together. Free ART for HIV-positive persons, where there is effective access, is an important impact mitigation intervention – and is an example of how impact mitigation and care and treatment programs can overlap and mutually reinforce each other.

Economic, social and psychological support for HIV-positive individuals may be effective even in the absence of treatment. This includes household emergency assistance, as well as comprehensive and focused programs supporting legal, housing, nutrition, psychosocial, and economic needs. Programs for HIV-positive infected children and youth, as well as children orphaned by HIV/AIDS, may include basic housing and food assistance, mentoring, education and psychosocial support, as well as access to pediatric ART and adherence support.

*Greater Involvement of People Living with AIDS (GIPA)*
Involving people infected with HIV/AIDS in the response to the epidemic was enshrined in 1994 when the Paris AIDS Summit Declaration called for the “Greater Involvement of People Living with HIV/AIDS,” or the GIPA principle. UNAIDS has broadened the GIPA Principle to include those **affected as well as infected** by HIV/AIDS, with the understanding that no one can speak for a person living with HIV except a person living with HIV, nor can anyone speak for the bereaved widow or orphan of someone lost to AIDS, except someone with that experience. GIPA is critical – to **include those living with the virus** in decisions that affect their lives and to **increase the effectiveness** of policy and programming design and implementation.

**GIPA Examples**

**UNDP (REACH) supported program in Guangdong Province, China.** The program's goals are to improve the lives and well-being of people living with and affected by HIV/AIDS, to provide care and support to people living with HIV/AIDS (PLWHA), to empower PLWHA to enhance GIPA in China, and to advocate for the prevention and the de-stigmatization of the disease. The program focuses on providing life-building supports like referrals and day centres, as well as advocacy skills.

**Bright Futures, Viet Nam.** The program was established in 2003 and is internationally funded, Bright Futures is a PLWHA group with a core Hanoi-based team that organizes and trains local Bright Futures groups throughout Viet Nam. By year-end 2005, there were 13 of these local groups in 10 provinces, with over 500 members nationwide. Bright Futures focuses on educating new members about HIV/AIDS, counseling members on opportunistic infections and ART, providing spiritual support and hot line counseling, providing home based care for PLWHA, facilitating access to health services, and working with Intravenous drug users (IDUs) on prevention.

**Examples of treatment for HIV positive children**

**Worldwide Orphans, Viet Nam.** This organization conducted the first training program on pediatric HIV/AIDS in Viet Nam in May 2004. This organization works with UNICEF to import pediatric three-drug ARV treatment into Vietnam and collaborates with the staff of the Tam Binh Orphanage outside HCMC to ensure that the children living there receive comprehensive and appropriate care. Worldwide Orphans is also committed to providing ART to 25 HIV+ orphans at Tam Binh, is developing plans to replicate training and treatment program at other sites in Viet Nam, and aims to eventually provide ART to all HIV+ children in Viet Nam who need it.

**II. Support for Households and Communities**

Effective interventions most often mean developing one or more of the following: emergency and short-term assistance, long-term income and other support programs, and anti-stigma and discrimination programs, including public awareness and advocacy. Emergency assistance may include any combination of key necessities, such as housing, food, income support, education, health care services, legal assistance, and psychosocial counseling and support. This latter type of service is one that has proven to be both badly needed and, when provided effectively, can help children as well as adults overcome the trauma and sorrow associated with losing loved ones. Long-term
income and support programs typically include support in one of the above areas, but with a longer time horizon and a focus on sustainability.

Examples of support for households affected by HIV/AIDS

Empathy Club Alliance, Viet Nam. This organization is managed by the Viet Nam’s Women’s Union and represents a model for support for women infected and affected by HIV/AIDS. Key objectives of the Alliance are to: reduce transmission of HIV/AIDS, minimize the impacts of HIV/AIDS on women, children, households, and broader communities, reduce stigma and discrimination against PLWHA and their families. By 2004, the Alliance had 102 clubs in 3 provinces, with a total of 3,974 members. Key activities included spiritual support, exchange of experiences, knowledge exchange, care and support, financial aid, training courses, and condom promotion and distribution.

III. Support for affected children, including orphans

As is the case with support for other individuals, support for children affected by HIV/AIDS, including orphans but other children as well, may be provided in a comprehensive or focused fashion. Effective forms of support include basic care (housing and food assistance, for instance), education, health care, psychosocial services, and protection of rights. Countries that have made a major commitment to assisting children affected by HIV/AIDS have put in place national policies and programs that focus on children. These countries include:

- Vietnam: National HIV/AIDS Strategy – policy of providing all HIV infected or affected children with treatment, care, and counseling
- China: through the “Four Frees and One Care” program, free elementary education is provided to children orphaned by AIDS
- Thailand: provides a range of comprehensive support programs for children
- Uganda: through the “National Strategic Programme Plan of Interventions” for orphans and vulnerable children, the national government provides comprehensive services for children affected by HIV/AIDS

Important lessons have been gained from the policies and programs that have been implemented thus far in various countries. First, it is clear that although local interventions may work in the short-run, sustainable solutions require collaborative, high-level support, usually with a vocal and committed government spokesperson or agency. Second, interventions for children are most effective when implemented before a parent dies, particularly because experience has shown that income and psycho-social impacts on children are greater after parental death. Third, although institutional care may be necessary in some cases, home and community care is preferable to institutions. Experts have long concluded that children raised in institutions often lack basic social and cultural skills, have lower educational attainment, cannot adjust to independence, have more difficulties with relationships, and lack parental skills. Fourth, programs for HIV/AIDS-affected children should not single them out as “HIV+” or as “AIDS orphans”. These designations exacerbate stigma and feelings of shame and, typically, their needs are similar to those of other children.
Examples of support for children affected by HIV/AIDS

Chi Heng Foundation, Hong Kong. This NGO provides assistance to AIDS-affected children and their families in several provinces of China that have been heavily impacted by HIV/AIDS, including Henan. The organization works with entire villages, not only selected households in a village. As of year-end 2005, Chi Heng was helping over 2,000 children, mainly by providing educational fees so that children are able to remain in school, but also by offering ART, housing, basic food, and psychosocial support to those in greatest need.

National Strategic Programme Plan of Interventions, Uganda. Beginning in the 1990s, Uganda's national government recognized that the country was in danger of creating a “lost generation” of children due to the devastating effects of HIV/AIDS. In 2001, the Ugandan government asked the Center for International Health and Development at Boston University School of Public Health to work with the Ugandan government, international NGOs, and Ugandan researchers to carry out applied research on Ugandan orphans and, later, to draft a National Strategic Policy and Plan of Interventions that focused on providing a broad range of services and assistance to children affected by HIV/AIDS. The Plan was approved by Parliament in 2003, and funded by the Global Fund to fight HIV/AIDS, TB, and Malaria. A multi-sectoral effort, the Plan included an implementation framework that outlined the roles and responsibilities of national and local government agencies, private sector agencies, multi-lateral agencies, and the media. Key areas identified for interventions were: socioeconomic security; food security and nutrition; care and support; mitigation of the impact of conflict; education; psychosocial support; health; child protection; legal protection; and capacity strengthening and resource mobilization.

IV. Support for workers in companies

Many companies around the world have implemented services that aim to provide prevention and treatment services for employees. Among them, Ford Motor Company, Heineken, and Coca Cola are known for their workplace HIV testing and treatment centers. Other companies have put in place support programs for affected families that provide effect impact mitigation assistance. These include Ford Motor Company, DaimlerChrysler, and Pan Pacific Hotels and Resorts. Such programs are often able to reach individuals and households that do not have access to other forms of support and therefore play an important role in the AIDS response.

Examples of support for workers in companies


- Prevention through information and education – gender specific programs; community outreach programs
- Training – for managers; workers’ representatives; health and safety personnel
• Testing – voluntary; prohibited for hiring, insurance
• Care and support – parity with other serious illnesses; counseling; healthcare services, benefits, and coverage; privacy and confidentiality; employee and family assistance programs

V. Support for regions/countries

At broader levels such as regions and countries, many of the most effective programs have been comprehensive assistance programs implemented by governments or other agencies. These may be included within a HIV/AIDS plan or other national assistance/welfare plans. Examples of such programs have been described above. There are also many examples of programs with a specific focus, such as on a particular population (PLWHA, children, female heads of household, the elderly, for example), on knowledge and attitudes (prevention, anti-stigma and discrimination programs, for example), and on types of assistance (emergency housing, food, health care services, psychosocial counseling and support, income support, education, legal assistance, for example).

Examples of support for regions and countries

*National Plan for the Prevention and Alleviation of HIV/AIDS, Thailand.* This plan covers 2002-06 and engages 12 ministries and the Prime Minister’s Office in meeting specific targets. The target most relevant to impact mitigation states that at least 80% of PLWHA and affected individuals will have access to and receive care and support from public, private and community providers of social, economic, education, and primary health care services. In 2004, the budget was 1.6 billion baht (US$ 40,000,000) for alleviation programs. For children, the government supported the engagement of numerous public organizations, temples, and over 600 NGOs that provide many basic needs for Thailand’s youngest affected population.

*National Strategy on HIV/AIDS Prevention and Control, Viet Nam.* The Strategy covers the years from 2004-2010 and engages People’s Committees, various ministries, the National Committee for AIDS, Drug and Prostitution Prevention and Control, and media organizations in implementing programs for those in Viet Nam who are infected and affected by HIV/AIDS. Its specific objectives include the provision of care and treatment to 90% of HIV+ adults and 100% of infected and affected children. Of six of the major solutions presented in the Strategy, one focuses on impact mitigation, stating that care and support for HIV/AIDS infected people and alleviation of social and economic impacts of HIV/AIDS are an important part of the National Strategy.

Continued challenges

In this part, we focus on the main challenges currently facing the design and implementation of impact mitigation policies and programs. First, while national policies tend to focus mainly on the medical aspects of HIV/AIDS, impact mitigation requires broad policy responses and strong leadership. One of the main challenges facing many aspects of an effective HIV/AIDS response is adequate funding. Countries may find it a relatively painless task to develop a national policy or plan, but backing it up with sufficient resources does not automatically articulating a plan. Typically, international and national agencies expect local groups to bear the financial burden of local interventions, often due to “tradition” or to a sense that only local groups know what
needs to be done and should therefore not only take the lead in developing solutions but also in paying for them. Because many programs are costly, some local areas simply do not have enough resources to them, and the only way to provide effective assistance is from higher level agencies.

Another major challenge is that HIV/AIDS continues to be a misunderstood, stigmatized illness that is associated with behaviors considered socially undesirable (i.e., IDU, commercial sex work). This tends to stifle policy and program development while inhibiting access to assistance.

Balancing short-term and long-term solutions is also extremely difficult. In an area where families are coping with the loss of income-earners, prioritizing immediate food needs or projects that improve longer term food security (i.e., micro-financing, training) is not simple or obvious.

**Effective Impact Mitigation**

Impact mitigation, because it deals with a wide range of different issues and problems, some of which – like psychosocial impacts on children – may be less obvious and more complicated than providing medical treatment, requires a particularly strong commitment and willingness to dedicate significant resources to considering and implementing interventions. Some specific aspects of this challenge include:

- National leadership and political commitment at all levels
- Adequate funding for financial sustainability – typically needs national resources
- Multi-sector response and collaboration
- Encouragement and support for local and international NGOs to operate
- Priority-setting, to maximize the effectiveness of scarce resources
- Participation of those affected and assisted

In meeting this challenge, the experience of different countries suggests that agencies at different levels may be better suited to certain tasks than others. For example, national and provincial agencies have typically been best at the following types of activities: providing political will and support, providing resources for long-term program sustainability, establishing policy agendas & institutional frameworks, and promoting an open, enabling, collaborative environment. Local level agencies, on the other hand, are often better at tasks such as: providing short-term, limited assistance, ensuring that interventions are suitable for communities, identifying and prioritizing local issues and needs, and ensuring the inclusion of key local stakeholders in design and implementation of interventions.

**Endnotes**

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