Community Action on HIV

A RESOURCE MANUAL FOR PREVENTION, CARE AND SUPPORT (2nd edition)

EDITORS: TAMARA KWARTENG, ROB MOODIE, MIKE TOOLE, WENDY HOLMES
Community Action on HIV:  
A Resource Manual for Prevention, Care and Support (Second edition)

Editors: Tamara Kwarteng, Rob Moodie, Mike Toole and Wendy Holmes

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### Abbreviations and acronyms

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>AIDS</td>
<td>Acquired Immune Deficiency Syndrome</td>
</tr>
<tr>
<td>ANC</td>
<td>Antenatal clinic</td>
</tr>
<tr>
<td>APCASO</td>
<td>Asia Pacific Council of AIDS Service Organisations</td>
</tr>
<tr>
<td>APN+</td>
<td>Asia Pacific Network of Positive People</td>
</tr>
<tr>
<td>ART</td>
<td>Antiretroviral therapy</td>
</tr>
<tr>
<td>ARV</td>
<td>Antiretroviral</td>
</tr>
<tr>
<td>AZT</td>
<td>Azidothymidine</td>
</tr>
<tr>
<td>BCC</td>
<td>Behaviour change communication</td>
</tr>
<tr>
<td>CBO</td>
<td>Community-based organisation</td>
</tr>
<tr>
<td>CD</td>
<td>Community development</td>
</tr>
<tr>
<td>CDC</td>
<td>Centers for Disease Control (United States)</td>
</tr>
<tr>
<td>CHES</td>
<td>Community Health Education Society</td>
</tr>
<tr>
<td>CMR</td>
<td>Child mortality rate</td>
</tr>
<tr>
<td>CMV</td>
<td>Cytomegalovirus</td>
</tr>
<tr>
<td>DHS</td>
<td>Demographic health survey</td>
</tr>
<tr>
<td>DNA</td>
<td>Deoxyribonucleic acid</td>
</tr>
<tr>
<td>DOTS</td>
<td>Directly observed treatment–short course</td>
</tr>
<tr>
<td>ELISA</td>
<td>Enzyme-linked immunosorbent assay</td>
</tr>
<tr>
<td>FGD</td>
<td>Focus group discussion</td>
</tr>
<tr>
<td>FHI</td>
<td>Family Health International</td>
</tr>
<tr>
<td>GPA</td>
<td>Global Programme on AIDS</td>
</tr>
<tr>
<td>HAART</td>
<td>Highly active antiretroviral therapy</td>
</tr>
<tr>
<td>HBC</td>
<td>Home-based care</td>
</tr>
<tr>
<td>HIV</td>
<td>Human Immunodeficiency Virus</td>
</tr>
<tr>
<td>ICASO</td>
<td>International Council of AIDS Service Organisations</td>
</tr>
<tr>
<td>IDU</td>
<td>Injecting drug user</td>
</tr>
<tr>
<td>IEC</td>
<td>Information, education and communication</td>
</tr>
<tr>
<td>IMR</td>
<td>Infant mortality rate</td>
</tr>
<tr>
<td>INGO</td>
<td>International NGO</td>
</tr>
<tr>
<td>KABP</td>
<td>Knowledge, attitudes, beliefs and practices</td>
</tr>
<tr>
<td>KAS</td>
<td>Kenya AIDS Society</td>
</tr>
<tr>
<td>KS</td>
<td>Kaposi's sarcoma</td>
</tr>
<tr>
<td>LAC</td>
<td>Latin America and Caribbean</td>
</tr>
<tr>
<td>MCH</td>
<td>Maternal and child health</td>
</tr>
<tr>
<td>M&amp;E</td>
<td>Monitoring and evaluation</td>
</tr>
<tr>
<td>MSM</td>
<td>Men who have sex with men</td>
</tr>
<tr>
<td>MTCT</td>
<td>Mother-to-child transmission</td>
</tr>
</tbody>
</table>
NGO(s) Non-government organisation(s)
NNRTIs Non-nucleoside reverse transcriptase inhibitors (antiretroviral drug)
NRTIs Nucleoside reverse transcriptase inhibitors (antiretroviral drug)
PCC Project coordinating committee
PCP Pneumocystis carinii pneumonia
PCR Polymerase chain reaction
PEP Post-exposure prophylaxis
PHC Primary health care
PI(s) Protease inhibitor(s)
PICT Pacific Island Countries and Territories
PLA Participatory learning and action
PLWHA People living with HIV/AIDS
PNG Papua New Guinea
PSI Population Services International
PTCT Parent-to-child transmission
RTI Reproductive tract infection
SMART Specific, measurable, achievable, relevant and time-bound
SPEHIS South Pacific Epidemiological and Health Information Service
STI(s) Sexually transmitted infection(s)
SW Sex worker
TASO The AIDS Support Organisation
TB Tuberculosis
TBA Traditional birth attendant
UNAIDS Joint United Nations Programme on HIV/AIDS
UNFPA United Nations Population Fund
UNDCP United Nations International Drug Programme
UNDP United Nations Development Programme
UNESCO United Nations Educational, Scientific and Cultural Organisation
UNICEF United Nations Children’s Fund
VCT Voluntary counselling and testing
WB Western Blot (confirmatory HIV antibody test)
WHO World Health Organization
Introduction

The first edition of Community Action on HIV was written in 1995 to support community responses to HIV. It was designed primarily for Australian development NGOs working in developing countries, with the secondary audience being the partner NGOs in developing countries. The response to the first edition was very encouraging. It was translated into Russian, Indonesian and Thai.

The Australian Agency for International Development (AusAID) supported the production and printing of this second edition, and translations into Hindi and Lao.

The manual consists of five sections: ‘Understanding HIV’; ‘Planning a response’; ‘Strategies for action’; ‘Focussing action’; and ‘Implementing a response’.

The first section, ‘Understanding HIV’, is a combination of factual information about the virus and infection, developments in treatments and vaccines, information about the status of the epidemic around the world, the impact of the epidemic and global responses to it.

The second section, ‘Planning a response’, provides information relevant to planning for HIV prevention, care and support. It covers questions, methods used to gather information effectively, and a guide to assist with developing a plan of action.

The third section, ‘Strategies for action’, presents a framework and strategies for responding to HIV, informed by lessons learnt from the past two decades of action on HIV. In Chapter 6, we describe a framework. The central theme of the framework for a community action of HIV is the integrated response, addressing all aspects of the multi-dimensional problem. The other chapters in the section describe the various strategies – behaviour change strategies; supportive health and social services; care and support of people infected and affected by HIV; and a supportive social and legal environment – which make up an integrated response.

In section four, ‘Focussing action’, we address selected issues important to effective responses to HIV and AIDS. To show how the broad strategies can be adapted to meet specific needs, we discuss prevention programs for specific population groups. We do not describe how prevention and care programs for every possible population group can be designed. We do, however, highlight similarities in strategies used for different groups, including chapters covering Women and AIDS; Sex work and HIV; and Injecting drug use. We also show that important differences between groups need to be considered when defining strategies.

The fifth section, ‘Implementing a response’, focuses on the practicalities of putting a community response to HIV in place. This includes practical issues involved in implementing, monitoring and evaluating an HIV project. We draw out lessons for facilitating community action, including a central lesson for all HIV responses: effective HIV prevention and care requires action within communities themselves. Relevant references and lists of additional resources can be found at the end of chapters.

You might use the manual as a reference to check information or to find relevant resources to assist in research about HIV to help in planning community-based HIV responses and writing proposals for funding. You could also look to the manual as a source of ideas for ways to incorporate HIV prevention and care activities into your work if you’re already working in HIV prevention and care, and to find suggestions about other strategies which you might try in your community.
The manual has been designed to encourage people to browse through any section, rather than reading through it from start to finish.

An African proverb states that ‘One who does not cultivate one’s field will die of hunger’. Governments and communities, including people living with HIV, can ‘cultivate’ effective HIV prevention, treatment and care. Despite the many success stories of community action around the world, we cannot assume that communities can go it alone.

This manual is designed to help people plan effective, community-based HIV responses. Community action is an essential ingredient of effective HIV responses.
1

Understanding HIV

Chapter 1: The basics: background information on HIV
Chapter 2: HIV in the world
Chapter 1
The basics: background information on HIV

by Wendy Holmes

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Introduction

Since the first clinical evidence of AIDS was reported, all aspects of the disease have been studied intensively. Following the discovery of Human Immunodeficiency Virus (HIV) in 1983, scientists have been able to determine the make-up of the virus, how it enters host cells and how it replicates. These studies have been important in the development of drugs to attack HIV. The discovery of the virus also enabled scientists to develop laboratory tests for the infection. Until then the infection was defined only by the illnesses that it caused.

We now know more about the long and variable natural history of the infection: a person infected with HIV may have no symptoms for up to ten years or more. But during this ‘hidden’ period, the virus continues to slowly infect and damage the defence cells of the body. The person then becomes open to other infections such as tuberculosis.

We are learning more about how to manage HIV-related illness. Preventing and treating opportunistic infections is important, especially when anti-HIV drugs are not available. Anti-HIV drugs are becoming more affordable and so more widely available. Protocols are being developed for lower-cost treatment and monitoring regimens, although rapid resistance of the virus to the drugs is a great worry.

Knowledge about the ways in which the virus can pass from one person to another has been essential for developing prevention strategies. In recent years particular attention has been paid to methods for preventing the spread of HIV from an infected woman to her baby. Many scientists are working on the development of HIV vaccines – the best hope for effective prevention. But the complex nature of this virus makes it likely that a safe and effective vaccine will not be available for many years.

In this chapter we describe the basic facts that have been learned about HIV infection in the past two decades. New information is becoming available all the time so it is important to keep up to date. In Appendix 2 we provide the addresses of some websites to help you to keep in touch with new information.
The virus

The Human Immunodeficiency Virus (HIV) causes AIDS (Acquired Immune Deficiency Syndrome). The syndrome, or pattern of illness, was first described in the United States in 1981, but the virus that causes the immune deficiency was not discovered until 1983.

Like other viruses, HIV is only able to multiply inside the cells of the infected person. This is because although viruses contain the instructions (genetic material) to make new viruses they lack the machinery to do so. Unlike many viruses, the genetic material of HIV becomes part of the genetic material of the host cell. When the infected host cells multiply, each new cell contains the genetic material of HIV. In this way, HIV sets up a permanent infection. When infected cells are stimulated they produce new viruses. ¹

HIV infects and damages or destroys the T4 white blood cells of the body. The T4 cells are responsible for coordinating the complex functions of the body’s immune system. HIV is also able to infect other cells of the immune (or defence) system, brain cells and gut cells.

In this manual we use HIV to refer to HIV-1.

There are ten genetic sub-types of HIV. These are labelled HIV-1 A to HIV-1 I, and HIV-1 O. The sub-types have different rates of transmission and disease development.³

HIV is able to survive outside the body for a brief period which depends on factors such as the fluid around the virus and the temperature. The virus is sensitive to heat and is killed at 56°C. It is best to sterilise needles, instruments and equipment by autoclaving, boiling or steam sterilisation. Chemical disinfection is satisfactory only if instruments are cleaned well before sterilisation. Organic matter, such as blood or secretions, may prevent the chemical from inactivating the virus. Sodium hypochlorite (bleach), glutaraldehyde (fresh 2% solution), formalin 4%, polyvidone iodine 2.5%, chloramine 2% and hydrogen peroxide 6% are all effective. Salt solution, 70% alcohol and phenolics such as Dettol have been found to be ineffective for sterilisation purposes.⁴

Stages of infection

During the first few weeks after exposure to the virus, HIV multiplies rapidly. Next, usually within three months, the person starts to produce antibodies to HIV; this process is called sero-conversion. Antibodies are formed to a variety of components of the virus. However, most of these antibodies are not neutralising antibodies; they cannot overcome the infection. The virus mutates frequently, especially the gene for the virus envelope which is the part of the virus that the host’s immune system recognises first. Also the virus sheds bits of protein (antigens) from the envelope which makes it difficult for antibodies to attach to the virus.

Many people experience an acute illness at the time of sero-conversion, with fever and enlarged lymph glands. Some have neurological symptoms. The illness lasts about 14 days, and may be mistaken for glandular fever, dengue fever or flu. Subsequently, most people infected with HIV have no symptoms for months or years; this period of silent infection is called the ‘latency period’. During the latency period the virus is replicating.

BOX 1.1: HIV-2

HIV-2 is another human retrovirus that damages the immune system and causes AIDS. The virus is quite similar to HIV-1, and is transmitted in the same ways, although less easily. Although the disease caused by HIV-2 is also fatal, it appears to progress more slowly and less severely. HIV-2 was first identified in West Africa and since has been identified in many parts of the world, including Asia. It is less common than HIV-1. The rate of mother-to-child transmission of HIV-2 appears to be low. Recent evidence shows that infection with HIV-2 provides partial immunity to infection with HIV-1.²
slowly and there are low levels of virus in the blood. The HIV antibody test is positive. Later, the number of T4 cells decreases and infected people develop clinical symptoms. They may suffer a wide range of symptoms including loss of weight, tiredness, fever, cough and diarrhoea. The latency period is long and variable, and may range from four months to greater than 10 years. A period of three years without symptoms is typical.

Acquired Immune Deficiency Syndrome, or AIDS, is the name given to the final stage of HIV infection when the immune system is very weak. Many micro-organisms then have the opportunity to infect the person so these infections are called ‘opportunistic infections’. The weak immune system may also allow cancers to develop. Tuberculosis, Pneumocystis carinii pneumonia, fungal infections and cryptococcal meningitis are opportunistic infections commonly seen in AIDS patients. Kaposi’s sarcoma and lymphoma are common cancers. Neurological disease, due to direct infection of brain cells by the virus, may occur early or late in the course of HIV infection. In addition to the clinical manifestations suffered by both sexes, HIV-infected women may also suffer from severe vaginal herpes, candidiasis (thrush), and pelvic inflammatory disease, and are more likely to develop cervical cancer.

Between 10% and 30% of people infected with HIV will develop AIDS within five years and another 25% to 30% develop HIV-related symptoms. Approximately 60% develop AIDS within 12 to 13 years. A small number of HIV-infected people have never developed symptoms or immune deficiency. This may be due to defects in the viral genome, the host immune response, or the host genotype. Shorter times between HIV infection and the first signs of illness, and shorter survival times with AIDS, have been reported in African and Caribbean countries in comparison with developed countries. Access to new combination antiviral therapies and to antibiotics that prevent and treat opportunistic infections is increasing these differences. Where laboratory resources are available, the T4 (or CD4) cell count and the level of virus in the blood (the ‘viral load’) are useful predictors of progression to AIDS. Age, gender, concurrent illness, nutrition and HIV-1 sub-type may affect the pace of progression. Older people have declining immunity causing faster progress. Those infected with sub-type B tend to get sick more slowly than those with other sub-types. Gender effects are not well understood but women may progress more rapidly at lower viral loads than men. Studies show that pregnancy has little or no adverse effect on the progression of immune deficiency in women infected with HIV.

Definition of AIDS

The US Centers for Disease Control and Prevention (CDC) definition of AIDS is based on a list of diseases which indicates immune deficiency, and includes laboratory evidence of HIV infection and a low T4 white cell count.

Where there are no facilities for the diagnosis of indicator diseases or the detection of HIV antibodies, the World Health Organization (WHO) clinical definition may be used (see Table 1.1). However, this definition is not very accurate in diagnosing AIDS because it includes symptoms and signs such as chronic cough, weight loss and recurrent fever that may be common in individuals with other conditions, particularly tuberculosis. Some countries use their own modification of the clinical definition.
### TABLE 1.1: WHO GUIDELINES FOR DIAGNOSIS OF AIDS IN ADULTS

<table>
<thead>
<tr>
<th>Major signs</th>
<th>Minor signs</th>
</tr>
</thead>
<tbody>
<tr>
<td>• weight loss of over 10% of body weight</td>
<td>• persistent cough for more than one month</td>
</tr>
<tr>
<td>• fever for longer than one month</td>
<td>• general itchy skin rash</td>
</tr>
<tr>
<td>• diarrhoea for longer than one month</td>
<td>• recurring shingles (herpes zoster)</td>
</tr>
</tbody>
</table>

At least two major and one minor sign in an adult, in the absence of any other clear explanation for the signs (such as cancer or malnutrition), defines AIDS.

### Prognosis

Where antiviral treatment and prophylaxis for opportunistic infections are not available, people usually die within a year of diagnosis of AIDS. Where intensive monitoring and treatment are available, people with AIDS may live for many years. The main causes of death in developing countries are chronic diarrhoea, chest infection, cryptococcal meningitis, tuberculosis and disseminated Kaposi’s sarcoma.

### Transmission of HIV

HIV spreads in three ways: through sexual intercourse, through blood, and from mother to child. Behaviours which carry a high risk of infection include unprotected anal or vaginal sex and sharing needles or syringes for injecting drug use with an infected person. Infection through blood transfusion is a common problem in areas where blood donations are not screened for HIV. Fortunately the risk of health care workers becoming infected through needle-stick injuries is very small.

People are more infectious in the weeks after they become infected with HIV when there is a steep rise in the number of virus particles in the bloodstream. When the person starts to make antibodies the viral numbers (viral load) decreases. Later, when the immune system is damaged, the virus multiplies and the viral load in the blood increases again. The person shows signs of severe immune deficiency and they are more infectious to others.

The virus cannot be transmitted by coughing or sneezing; by shaking hands; by sharing a drinking glass, plates or cutlery; by hugging or kissing; by insect bites; by walking barefoot where people have spat; or by living or working with someone who has AIDS or HIV infection.
The pattern of transmission depends on behaviour patterns and varies from place to place, and in different groups within a population. HIV spreads rapidly where there is poverty or inequality.

**Transmission through sex**

Sexual activity is the most common route of transmission of HIV. Anal sex (whether male to male, or male to female) carries a higher risk of transmission than vaginal sex.

The risk of infection from a single act of vaginal intercourse when both partners have healthy genitals is low. The presence of sexually transmitted infections (STIs), especially those that cause genital ulcers or sores, increases the risk of both acquiring and transmitting HIV in men and women. This is because STIs increase the shedding of virus particles from inflamed surfaces and provide an entry site for the virus. Chlamydia and gonorrhoea are more common than ulcerative STIs. They may cause no symptoms and so remain untreated for long periods. For these reasons they may be relatively more important than ulcerative STIs in adding to the risk of transmission. An important study in rural Tanzania demonstrated that an affordable program of training health workers, providing simple antibiotics and public education to prevent and treat STIs reduced the incidence of HIV by about 40%. Other infections of the reproductive tract, not necessarily sexually transmitted, such as thrush (candidiasis) and bacterial vaginosis, may also increase vulnerability to HIV.

This is important because these are common and easily treatable conditions.

Studies in Europe have suggested that HIV passes from an infected man to a woman during sex more easily than it passes from an infected woman to a man. A study from Uganda found no difference in the risk. Young women are especially vulnerable to HIV. HIV is more likely to spread when sexual activity is rough or repeated frequently. Anything that increases the risk of vaginal abrasion such as use of sex ‘toys’, twigs or herbs to dry the vagina, is likely to increase the risk of transmission. There is evidence that uncircumcised men are at greater risk of becoming infected with HIV than circumcised men.

Women may be especially vulnerable to HIV infection when pregnant and post-partum. For social and cultural reasons they are more likely to be exposed to infection, and are more susceptible to infection for biological reasons.

Both male and female condoms reduce the risk of transmission through sexual intercourse.

<table>
<thead>
<tr>
<th>Mode of transmission</th>
<th>Infections per 100 exposures</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unprotected penis–vagina sex</td>
<td>0.05–0.1</td>
</tr>
<tr>
<td>Unprotected anal sex (Receptive)</td>
<td>0.8–3.2</td>
</tr>
<tr>
<td>Unprotected anal sex (Insertive)</td>
<td>0.03–0.09</td>
</tr>
<tr>
<td>Puncture of health care worker by contaminated needle</td>
<td>0.25</td>
</tr>
<tr>
<td>Use of contaminated injecting drug equipment</td>
<td>0.67</td>
</tr>
<tr>
<td>Mother-to-child transmission</td>
<td>15–45</td>
</tr>
<tr>
<td>Exposure to contaminated blood product</td>
<td>90–100</td>
</tr>
</tbody>
</table>

i In the absence of co-factors, such as other STIs and variations in infectiousness, over the incubation period.
Transmission through blood

Injecting drug use is becoming increasingly common in many countries, especially Asia. HIV and other blood-borne viruses spread very easily between people who inject drugs together and share needles, syringes and other injecting equipment. Blood drawn back into the syringe can pass directly into the bloodstream of the next person to use the syringe. HIV can then spread from infected drug users to others in the population through sexual intercourse or through blood transfusion.

Transfusion of contaminated blood can transmit HIV. Whole blood, red blood cells, platelets, plasma and clotting factor concentrate may contain HIV. Haemophiliacs lack a blood clotting factor and require injections of this factor to prevent bleeding. In the early years of the epidemic many haemophiliacs became infected in this way but now the clotting factor is heat treated and is no longer a source of HIV infection.

Since 1985 it has been possible to test donated blood for HIV antibodies before transfusion. Routine testing of all blood for transfusion greatly reduces the chances of transmitting HIV through blood transfusions, but there always remains a risk. This is because a donor can give blood after infection, but before they have developed antibodies, and before the test has become positive – the ‘window period’. The risk is greatest in areas where many people are becoming infected with HIV.

Detailed interview and physical examination in addition to blood testing are very important in screening potential donors before they give blood. In some countries routine screening of blood for transfusion is still not available everywhere.

In many countries most blood for transfusion is donated by volunteers or family members. In others there are people who regularly donate their blood for money. Some blood product manufacturers and commercial blood banks re-use needles and do not sterilise equipment. This practice has caused some paid blood donors to become infected. Some injecting drug users who are at high risk of HIV infection may sell their blood to obtain money for drugs. It is important to find another source of income for professional blood donors when a change is made to voluntary donation and screening.

Dual infection with HIV-1 and HIV-2 may occur so test kits that can detect both are necessary for screening of blood.

Whether blood for transfusion is screened or not, it is important to give blood transfusions only when it is absolutely necessary. Strict criteria for blood transfusion can reduce transfusions greatly without increase in mortality. It is sometimes possible to use the patient’s own blood for transfusion during or after operations.

HIV can also be transmitted from one person to another through transplantation of any organ or tissue. It is essential to screen the donor for HIV antibodies before any transplant, including corneal and skin grafts.

Transmission from mother to child

Timing of transmission

The risk of transmission from an infected mother to her child is between 15% and 45%. Transmission may occur across the placenta, at delivery, or after birth through breastfeeding. Maternal HIV antibody crosses the placenta so the HIV antibody test is positive whether the baby is infected or not. This has made it difficult to study the
timing of transmission. These maternal antibodies stay in the baby for as long as 18 months, although most babies lose maternal HIV antibodies by nine months of age. A review of the evidence suggests that in breastfeeding populations there is a 5–10% risk of infection during the pregnancy, 10–20% during labour, 2–10% in the first two months of breastfeeding, and a further 5–10% risk during later breastfeeding.

The number of children infected with HIV is increasing rapidly in countries where HIV has spread widely in adults. Most women who become infected with HIV are in the reproductive age group.

Factors that influence transmission

We are still learning about why some babies become infected and others do not. Studies show that the following factors affect the risk of transmission.

The mother’s viral load

This is the most important influence. It is high soon after infection and again, years later, when the white cell count drops and the woman becomes ill. So the risk is higher when:
- a woman becomes infected with HIV during pregnancy, especially late in pregnancy, or during lactation;
- a pregnant or breastfeeding woman has an HIV-related illness.

The health of the mother

The risk is higher when:
- the placenta and amniotic fluid are infected;
- there is poor maternal nutrition, especially micronutrient deficiencies;
- the mother has a sexually transmitted infection;
- a baby is born prematurely, before 34 weeks gestation.

Unfortunately studies of vitamin supplementation to pregnant women have not shown a reduction in risk of transmission.

Labour and delivery

The risk is higher when:
- there is prolonged rupture of membranes;
- interventions such as artificial rupture of membranes and foetal scalp electrodes are performed;
- the mother has a blood transfusion – especially when the blood is not screened.

It is possible that episiotomy increases risk, and there is good evidence that routine episiotomy does not improve outcomes for babies or mothers. Elective caesarean section (before the onset of labour) reduces risk, but in resource-poor settings it is important to consider the safety of the operation, access to surgery, long-term obstetric risks for the mother, the expense, and the need to explain to others why they are avoiding labour. Wiping the birth canal with the antiseptic chlorhexidine does not seem to reduce the risk of transmission, unless there has been prolonged rupture of membranes.

Breastfeeding

The risk is higher:
- when maternal immunity is low and viral load is high;
- when viral load in breast milk is high;
- in the first weeks of life;
- the longer the duration of breastfeeding;
- when there are breast problems (cracked nipples, mastitis, abscess);
- when the baby has oral or gut problems such as thrush and ulcers;
- and, probably, when breastfeeding is not exclusive.
Since 1994 a series of clinical trials has shown the efficacy of short courses of anti-HIV drugs during pregnancy in reducing the risk of transmission from an HIV-positive mother to her baby.\textsuperscript{18}

Because treatment with antiretroviral drugs lowers the viral load, women who are receiving combination therapy for HIV infection have a lower risk of transmission to their baby.

**Breastfeeding**

For many years the risk of transmission of HIV through breastfeeding was thought to be very small. A summary analysis of early observational studies in 1992 suggested that the additional risk of transmission through breastfeeding was 14\% when the mother was already infected during the pregnancy, and 29\% when the mother becomes infected during lactation.\textsuperscript{29} The only randomised controlled study of breastfeeding compared with formula feeding, which was carried out in Kenya, found an additional risk of HIV infection of 16\% attributable to breastfeeding.\textsuperscript{30} The data confirmed that most postnatal HIV transmission occurs early during breastfeeding, although some risk continues throughout the period of breastfeeding.

It is important to note that most babies born to and breastfed by HIV-infected mothers do not become infected with the virus and may benefit from the general and HIV-specific antibodies in breast milk.

Breastfeeding plays a vital role in protecting children’s health and has important nutritional and immunological advantages. Babies who are not breastfed have a high risk of death from malnutrition, diarrhoea, and respiratory infections.\textsuperscript{31} Breastfeeding also has important child-spacing, psychological and social advantages. The health benefits of breastfeeding are of most importance in the first six months of life.

It is biologically plausible that exclusive breastfeeding is less likely to lead to transmission of HIV, and may even protect babies against infection with HIV transmitted at the time of delivery. Exclusive breastfeeding means that the baby receives nothing but breast milk and is a rare practice in all societies.\textsuperscript{32} It is common for feeds of water or other fluids to be given before the milk ‘comes in’, and for cereals to be introduced in the first weeks of life. Breast milk contains protective antibodies and growth factors that promote maturity of the gut wall. Babies do not need to receive any food or fluids other than breast milk for the first six months of life. Other fluids or foods may result in inflammation of the gut wall that may increase the risk that HIV in the breast milk can enter the baby through the gut wall. Studies have shown that interventions to support mothers to breastfeed exclusively are effective.\textsuperscript{33}

The suggestion that exclusive breastfeeding may be protective has been strengthened by the findings of a South African study.\textsuperscript{34} The study found that the babies who were exclusively breastfed had a similar risk of infection with HIV to the babies who were never breastfed, and a lower risk of infection than those who were fed both breast milk and formula. However, because the mother–baby pairs were not randomly allocated to different feeding groups there may be other explanations for these findings.\textsuperscript{35} Further research is being conducted to determine the safest patterns of infant feeding for the babies of HIV-positive mothers.

The fact that breastfeeding carries a significant risk of transmitting a fatal infection presents policy makers with a difficult dilemma. The balance of risk will vary for different mothers in different settings. We discuss policy issues and recommendations in relation to HIV and infant feeding in Chapter 10.
Knowledge and experience of how to prevent HIV infection in children and provide care and support to infected mothers and their babies has increased rapidly in recent years. We discuss prevention and care strategies in Chapter 10.

**HIV infection in children**

Most HIV infection in children results from transmission from an infected mother. Some children become infected through blood transfusions, or from re-use of contaminated needles. Many children have become infected through sexual activity. In order to avoid exposure to HIV, older men may look for young girls, especially virgins. Poverty forces some young girls to become prostitutes, and some children are sexually abused in their own families.

Because maternal HIV antibodies cross the placenta, diagnosis of HIV infection is difficult in babies less than 18 months of age. Most of the signs and symptoms of HIV infection in children are common and non-specific, which makes it difficult to be certain of a clinical diagnosis.

Babies born to HIV-infected women have an increased risk of stillbirth, prematurity, low birth weight, and a higher risk of dying in the first week of life. The risk of these outcomes is higher when the mother has HIV-related illness.

The most common clinical features of HIV infection in children are failure to thrive, recurrent bacterial infections, especially pneumonia, recurrent and persistent diarrhoea, oral thrush, generalised enlargement of glands, itchy rashes, chronic cough, delayed development, neurological problems, and inflammation of the parotid salivary glands. In developing countries tuberculosis, malnutrition, post-measles syndrome, persistent diarrhoea and congenital syphilis cause the greatest problems in differential diagnosis. This difficulty is the greater since all these conditions may occur in HIV-infected children.

Several studies in Africa have followed up children born to HIV-infected mothers from birth. The course of HIV disease in most HIV-infected infants is more rapid than in adults. The highest incidence of AIDS is during the first year of life. This more rapid progression may be related to the immaturity of the infant’s immune system at the time of HIV exposure.

The prognosis for children who develop manifestations of HIV infection before they are one year old is poor. Their condition often steadily deteriorates until they die in their first, second or third year of life. Some children develop symptoms for the first time in their second or third year. Many of these children continue to grow well, although they may have frequent minor illnesses. They may not present with AIDS until many years later, when doctors may confuse their condition with malnutrition or neglect. These different patterns of progression may relate to different viral strains, genetic factors, the timing of infection, the immune status of the mother, and other infections.

Social circumstances and availability of medical care affect the course of the disease. When malnutrition combines with immune suppression due to HIV, children quickly die from infections, especially bacterial blood infections and severe pneumonia.

A study from Europe found that children who became infected through blood transfusion or blood products after the age of four months remained free of symptoms for much longer than children with congenital HIV infection. Infection after the age of four months seems to follow a course similar to adult HIV infection.
The uninfected children of infected parents often have poor health and nutrition, and suffer the emotional and social effects of chronic illness and death of their parents. UNAIDS estimates that there are over 13 million children under 15 years that have lost one or both parents to AIDS, most of them in sub-Saharan Africa. They expect this number to increase to 25 million by 2010.

Testing for HIV infection

Rapid and simple tests for HIV infection are now widely available. These tests detect the presence of HIV antibodies rather than the presence of the virus itself. Therefore, in the early phase of infection before antibodies have been produced, it is possible for infected persons to test negative.

Infected persons usually test positive for HIV antibodies within one month after infection. However, in a small number of people this may take three months or more (the 'window period'). When people become very ill with AIDS they may stop making antibodies to the virus so the antibody test may be negative. However, they are still able to transmit the virus to other people.

HIV antibodies can also be detected in other body fluids including saliva and urine, and tests can be performed on dried blood specimens on filter paper. This is a useful alternative to serum for use in surveillance testing.

HIV antibody tests are used for several purposes:
- when a person wants to know their HIV status;
- for diagnosis, when a person has signs and symptoms suggestive of HIV;
- for antenatal testing when interventions are available to reduce mother-to-child transmission;
- to screen donated blood before transfusion;
- for surveillance of HIV infection to follow the spread of the epidemic;
- for research.

The Enzyme Linked Immuno-Sorbent Assay (ELISA) antibody test is most commonly used for screening blood and for surveillance purposes. The testing kits are designed to screen 96-100 specimens at a time and require technical expertise, equipment and a constant power supply. The ELISA test is very sensitive, but a small percentage of false positive results do occur so it is necessary to confirm positive results with a second antibody test, especially in low prevalence populations.

Several simple and rapid antibody tests have been developed which are more suitable for use in small hospitals and laboratories. They do not need trained technical staff or expensive equipment and are usually provided in kit form. The cost of an individual ELISA test is usually less than that of a simple/rapid test, but because the ELISA tests are carried out in batches, simple/rapid tests are cost-effective when small numbers of tests are performed.

The Western Blot is the most commonly used confirmatory test. It detects antibodies to specific structural components of HIV, but is expensive.

There are several tests which detect the presence of the virus itself. The most widely used is the Polymerase Chain Reaction (PCR) test, which detects viral DNA inserted in the DNA of infected cells.

Several strategies can help to reduce the cost of HIV antibody testing. The use of a combination of rapid and/or simple tests can avoid the use of expensive tests such as the Western Blot for confirmation. UNAIDS and WHO recommend three testing strategies according to test objective and prevalence of infection in the population, to maximise accuracy while minimising cost (see Annex 1.1).
Some countries have developed their own local production facilities for low-cost HIV antibody tests to reduce transport costs and need for foreign exchange. Bulk purchases of test kits can also reduce costs. It is possible to pool several specimens of sera and test them together. If the pooled samples test positive, each sample is then tested to find out which was positive. To maintain a high sensitivity the recommended pool size is five samples. Rapid tests, such as HIV Check, that have been used to test a negative sample, can be re-used, once only, to reduce costs.

**Surveillance**

Surveillance means collecting data regularly and systematically so that it is possible to follow trends in the prevalence of HIV infection in different groups within a population.

It is not necessary to test everyone in a country to get a good picture of the extent of spread of HIV infection. It is more cost-effective to choose several groups from which samples are tested intermittently to build up a picture. This is called ‘sentinel surveillance’. Testing should be anonymous and unlinked. This means that blood specimens taken for other purposes are tested for HIV antibodies after all identifying information is removed. No one is able to tell who the HIV-positive specimens have come from and individuals are not informed of their results. This avoids participation bias.

HIV testing for surveillance is very different from voluntary named testing, when individuals are told their result. **Voluntary named testing should always be accompanied by counselling and informed consent.** When voluntary testing is offered there will always be some people who do not want to be tested. Voluntary counselling and testing services are important for HIV prevention and care (see Chapter 7) but are not useful for the purpose of surveillance. It is important to understand that the results from voluntary testing services and from cases reported by doctors cannot give information about rates of HIV in the population.

Groups that are often chosen for sentinel surveillance include those that are similar to the general population, such as pregnant women and blood donors. Sentinel groups may also represent vulnerable members of the community, such as those who inject drugs, sex workers and their clients, truck drivers, STI clinic patients and tuberculosis patients. Comparing results of sentinel surveillance between countries may be difficult because of different definitions of sentinel groups. For example, some countries may test all drug users, others only those who inject, and others those who present to treatment centres.

It is important to understand the difference between anonymous unlinked testing for surveillance purposes and mandatory or compulsory testing. In mandatory testing the person is tested for HIV antibodies without their informed consent. The result may be used to discriminate against them in some way; for example, they may be isolated within a prison, or denied surgery. Compulsory testing breaches human rights and does not help to prevent the spread of HIV because people are unwilling to come forward for HIV testing if they fear discrimination.

In addition to tracking trends in prevalence it is useful to follow changes in relevant knowledge, attitudes and behaviours over time. Repeated standardised questionnaire surveys provide useful behavioural surveillance data. Qualitative findings can help to explain the survey data. The combination of serological and behavioural surveillance is often called ‘second generation HIV surveillance’.
Treatment for HIV infection

At present, there is no cure for AIDS. However, there are treatments for the relief of symptoms, treatments for opportunistic infections, and an increasing range of antiretroviral drugs which attack HIV itself.

Unfortunately, the countries that have the largest numbers of people infected with HIV are unable to afford the high cost of the new antiretroviral drug combinations; many cannot afford to provide treatment for opportunistic infections; and many people affected by HIV are unable to afford even medicines to relieve symptoms.

In recent years advocacy groups have had great success in achieving significant reductions in the prices of drugs and increased commitment to improve access to treatment. Much advocacy is still needed to ensure that the rich countries and corporations of the world act to improve access to treatment for all. Introducing antiretroviral drug treatment where health care systems are weak presents many challenges. These are discussed further in Chapter 8.

Treatment for HIV-related symptoms

Good nursing care can do much to relieve the symptoms of HIV-related disease such as fever, sweating, itching, diarrhoea, pain, headache, and cough. Local homemade remedies and traditional healers can be very helpful. Paracetamol, aspirin, oral rehydration solution, gentian violet and antiseptic cream are useful; morphine helps to relieve pain in dying patients at low cost. Nutrition and food preparation advice are also important.

Prevention of and treatment for opportunistic infections

Prevention of and treatment for opportunistic infections such as tuberculosis, diarrhoea, fungal infections and *Pneumocystis carinii* pneumonia can extend and improve the life of people living with HIV and their families. Effective low-cost generic drugs for opportunistic infections should be on ‘essential drugs lists’ and made more widely available.

Tuberculosis is the most common opportunistic infection, and major epidemics accompany the spread of HIV. This makes it important, both for the individual and the community, to treat tuberculosis. Short-course treatment with three drugs used for six months has been shown to be effective, but it has been difficult to ensure that patients take the drugs correctly. A strategy of ‘directly observing patients taking their treatment’ (DOTS) has been promoted by WHO and successfully adopted in many countries of the world. Isoniazid prophylaxis is recommended for people living with HIV at risk of tuberculosis, such as those with a positive tuberculin skin test or those who are living in areas where the disease is endemic.

Thrush (candidiasis), toxoplasmosis and pneumonia can be treated at low cost. Such treatment enables a person with HIV to live for several more years. Treatment for opportunistic infections and cancers that occur late in the course of the illness, such as cryptococcal meningitis and Kaposi’s sarcoma, may be expensive and offer little to lengthen survival.

Studies show that the antibiotic co-trimoxazole can prevent many bacterial and parasitic opportunistic infections in adults and children living with HIV, including toxoplasmosis, salmonellosis, pneumococcal pneumonia, and bacteraemia. This is a cost-effective intervention for people living with HIV and for governments because it reduces hospital admissions and mortality.
Antiretroviral treatment

There are now several classes of drugs that prevent HIV from multiplying by blocking the action of viral enzymes, but they do not remove the virus from the body. They include the nucleoside reverse transcriptase inhibitors (NRTIs), non-nucleoside reverse transcriptase inhibitors (NNRTIs) and protease inhibitors (PIs). Researchers are developing new types of antiretroviral drugs.

Because HIV mutates rapidly within the body it quickly becomes resistant to drugs. For this reason antiretroviral drugs are usually given as a combination of three drugs. It is important to monitor the patient’s viral load, blood cells, and liver and renal function for side effects of each drug and to track the response. Some patients are not able to tolerate the side effects.

Adherence to taking the drugs regularly is extremely important to avoid resistance developing. Guidelines for treatment of HIV recommend lifelong triple therapy, commonly two NRTIs, combined with a PI or NNRTI.52 These combinations are called ‘highly active antiretroviral therapy’ (HAART). For the drugs to be effective the person has to take them correctly at least 95% of the time, and they have to be taken for life.

WHO recommends that in antiretroviral treatment programs in resource-limited settings HIV-infected adolescents and adults should start antiretroviral therapy when they have:

- WHO stage IV of HIV disease (clinical AIDS);
- WHO stage I, II or III or HIV disease, with a CD4 count below 200/m$^3$; or
- WHO stage II or III or HIV disease with total lymphocyte count below 1200/m$^3$.53

Now that the drugs have come down in price there is much work being done to develop and test low-cost protocols that will be feasible to provide effective treatment and monitoring for people living with HIV in resource-poor settings. Pilot implementation studies are underway in several countries and it will be important to learn from their experiences.54

The issue of availability of antiretroviral therapy in developing countries is discussed in more detail in Chapter 8.

Protection against infection after exposure to the virus

Antiretroviral drugs taken after accidental occupational exposure to HIV may protect the person from becoming infected with the virus.55 This process is called post-exposure prophylaxis.

Health care workers who have a documented exposure to HIV-infected blood through needle-stick injury or splash to mucous membranes, and survivors of rape, can take a four-week course of two antiretroviral drugs to lower the risk of infection.56 It is important to develop protocols in health care services for this post-exposure prophylaxis.

There is concern that some people may try to use the drugs after high-risk sexual exposure to prevent themselves becoming infected with HIV. If those who can afford these drugs use them in this way it may undermine efforts to promote behaviour change. Such use is likely to lead to resistant strains of the virus. Also, these drugs cause severe side effects and there is concern about their use by people who may not be infected.
HIV vaccine development

The genes of the virus mutate frequently, especially the gene for the virus envelope. This is the part of the virus that the immune system recognises first. Because the envelope pattern changes so frequently, antibodies produced by the body in response to infection are unable to recognise the virus. Thus, the presence of antibodies, produced naturally by the body or artificially by vaccination, does not mean that these antibodies are protective. This is one of the reasons why it is difficult to develop an effective vaccine.

Researchers are trying to develop two types of vaccine: one to prevent infection with HIV and the other to prevent progression to AIDS once a person is already infected with the virus. Several potential preventive vaccines have undergone small trials in different parts of the world. In 2003 a large-scale trial of an HIV vaccine was conducted in Thailand among people who inject drugs, but it failed to protect them against infection. Researchers do not believe that there will be a vaccine widely available for at least five years.

The International AIDS Vaccine Initiative is working with several groups to evaluate trial vaccines and to provide up-to-date information on the progress of vaccine development.57

Scientists have discovered that it is possible for people infected with one strain of HIV to become ‘superinfected’ with a more virulent strain of the virus. If infection with live HIV does not provide protection it increases doubts that a vaccine made from weakened or inactivated viruses, or HIV substitutes, will be able to do so.

A group of Kenyan women was being studied because the women had not developed HIV despite repeated exposure to HIV. They had developed immunity to HIV with high levels of white cells active against HIV. However, it has been reported that some of these women have lost their immunity once they no longer had frequent exposure. This suggests that a vaccine that produces immunity through stimulating production of white cells active against HIV might need to be given repeatedly.
ANNEX 1.1: HIV TESTING STRATEGIES

Several strategies can help to reduce the cost of HIV antibody testing. The use of a combination of rapid and/or simple tests can avoid the use of expensive tests such as the Western Blot for confirmation. WHO and UNAIDS have recommended the following HIV testing strategies according to test objective and prevalence of infection in the population.46

The strategy for testing depends on:
- the purpose of the test
- the prevalence of HIV in the population.

<table>
<thead>
<tr>
<th>Reason for HIV antibody test</th>
<th>HIV prevalence</th>
<th>Testing strategy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Identification of asymptomatic HIV-infected people</td>
<td>&lt; 10%</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>&gt; 10%</td>
<td>2</td>
</tr>
<tr>
<td>Diagnosis of HIV-related disease</td>
<td>&lt; 30%</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>&gt; 30%</td>
<td>2</td>
</tr>
<tr>
<td>Epidemiological surveillance</td>
<td>&lt; 10%</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>&gt; 10%</td>
<td>1</td>
</tr>
<tr>
<td>Screening blood for transfusion</td>
<td>All prevalences</td>
<td>1</td>
</tr>
</tbody>
</table>

Strategy 1

A sample which tests positive can be counted as positive for the purpose of surveillance, or rejected as positive for the purpose of screening for transfusion.

However, if the donor is to be informed of the result then proceed as for 'Identification of asymptomatic HIV-infected people' with Strategy 2 or 3 depending on the prevalence of HIV.

If the sample tests negative then the result can be reported as negative to the donor (with post-test counselling).

Strategy 2

If the sample tests negative then the result can be reported as negative to the client/patient (with post-test counselling).

If the sample tests positive on the first test repeat the test with a different type of test based on a different antigen preparation or different testing principle.

If the second test is also positive the result can be reported to the client/patient, with counselling.

For samples which have tested positive on the first test and negative on the second test:
- Re-test the sample with the same two tests.
- If both tests are positive the second time, then confirm that a second sample is positive before telling the client/patient that they have a positive test result and counselling them.
- If both tests are negative the second time, tell the client/patient that they have a negative test result and counsel them.
- If the two test results still differ then consider the result uncertain or ‘indeterminate’. Repeat this testing strategy on a different sample taken 14 days later.
Strategy 3

If the sample tests negative then the result can be reported as negative to the client/patient, with counselling.

If the sample tests positive on the first test repeat the test with a different type of test based on a different antigen preparation or different testing principle.

If the second test is also positive the result can be reported to the client/patient, with counselling.

For samples which have tested positive on the first test and negative on the second test:

- Re-test the sample with the same two tests.
- If both tests are positive the second time, then test the sample with a third different test.
- If the third test gives a positive result, then confirm that a second sample is positive before telling the client/patient that they have a positive test result and counselling them.
- If the third test is negative, then consider the result uncertain or ‘indeterminate’. Repeat this testing strategy on a different sample taken 14 days later.
- If one test is positive and one test is negative, then test the sample with a third different test.
- If the third test gives a positive result, then consider the result uncertain or ‘indeterminate’. Repeat this testing strategy on a different sample taken 14 days later.
- If the third test gives a negative result and the client/patient has been at risk of HIV infection in the previous three months, then consider the result uncertain or ‘indeterminate’. Repeat this testing strategy on a different sample taken 14 days later.
- If the third test gives a negative result and the client/patient has not been at risk of HIV infection in the previous three months, tell the client/patient that they have a negative test result and counsel them (but do not use their blood for transfusion).
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26 Fowler MG, Rogers MF. Overview of perinatal HIV infection. J Nutr 1996;126(10 Suppl):2602S–2607S.


Introduction

The story of the AIDS epidemic is one of hope in the midst of a crisis. The scale of the epidemic is far more extensive than was predicted even a decade ago. UNAIDS gathers data from different countries to produce an epidemiological report each year that presents a comprehensive picture of the scale of the epidemic. Since the epidemic began, at least 60 million people have been infected with the virus. More than 20 million people have died from the disease in the past 20 years. Forty million people are now estimated to be living with HIV or AIDS. This is more than 50% higher than 1991 projections by the WHO’s Global Programme on AIDS.

The pattern of the epidemic, its impact and the ability of communities and countries to cope with the consequences vary enormously from place to place. The epidemic flourishes where there are social and economic problems.

Sub-Saharan Africa remains by far the worst affected region in the world, with between 25 and 28 million people living with HIV. In 2003, 2.2–2.4 million African people died from AIDS. This is more than ten times greater than those killed in the region’s wars and civil conflicts. As well, there is an alarming increase in the number of infections in Asia. More than seven million people are living with HIV – a figure that is set to multiply many times unless concerted and determined measures to stop the epidemic are quickly put in place.

Eastern Europe and Central Asia have the fastest growing epidemics in the world. Infection rates are climbing exponentially where HIV spreads through both injecting drug use and sexually transmitted infections. In 2003 there were an estimated 200,000 new infections in this region, making a total of people living with HIV between 1.2 and 1.8 million. New epidemics are emerging in Estonia and Uzbekistan.

In Latin America and the Caribbean between 1.5 and 2 million adults and children have HIV. The epidemic is driven by a complex mix of factors including male-to-male sex, sex between men and women, and injecting drug use.

In the high-income countries of North America, Western Europe, Australia and New Zealand, about 2 million people are infected. The availability of antiretroviral therapy means that people with HIV are living longer, more productive lives. Unfortunately, prevention efforts appear to have stalled in many countries, and new infections are being seen among young gay men, and in disadvantaged groups.

In the midst of all the devastation, there is hope. Even in the worst affected countries, it is possible to turn the epidemic around. This is the story of Uganda and Thailand. A handful of other sub-Saharan African countries are also seeing encouraging signs of a turnaround in the epidemic. Brazil has been successfully containing the HIV epidemic through enthusiastic efforts that link care and prevention.

In this chapter we give an overview of the epidemic in each of the world’s regions. We describe the main ways in which the virus is spread, the underlying forces that drive the epidemic and the consequences for individuals, families and communities. Finally, we describe the responses; in particular, the efforts by the United Nations to galvanise global action.
Current global situation

The quality of estimates of prevalence and incidence of HIV has been improving. UNAIDS estimates for 2003 were similar to 2002 – but this reflects more accurate estimates rather than that the epidemic had ceased to spread.\(^1\)

UNAIDS reports that by the end of 2003, over 40 million people were living with HIV and more than 20 million people around the world had already died (Table 2.1).\(^1\) During 2003, 3 million people died; 5 million people became infected. One in every 100 adults in the most sexually active age group (15–49 years) is living with HIV. However, only a tiny fraction, less than one in every ten, know about their infection.

<table>
<thead>
<tr>
<th>Category</th>
<th>All adults</th>
<th>Children</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of people living with HIV</td>
<td>37 million (31–43)</td>
<td>2.5 million (2.1–2.9)</td>
<td>40 million (34–46)</td>
</tr>
<tr>
<td>People newly infected with HIV in 2003</td>
<td>4.2 million (3.6–4.8)</td>
<td>700,000 (590,000–810,000)</td>
<td>5 million (4.2–5.8)</td>
</tr>
<tr>
<td>Deaths due to AIDS in 2003</td>
<td>3 million (2.5–3.5)</td>
<td>500,000 (420,000–580,000)</td>
<td>3 million (2.5–3.5)</td>
</tr>
</tbody>
</table>

HIV infections are not spread evenly around the world. As Figure 2.1 shows, infections are concentrated in the developing world. More than 95% of HIV-infected people live in the developing countries of sub-Saharan Africa, South and South-East Asia, and Latin America and the Caribbean. This is because the societal and structural factors that fuel the spread of the virus, such as poverty, war, and the subordinate status of women, are very widespread in the developing world. The worst-affected countries in sub-Saharan Africa and Asia together account for less than 10% of global gross national product. In high-income countries, HIV affects predominantly disadvantaged populations, including those who inject drugs, sex workers, and homosexual and bisexual men.

FIGURE 2.1: ADULTS AND CHILDREN ESTIMATED TO BE LIVING WITH HIV AT THE END OF 2003

Sub-Saharan Africa has only 10% of the world’s population, but more than 70% of those infected with HIV – about 26.5 million men, women and children. The 15 countries with the highest HIV prevalence in the world are all in sub-Saharan Africa. AIDS has exceeded malaria and other conditions as the leading cause of adult death between the ages of 15 and 49 in Botswana, Burundi, Malawi, Rwanda, Tanzania, Uganda, Zambia and Zimbabwe.

HIV is spreading fast in the more densely populated Asian continent where the epidemic started later than in other regions. In 1987, the World Health Organization stated that although HIV was certainly present in Asia, it had yet to spread out of groups with high-risk behaviour such as male–male sex and injecting drug use. By the end of 2003, UNAIDS estimated that between 4.6 and 8.2 million people were infected (see Figure 2.1).

The evolving picture of the global HIV epidemic

A decade ago, Jonathon Mann described the epidemic as dynamic, volatile and unstable. The picture of the epidemic changes constantly – under the influence of social, cultural, political and economic factors specific to each community. Scientific advances in management of HIV and opportunistic infections are also affecting the picture of the global epidemic.

High-income countries

In Australia, New Zealand, Western Europe, Canada and among some populations in the United States, the number of HIV-infected people developing AIDS and dying have reduced significantly. As Figure 2.2 shows, the number of new AIDS cases in Western Europe dropped by nearly 40%, from approximately 24,000 in 1995 to under 15,000 in 1997. In the United States the number of people dying from AIDS dropped by 42% in 1996–97. The decline has since levelled off.

FIGURE 2.2: NUMBER OF NEW AIDS CASES, WESTERN EUROPE, 1987–97

![Graph showing the number of new AIDS cases in Western Europe from 1986 to 1997. The number of cases decreased significantly from approximately 24,000 in 1995 to under 15,000 in 1997. The decline has since levelled off. Source: European Centre for the Epidemiological Monitoring of AIDS (CESES), France]
The fall in AIDS cases is due in part to prevention measures taken since the start of the epidemic by affected communities, particularly gay communities. New antiretroviral drugs have also prevented new AIDS cases in industrialised countries. However, even in the United States, poorer people without health insurance may find it hard to access treatment.

Unfortunately, the decrease in the HIV infection rate in most high-income countries has stalled in recent years. There have been new infections among men who have sex with men (MSM) in Australia, Canada, the United Kingdom and Spain. In San Francisco, reported HIV infections rose from 1.1% in 1997 to 1.7% in 2000 and appear to be rising still. Sharp increases in sexually transmitted infections (STIs) in Amsterdam, Sydney, London and southern California confirm that MSM are taking more risks rather than following the safer-sex ethic promoted so effectively in the 1980s and 1990s.

The focus of the epidemic is shifting increasingly to poorer sectors of the population and to women. This is particularly true of the United States where African-Americans, who bear a larger share of poverty, underemployment and inadequate access to health care services, are now more than eight times as likely as white people to become infected with HIV.

Central and Eastern Europe

Infection rates are climbing alarmingly in Eastern Europe, where high levels of injecting drug use and STIs help the virus to spread. In 2003, an estimated 250,000 infections occurred in the region, raising the total infected to about 1 million. In Ukraine, for example, numbers increased from 1,500 in 1994 to an estimated 250,000 in 2000, and in Estonia they jumped from 12 in 1999 to 1,112 in the first nine months of 2001. The actual number of people living with HIV in the Russian Federation is estimated to be many times higher than the reported figures.

Although the epidemic is concentrated among those who inject and their sexual partners, growth in sex work and high levels of STIs could cause it to spread rapidly among the general population. Several Central Asian republics, including Kazakhstan, Kyrgyzstan, Tajikistan and Uzbekistan, are also experiencing outbreaks of HIV infection related to injecting drug use.
**Sub-Saharan Africa**

AIDS killed over two million people in sub-Saharan Africa in 2003. In this region, where the HIV epidemic has been spreading for nearly two decades, the picture of the epidemic is also changing. From the early 1980s the epidemic was concentrated in East and Central Africa, with Uganda, Kenya, Tanzania, Malawi, Rwanda and the Central African Republic among the most seriously affected. In the past ten years the epidemic has been spreading south. With a total of 5.3 million infected people (end of 2002), South Africa has the largest number of people living with HIV in the world.\(^1\) Surveillance data show that the average rate of HIV prevalence in pregnant women attending antenatal clinics has remained roughly at the same high levels since 1998 – ranging between 22% and 23% in 1998–1999 and then shifting even higher to around 25% in 2000–2002.

Figure 2.4 illustrates the rapid spread of HIV in southern Africa.

![Figure 2.4: Increasing HIV Prevalence Among Pregnant Women in Selected Urban Areas of Southern Africa](image)

In several southern African countries, at least one in five adults is HIV-positive. Adult prevalence rises as high as 20% in Namibia and Zambia, 24% in Lesotho, and 25% in Swaziland and Zimbabwe. In Botswana, 36% of adults are now infected with HIV, with 43% of pregnant women testing HIV-positive in the major urban centre of Francistown.

In recent years prevalence has stabilised in many countries. However this does not mean that HIV has ceased to spread. It reflects a persisting high level of new infections and a high number of deaths from AIDS.

Overall, West Africa is experiencing a less severe HIV epidemic than East and Southern Africa. But in Nigeria, the most populous West African country, with well over 100 million inhabitants, the epidemic is growing, with an estimated 2.2 million people living with HIV. Cote d’Ivoire is already among the 15 worst-affected countries in the world.

African women were at least 1.2 times more likely to be infected than men, and the ratio of women infected to men is highest among young people.

Amid the grim news about the enormity of the epidemic in many sub-Saharan African countries, a new picture is emerging of countries that are recording successes in the national efforts to stem the tide of the epidemic. HIV infection rates are falling in Uganda. From a peak of nearly 30% in urban antenatal clinics in the early 1990s HIV...
prevalence has fallen to about 8%. The biggest change has been seen in young women.\(^5\) While some of the decrease in prevalence can be attributed to deaths of those infected, there is evidence that there have been changes in sexual behaviours such as later sexual initiation, fewer partners and more condom use (Figure 2.5). Likewise in Tanzania, in areas of active prevention programs, HIV prevalence in young women fell by 60% over a period of six years. There are also encouraging signs that Zambia’s epidemic may be following the course charted by Uganda.\(^6\) Senegal has maintained a low HIV infection rate at a time when the epidemic is expanding in neighbouring countries.\(^7,1\)

**FIGURE 2.5: CONDOM USE IN URBAN UGANDA, 1989 AND 1995**

The most important element of the success stories has been effective leadership. The example of Uganda stands out. Firstly, by openly acknowledging that an epidemic was taking place in the country, President Yoweri Museveni led the response by the government and encouraged action by other groups in the society, including religious leaders and community-based organisations.

**South and South-East Asia**

The epidemic is newer in Asia than Africa and is changing very fast. In the relatively short time since the infection was first detected in this region, it has spread swiftly. In 2003, about one million adults and children were newly infected with HIV in the region, bringing the total infected to between 4.6 and 8.2 million. Because this part of the world is so populous, with 60% of the world's population, Asia will soon dominate in terms of total numbers infected.

No Asian country has yet reached the prevalence found in some countries of sub-Saharan Africa. Nevertheless, HIV is now well established across the region. In most Asian countries for which there is information, HIV has risen to high levels among vulnerable groups.

There is enormous variation in the picture of the HIV epidemic across the Asian region, ranging from countries with low rates of infection such as Bangladesh, Laos, Pakistan, the Philippines and Sri Lanka, where less than one adult in 1,000 is infected, to countries with more severe epidemics, such as Thailand, Cambodia, Myanmar and India.

**BOX 2.2: HIV IN SUB-SAHARAN AFRICA – SOME FACTS**

- 70% of people living with HIV live there.
- 80% of women living with HIV live there.
- 87% of children with HIV live there.
- 7.4% of all those aged 15 to 49 years are infected.
- More than 1.4 million new adult infections in Africa each year since 1991 – an average of 3,800 new infections each day.
- About 90% of all HIV transmission is by sex between men and women.
- HIV accounts for one-third of all deaths from infectious disease.
- In Zimbabwe, AIDS has reduced life expectancy by 22 years.
FIGURE 2.6: SEXUAL BEHAVIOUR, STIs AND HIV IN 21-YEAR-OLD MEN, NORTHERN THAILAND, 1991–95

There is more information about the HIV epidemic in Thailand than any country in South and South-East Asia. With almost 700,000 people (2.3% of the adult population) living with HIV, Thailand has one of the largest epidemics in the region and AIDS has become the leading cause of death. However, sustained, well-funded and comprehensive prevention efforts in the early 1990s have reduced annual new infections to about 20,000 in 2002 from a high of 140,000 a decade ago. Thailand’s prevention programs aimed at increasing condom use, discouraging men from visiting sex workers, and offering young women better educational and other prospects to discourage their entry into commercial sex work. As Figure 2.6 shows, there have been significant changes in the sexual behaviour of young men from northern Thailand since 1991. The proportion of 21-year-old northern men who visited sex workers dropped from 60% in 1991 to less than 25% in 1995. More importantly, there is evidence that young Thai men are practising safer sex. Those who did not use a condom on their last visit to a sex worker decreased from 40% in 1991 to less than 10% in 1995. Associated with the changes in sexual behaviour of the young men is a decrease in the level of STIs, from 42% in 1991 to 18% in 1991 as well as a decrease in the proportion of young men infected with HIV. There are indications that more than half of new infections occur through transmission between spouses. This is a reminder of the importance of general prevention in addition to reaching specific vulnerable groups.

Prevention measures have also had success in Cambodia. Large-scale prevention programs, which began in the mid-nineties, saw high-risk behaviour in men fall and condom use rise consistently in the late 1990s. Consequently, HIV prevalence among pregnant women fell from 3.2% in 1997 to 2.3% at the end of 2000. Among brothel-based sex workers prevalence has fallen from 43% in 1998 to 29% in 2002.

In other countries in the region, the situation is less positive. In Myanmar, HIV infection among sex workers rose from 4% in 1992 to over 20% in 1996; as well, two-thirds of those identified as injecting drugs are infected. Vietnam is also witnessing a rapid spread of the epidemic. Although more than three-quarters of infections are attributed to transmissions through injecting drug use, heterosexual transmission is increasing. In Ho Chi Minh City, the percentage of sex workers with HIV has risen sharply since 1998, reaching more than 20% in 2000.

Indonesia offers an example of how quickly an HIV epidemic can emerge. For more than a decade, very few infections were seen in this country, even among sex workers,
who are regarded as a group at high risk of infection with the virus. However, the country is now seeing infection rates rapidly increasing among those who inject drugs and sex workers. Forty per cent of drug injectors in treatment in Jakarta were infected in 2000, a quarter of those tested in Bogor, and 53% of drug-using prisoners in Bali.

In India, HIV infection rates, at under 1% of the total adult population, are still relatively low. However, it is estimated that up to 4.6 million people in India are living with HIV, more than any other country except South Africa. In at least five states, sentinel surveillance in antenatal clinics shows that more than 1% of pregnant women in urban areas are infected. The epidemic is also spreading in rural areas – a survey in Tamil Nadu has revealed that almost 500,000 people are already infected and that the infection rate is three times higher in villages than in the cities.

The rate of spread of the epidemic in China is difficult to predict but many national and international experts estimate that there were over 1 million HIV infections in China in 2001. While the national prevalence estimates remain relatively low there are concentrated epidemics in several states, especially among people who inject drugs. In the most highly infected province, Yunnan, which is adjacent to international drug routes, male injectors account for 78% of HIV infections. In four other provinces, Guangdong, Guangxi, Sichuan, and Xinjiang, HIV prevalence among people who inject drugs ranges from 11% to 40%.

Increasing evidence has emerged of serious epidemics in Henan Province in central China, where many tens of thousands of rural villagers have become infected since the 1990s by selling their blood to collecting centres that did not follow basic blood donation procedures.

The virus is also spreading sexually in China. A second, newer epidemic is emerging among heterosexuals, particularly in the eastern provinces. In 2000, HIV rates among sex worker populations in Guangxi, Yunnan and Guangdong were measured at 10.7%, 4.6% and 3.0% respectively. The economic reforms that helped to reduce the number of people in poverty by more than half since the late 1970s also led to large increases in internal migration, which facilitates the spread of HIV and STIs. Studies have estimated that nearly 100 million people, roughly one in twelve people in China, have moved from their registered residence. Twenty million have moved from the poor areas of western China to eastern provinces. Most are young, single and male, but many women have also migrated. There are clear warning signs of high-risk behaviour – STIs which were all but eliminated in China in the 1960s are rising rapidly.

Most countries in the Asia region were affected by the economic crisis that began in 1996, which has impoverished millions of people and increased their vulnerability to HIV.

**The South Pacific**

The countries and territories of the South Pacific are often included as part of the Asian region in descriptions of the HIV epidemic. However, the picture of the epidemic among Pacific Island Countries and Territories (PICTs) is different from that in Asia. Over the past decade HIV has spread widely in the Pacific, with 15 of the 22 countries reporting infections. However, with the exception of Papua New Guinea (PNG), the rates of infection are low. There is limited surveillance data from the countries in the region; countries report cases to the South Pacific Epidemiological and

**BOX 2.3: HIV IN INDIA – SOME FACTS**

- Between 3.8 and 4.6 million people were infected at end of 2002.
- Epidemic highly diverse; some states show no HIV infection, others have 2% adult prevalence.
- In Manipur, over 70% of people who inject drugs are HIV-positive; 2.2% of pregnant women are infected.
- 25% of sex workers in New Delhi, Hyderabad, Madurai, Pune, Tirupati and Vellore tested HIV-positive.
- HIV prevalence among sex workers in Mumbai reached 71% in 1997.
Health Information Service (SPEHIS). At the end of 1999, a total of 2,164 HIV cases had been reported to the SPEHIS by 15 countries in the region. Compared to the magnitude of the HIV epidemic in sub-Saharan Africa and Asia, the numbers are small – but they represent a relatively high prevalence.

A 1996 UNDP report, *A time to act*, described the Pacific as being a vulnerable region for the following social, economic and cultural reasons:

- movement of people out of, into, and within the region;
- the youthful age structure of Pacific Island populations;
- the very slow-growing economies of the region, and consequently, very limited opportunities for employment;
- the growing impoverishment of some people;
- socio-cultural factors that affect the status of women and the behaviour of men.

**Latin America and the Caribbean**

Some 1.8 million people in this region are living with HIV, including between 165,000 and 260,000 adults and children who became infected in 2003. The situation in Latin America and the Caribbean is fragmented, although nearly every country in the region has reported infections. In more than half the countries in the region HIV has risen to high levels in specific vulnerable groups. These include men who have sex with men (MSM) and people who inject. For example, studies in Mexico suggest that up to 30% of men who have sex with men may be HIV-positive; and close to 50% of drug injectors in Argentina and Brazil are infected with HIV. Some countries in the region have nascent epidemics, meaning that HIV prevalence is low, even among people who practise high-risk behaviour.

The Caribbean is the second-most affected region in the world, with adult HIV prevalence only exceeded by those of sub-Saharan Africa. In several Caribbean countries HIV has become the leading cause of death. Haiti and the Bahamas are the worst-affected countries in the region, with adult HIV prevalence above 4%.

Overall, heterosexual transmission is becoming more prominent in the region. There is also clear evidence that HIV infection is increasing among poorer and less educated members of the population.

Brazil has seen a substantial decline of HIV prevalence among those who inject drugs in urban areas. This suggests that harm reduction activities are working. Brazil’s prevention efforts are complemented by an extensive treatment and care program that guarantees state-funded antiretroviral therapy for those living with HIV. To date, an estimated 105,000 out of the 600,000 Brazilians with HIV infection are receiving antiretroviral therapy through the public health system.

**Increasing infection among women**

More women are becoming infected with HIV. In 1980, an estimated 80% of HIV-infected people were men. Today, over 47% of HIV infections are in women. In sub-Saharan Africa, the female-to-male ratio was nearly equal during the first decade of the epidemic. More recently, studies in Uganda and Tanzania show that infection rates for women exceed those for men, with female-to-male ratios ranging from 1.3:1 to 1.7:1. In other parts of the world, the proportions of men and women infected is also changing. In 1984 in Brazil the male-to-female ratio of HIV infection was 120:1 – now a quarter of the 550,000 HIV positive adults are women. In Thailand, the male-to-female ratio changed from 17:1 in 1986 to 5:1 in 1990. In New York State, nearly 50% of adolescents with AIDS are young women.
TABLE 2.2: PERCENTAGE OF HIV-POSITIVE ADULTS WHO ARE WOMEN

<table>
<thead>
<tr>
<th>Geographical area</th>
<th>Percentage of HIV-positive adults who are women</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sub-Saharan Africa</td>
<td>55%</td>
</tr>
<tr>
<td>South and South-East Asia</td>
<td>35%</td>
</tr>
<tr>
<td>East Asia and Pacific</td>
<td>20%</td>
</tr>
<tr>
<td>Latin America</td>
<td>30%</td>
</tr>
<tr>
<td>Caribbean</td>
<td>50%</td>
</tr>
<tr>
<td>Eastern Europe and Central Asia</td>
<td>20%</td>
</tr>
<tr>
<td>Western Europe</td>
<td>25%</td>
</tr>
<tr>
<td>North America</td>
<td>20%</td>
</tr>
<tr>
<td>Australia and New Zealand</td>
<td>10%</td>
</tr>
<tr>
<td>Overall global</td>
<td>48%</td>
</tr>
</tbody>
</table>

Women often become infected at a younger age than men. The number of new infections among women reaches a peak between the ages of 15 and 25 years. For men this peak occurs ten years later, between 25 and 35 years old. A community study in Kenya showed that 22% of 15- to 19-year-old girls were infected, compared with 4% of boys of the same age. In a Zambian study of young city dwellers in the same age group, HIV infection was reported in 12.3% of girls and 4.5% of boys. The factors that drive the increasing HIV epidemic among women in general and young women in particular are discussed in Chapter 6.

How are people infected?

Differences in individual risk behaviours do not entirely explain the unequal spread of HIV around the world. For example, differences in sexual behaviour patterns alone cannot explain why 25% of adults in Zimbabwe are infected, compared to 2.5% in Ghana. Nor why in one part of Ghana 5% of pregnant women are infected but in another 20% have the virus.

We do not yet fully understand the reasons for these differences. Clearly, social, economic, cultural and political features of an area influence spread of the virus, which is also determined by the particular patterns of sexual networking. There may be high levels of sexual activity with different partners in a group – but if none of the group has sex with someone outside that group they will not become infected. On the other hand married women who have no partners but their husbands will quickly become infected if their husbands have sex with an infected partner. Some populations also have genetic variations that make them less susceptible to infection with HIV, and different strains of the virus are less infectious than others.

Sexual intercourse between men and women is the most common route of infection of HIV worldwide. Because male-to-male sex and injecting drug use are hidden behaviours it is difficult to estimate the proportion of infections that we can attribute to these routes of spread. Transmission through injecting has been the major way in which HIV has spread in Eastern Europe and some Asian countries such as China, Vietnam, Myanmar and parts of India. Injecting drug use is also thought to account for about one-quarter to one-third of transmissions in Brazil and Argentina.

Where large numbers of women of child-bearing age are infected, transmission from mother to child results in a significant proportion of all infections.

There has been debate about the contribution of unsafe medical practices, including injections with unsterile needles or syringes, and transfusion of unscreened blood. It is estimated that about 10% of infections worldwide occur in medical settings. This is
likely to vary depending on the frequency of injections and transfusions, and the proportion of these administered in an unsafe way. Gisselquist et al have argued that the proportion is much higher\textsuperscript{13} – however, the trend of the HIV epidemic has been very different to that of the other blood-borne viruses, hepatitis B and hepatitis C, which spread more easily through unsafe injection practices.\textsuperscript{14} It is important to do more to prevent unsafe injections and to ensure the availability of safe blood transfusions – but it remains appropriate for prevention efforts to focus predominantly on the prevention of spread through sex.

**Forces that drive the epidemic**

Poverty, unequal distribution of income, and unequal relations between men and women stimulate the spread of HIV. People moving in search of work or as a result of conflict are likely to be exposed to infection. Deaths from AIDS worsen existing poverty and social inequality, increasing the vulnerability of dependents to infection, thus creating a vicious circle. Cultural and religious practices and beliefs also influence the spread of the virus.

**Health-related factors**

The key role of STIs in the spread of HIV infection is well established.\textsuperscript{15} Untreated STIs can increase the risk of acquiring and passing on HIV infection during unprotected intercourse by a factor of three to five times. A Nigerian study highlighted the importance of STIs in increasing women's risk of infection.\textsuperscript{16} A community survey of genital tract infection among rural adolescent girls showed that 44% had a genital tract infection, but less than 3% had sought treatment. They were ashamed to go to the local health care service because of the stigma attached to STIs, and could not afford to pay for treatment.

**Movement of people for work**

People move because there are few opportunities for survival where they live, or attractive opportunities elsewhere. Many head for large urban centres where they often have difficulty finding work. Mining, logging, and fishing industries also attract migrant labourers, who often live in single-sex dormitories, far from their families. Many visit sex workers. When they return home they may carry HIV and STIs to their wives and home communities. For example, 60% of households in Hlabisa, a rural district of KwaZulu, South Africa, have one or more male migrants. In 1997, 26% of pregnant women in the district were infected with HIV. The link between male migrant workers and HIV infection in female partners in their home communities was shown in a 1995 study.\textsuperscript{17} Thirteen per cent of women whose partners spent less than a third of the time at home were found to be HIV-positive, compared to no infections among women with husbands at home more than two-thirds of the time.

**Wars and armed conflicts**

Wars and armed conflicts result in circumstances that increase the likelihood of spread of HIV. People, mostly women and children, are driven from their homes and live in temporary settings such as refugee camps. In these situations, violence, rape, and the need to sell sex to survive make refugees vulnerable to HIV infection. Blood may be transfused without screening. Normal patterns of sexual behaviour are often disrupted, and young people may have sex more often and with more partners than they would in

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**BOX 2.4: MIGRANT WORKERS AND HIV – AN IMAGE FROM SOUTH AFRICA**

Carltonville, at the heart of South Africa’s gold mining industry, is home to 88,000 mine workers, 60% of them migrants from other parts of South Africa or from the nearby countries Lesotho, Malawi and Mozambique. The large number of miners in employment means regular wages – some US$18 million a month – to buy all kinds of goods and services, including sexual services. There are 400 to 500 sex workers at the Carltonville mines. Carltonville has one of the most serious HIV epidemics in South Africa. Around 22% of adults in the city are infected with the virus, a rate over two-thirds higher than the national average. A small survey of sex workers found that three-quarters were infected with HIV, while one mine worker in five is thought to be infected.

Source: AIDS epidemic update (December 1998)\textsuperscript{17}
their usual circumstances. Local or international military, and the host population, may be interacting sexually with the refugee population, and may have higher rates of STIs and HIV.\textsuperscript{18} The wars in Uganda during the 1980s and more recently in Rwanda and the Democratic Republic of the Congo have shown the effect of conflicts on the spread of HIV. A 1997 survey in Rwanda found that 8.5% of refugees were infected with HIV. Most had fled from rural areas where pre–conflict HIV prevalence was just 1.3%.

**Poverty and HIV**

The struggle to survive every day overshadows concern about a virus that does not show any immediate harm. Everywhere, HIV is perceived as a distant threat until it has a visible presence demonstrated by illness and death. Poverty deprives people of access to health facilities, schools and media, and thus limits their access to information about HIV. Poverty pushes families to send children into the workforce or to traffickers, making them vulnerable to sexual abuse. When HIV appears in poor households there are limited means to respond, the impact is severe and the pressures and pain of poverty increase. The productivity of infected parents, teachers, labourers, drivers, and farmers is affected so economic and social structures of communities suffer. The need for services increases with fewer able people to provide them.\textsuperscript{19}

**Economic development and HIV infection**

The World Bank regards national economic development that generates jobs, improves income levels and reduces inequality, as the most effective means to slow the epidemic.\textsuperscript{20} Unfortunately, some of the processes to achieve these goals may also stimulate the spread of HIV, as the examples in Boxes 2.4 and 2.5 illustrate.

**Gender and HIV**

Gender roles and relations strongly influence the course and impact of the HIV epidemic. Inequality between males and females is a major driving force behind the HIV epidemic. The different attributes and roles that societies assign to males and females profoundly affect their ability to protect themselves against HIV and to cope with its impact. Gender-based inequalities overlap with other social, cultural, economic and political inequalities, and affect women and men of all ages.

Biological and social factors make women and girls more vulnerable to HIV than men. All over the world, women find themselves at special risk of HIV because they lack the power to determine where, when and whether sex takes place.

**BOX 2.5: HIV AND ECONOMIC DEVELOPMENT – A CASE STUDY FROM GHANA**

A monument to the development philosophy of the 1950s and 1960s is the gigantic Volta Lake in Ghana, one of the largest man-made lakes on earth. The lake was created by the construction of the Akosombo hydro-electric dam between 1961 and 1966 with financing from the World Bank and the United States Government. The dam was a major element of a largely unsuccessful attempt to establish Ghana as a major industrialised country in Africa. The town of Agomanya is the administrative centre of a rural district which is close to the Akosombo dam. HIV infection among pregnant women in Agomanya is \textbf{five to ten times} more prevalent than in the rest of the country. The reason for the high rate of HIV infection in this town can be traced back to events of 30 years ago.

In the 1960s, the newly created Volta Lake flooded a large area and displaced about 80,000 inhabitants, many of them belonging to the Krobo ethnic group. The Krobos, traditionally farmers, lost most of their arable land. The men became fishermen, some migrated downriver to work in the construction of the dam. Many women started to work in the only profitable and growing business: as service workers in the hotels and drinking spots that sprang up in the small towns of the area. From there it was only a small step into sex work, which was one of the few uncontested areas for women to develop their entrepreneurial ambitions. When, after five years, the main workforce of construction workers left, the women took their business to the main cities of the country and throughout West Africa. The remittances of women working in prostitution became an important source of development funds in some towns in the region.

Inheritance in Krobo society is patrilineal. A child who does not know his or her father cannot inherit. There were few opportunities for economic survival for the many illegitimate children born during the construction boom. Many of the daughters of construction workers for whom there were no other economic choices followed their mothers into sex work.

Twenty years after the women began to travel throughout West Africa as sex workers, they began to return home sick and destitute. A 1992 sero-prevalence survey in Abidjan found that almost all the Ghanaian sex workers in Côte d’Ivoire were infected with HIV. A large proportion of the women were from Agomanya – hence the very high prevalence of HIV among pregnant women. Prostitution is no longer an attractive option to ensure economic survival, although there are still few alternatives. Entry of young girls into sex work appears to have slowed, and HIV infection rates among younger Krobo women are approaching the lower rates seen in the rest of Ghana.

Source: adapted from Decosas (1996)\textsuperscript{21}
Violence – or the threat of violence – against women increases their vulnerability to HIV and reduces their ability to protect themselves against infection. Women’s economic dependence on men makes women less able to protect themselves, while social norms limit their access to information about sexual matters. At the same time, greater social acceptance of high-risk male sexual behaviour can expose both men and their partners to infection.

Cultural beliefs and expectations also heighten men’s vulnerability. Young men die more often than young women, mainly from traffic accidents and violence. Ideas of ‘manhood’ tend to encourage boys to take risks or use violence, including sexual and drug-related risk-taking.

Men and women have different roles in all societies, but their status should be equal. Men and women, young and old, should be treated with respect and dignity. To prevent the spread of HIV communities need to discuss relationships between men and women and to recognise how stereotyping masculinity and femininity can cause problems. They need to find better ways to communicate with each other about important issues such as sex, contraception, condoms, pregnancy, childbirth, infant feeding and caring for the sick.

The impact of HIV infection

The HIV epidemic is one of the major development challenges facing developing countries today. It threatens achievement of the eight Millennium Development Goals set by the international community in September 2000. The impact of the HIV epidemic has occurred when many governments have been encouraged to cut social, health and education services as part of structural adjustment programs. HIV strikes adults in the prime of their life – often people who are parents, caregivers, breadwinners and taxpayers. The chronic ill health in the later stages of the infection affects the ability of individuals to continue to earn a living to support themselves and dependents. The eventual death results in loss of skilled workers which harms the development prospects of the society. While it is difficult to measure the specific impact of HIV at a national level, in most hard-hit countries a great deal of information does exist about how the epidemic affects households and the public and private sectors of the economy.

Impact on health

HIV has more than doubled the adult death rate in some countries, and is now the world’s leading cause of death in adults aged 15–59 years. According to recent WHO estimates, malaria causes over 1 million deaths a year. In 2003, about 3 million people died from AIDS.

HIV and TB

In addition to being a leading cause of death, HIV has increased the disease burden from tuberculosis in most countries. There has been a resurgence of tuberculosis even in high-income countries. In the developing world, where tuberculosis is the second biggest cause of death among adults, HIV has aggravated an already dangerous situation. In 1999 there were an estimated 8.4 million new tuberculosis cases, up from 8.0 million in 1997; the rise is due largely to a 20% increase in incidence in African countries most affected by the epidemic of HIV. If present trends continue, 10.2 million new cases are expected in 2005, and Africa will have more cases than any other region.

Infection with HIV increases the risk of developing active tuberculosis among those with latent infection. WHO has estimated that around 1.7 billion people, or one-third of the world’s population, are infected with *Mycobacterium tuberculosis*, but without disease. Most people with latent tuberculosis live in Asia, sub-Saharan Africa and Latin America. Already overburdened health systems are being overwhelmed by the increase in active tuberculosis infections.
Health sector overburdened
Public health services in many developing countries have been severely stressed by the increased demand for health care from people with HIV-related illnesses. In the mid-1990s it was estimated that two-thirds of public health spending in Rwanda was used for treating people with HIV-related illnesses. In recent years HIV-positive patients have occupied half the beds in the Provincial Hospital in Chiang Mai, Thailand. The increased affordability of antiretroviral drugs will further raise health sector costs for infrastructure, drugs, training, and personnel.

The growing demand on health care systems is occurring while many trained personnel are becoming sick and dying. In some countries health care systems are losing up to a quarter of their staff. A study in Zambia showed that in one hospital, deaths in health care workers increased thirteen-fold over the ten-year period from 1980 to 1990, largely because of HIV.

Life expectancy
One of the basic measures of human development is life expectancy at birth. From 1900 to 1990, dramatic progress in the fight against infectious diseases raised life expectancy in developing countries from 40 to 64 years. The difference in the life expectancy between the developing countries and the industrialised world was reduced from 25 to 13 years. The HIV epidemic has slowed and in some countries reversed the improving trend in life expectancy.

Projected changes in life expectancy in some sub-Saharan African countries with high HIV prevalence is shown in Figure 2.8 below. The impact of the epidemic on life expectancy is proportional to the severity of the local epidemic. In Botswana, for example, where more than 36% of adults are infected, life expectancy reached a peak of around 63 years in 1990. Since then there has been a rapid decline. At the beginning of 2000, a child born in Botswana could have expected to live to just over 50 years – a reduction of ten years in a decade. Without HIV, people born in Botswana in 2000 could have expected to live to the age of 70 years. In the nine African countries – Botswana, Kenya, Malawi, Mozambique, Namibia, Rwanda, South Africa, Zambia and Zimbabwe – where 10% or more of adults are HIV-positive, the AIDS epidemic is expected to reduce the life expectancy by 17 years.

FIGURE 2.8: PROJECTED CHANGES IN LIFE EXPECTANCY IN AFRICAN COUNTRIES WITH HIGH HIV PREVALENCE, 1995–2000

Social and economic impacts

The toll on individuals, families and communities

Families with a person suffering from HIV-related illness experience a decrease in income, consumption and savings. In Cote d’Ivoire, urban households that have lost at least one family member to HIV have seen their incomes drop by more than half while spending on health increased four-fold. To cope, they have cut their food consumption by up to 41%. Rural households facing similar problems in Thailand are seeing their agricultural output shrink by half. In many households, children are removed from school to take care of ill family members and to regain lost income. Almost everywhere the extra burdens of care and work are shouldered by women, especially the young and the elderly.26 This situation contrasts with that in most high-income countries, where many such costs are met by state or private insurance.

The impact of HIV infection among low-income groups is especially devastating. The poor are already on the margins of survival and are unable to cope with health and other costs. These include the costs of drugs, when available, to treat opportunistic infections, transport costs to health centres, reduced household productivity through illness and diversion of labour to caring roles, losses of employment through illness and job discrimination, and funeral costs. Poor families become even poorer through losses of productive family members to death and migration, and through the sales of any productive assets they once possessed.27

There is enormous strain on the capacity of families to cope with psycho-social and economic consequences of illness. One of the consequences of adults dying young is that elderly grandparents (mostly grandmothers) assume responsibility for their grandchildren. This experience is well reflected by the story of Lucy (see Box 2.6) who has seen her expectations as a mother and grandmother completely overturned by HIV.

The impact of AIDS on a rural household in Uganda and their coping strategies are well described by Barnett and Blaikie in Figure 2.9.28

The impact on the workplace

It is estimated that at least 23 million workers aged 15–49 years are infected with HIV. By 2005, Zimbabwe will have lost 19% of its workforce to AIDS, Botswana 17%, South Africa 11%, the United Republic of Tanzania 9% and Côte d’Ivoire 8%.

AIDS weakens economic activity by squeezing productivity, adding costs, diverting productive resources and depleting skills. Productivity is affected by absenteeism, loss of skills and of ‘organisational memory’. Production cycles can be disrupted, equipment stands idle and temporary staff may need to be recruited and trained. A study in several southern African countries has estimated that the epidemic could cut profits by at least 6–8%.

BOX 2.6: LUCY

By the time my sons became ill with AIDS, one of my daughters-in-law had already died of tuberculosis, and the other had become mentally sick. I had to resume the role of a mother caring for her sick children. I was the only one who could ensure that their physical and emotional needs were met. It was very touching having to nurse my sons again and watching them bedridden and deteriorating day by day. My heart shrunk whenever I thought of caring for my grandchildren after the death of their fathers. Their sickness had started encroaching on the savings I had made for my own welfare in old age. When I was a young girl of 17 getting married, I never dreamed that someday I would see three of my sons die.

My sons left behind six orphans, and now I am once again a mother to children ranging in age from 8 to 15 years. Two of my grandchildren were also HIV-infected. One has already died, and one is still living at age 8, though she has started falling sick. I am taking care of them alone because in our culture, it is the family of the father who must care for orphans. This is a great challenge having to look after young children again after counting myself among those who had graduated from the responsibility of being a mother. Before my sons became ill, I had hoped that my role as a grandmother would be to care for my grandchildren occasionally during school holidays, but now I am alone in caring for them. In the old days, children were not exposed to so many outside influences, but now Uganda society has changed so much. I find that some of the tactics I used to instil discipline in my own children no longer yield the desired response from my grandchildren. I find the children less respectful and undisciplined in spite of my effort. I feel so sad that I have gone back to the beginning and I have to struggle to get resources to ensure that their basic needs are met, such as school fees, medical care, clothing and other needs.

Source: Cohen (1998)27
FIGURE 2.9: THE IMPACT OF AIDS ON A FAMILY IN UGANDA

**Family Home**

- 17 childrens Ages
- F M 12 10 5 3 1

**Family Farm (Two acres)**

- Plantation in: Bananas
- Annual crops
- Herbs
- Coffee
- Herbs

**1980 Stage 1.**

- F M 15 13 8 6 4
- 20 Dies
- Taken out of school

**1983 Stage 2.**

- F M 17 15* 10 8 6
- 23 Dies
- Taken out of school

**1985 Stage 3:**

- M II 19 17 12* 10 8
- F Dies
- Placed with Grand-parents

**1987 Stage 4.**

- M II 21 19 14 12
- Part-time wage labouring for other households.

**1989 Stage 5.**

- M II
- Plantation reduced
- Annual Crop
- Coffee

A direct consequence of increasing numbers of women of reproductive age being infected with HIV is an increase in the numbers of children infected with the virus. The big decline in life expectancy in the countries most seriously affected the HIV epidemic is due not only to deaths of adults, but also to child deaths.

The effect of the HIV epidemic on children is most severe in sub-Saharan Africa. HIV is contributing substantially to rising infant mortality rates (death rate for children under one year of age) in many areas of sub-Saharan Africa, reversing gains in child survival. By 2010, for example, 71 of every 1,000 infants born in Zimbabwe are expected to die before the age of one year. In the absence of AIDS, infant mortality would have been as low as 31 per 1,000. The decline in Botswana is worse still. With AIDS in the picture, the infant mortality rate is expected to reach 66 per 1,000, but without AIDS the country could have expected a far lower rate of 26 per 1,000.

Orphans

Orphans are usually cared for by members of their extended family. But urbanisation, migration, and increasing deaths among adults are exhausting the capacity of extended families to cope. In Cambodia, where decades of war and civil strife have already taken a heavy toll on family structures, families will need support to care for orphans. Fear of discrimination may lead families to keep secret the knowledge of HIV infection within the household rather than seek help. Others seek help but are rejected or abandoned, even by family members, when they reveal the nature of the illness. Fear, discrimination, ignorance and social stigma associated with HIV, in addition to overwhelming demands on caring adults, leave children isolated with their grief and suffering while they watch parents and other loved ones die.

In many sub-Saharan African countries, the care of orphans is increasingly becoming the responsibility of grandparents as more and more young adults (parents, aunts and uncles) die from AIDS. A study of 300 orphan households in Zimbabwe in 1995 found that nearly half of the caregivers were grandparents. The average age of grandparent caregivers was 62 years.

In some cases the older siblings (who are often still children themselves) take on responsibilities for the survival of the family and home. The Zimbabwe study found that about 3% of households were headed by siblings. The children in these situations work long hours doing household tasks, supervising younger children and engaging in income-generating work in order to support the family. Many quit school and jeopardise their own health and developmental needs to take on roles as parents, nurses and providers.

The care that older siblings can provide for younger children is likely to be inadequate because of the increased poverty of the household and the lack of maturity and
experience of the caretaker, leading to poor health, hygiene and nutrition; absence from school; and developmental delays. The poverty and disadvantage of the household continues into the next generation.

The impact on the health and social development of large numbers of orphaned children has implications for the national development of countries severely affected by HIV.

As well, large numbers of children growing up in poverty will be vulnerable to behaviours and exploitation that put them at risk of infection with HIV.

**State of the global HIV response**

Communities, governments and the international community have been responding to the HIV epidemic for more than twenty years. However, the commitment of the international community has been weak, and in many countries, strong national leadership to take on the many challenges of the epidemic has been lacking.

After years of comparative indifference, the level of political commitment to responding to HIV has increased dramatically on every continent. Increasingly, governments, the private sector, religious organisations, and community groups in many countries are openly stating their resolve to respond effectively to the epidemic. Regional bodies such as the Organisation of African Unity (OAU), the Association of South-East Asian Nations (ASEAN), and Caribbean Communities Secretariat (CARICOM) now highlight the need to confront the HIV epidemic.

**Successful national responses**

Two decades of action against the epidemic have given us important insights into what works in responding to HIV. While international political, financial and technical support are important, prevention, care and support efforts must be led by national governments. We have mentioned the success of national responses in Uganda, Senegal and Thailand. The Executive Director of UNAIDS in a speech to the US Senate in February 2002 mentioned other successes:

• In Cambodia, despite the pressures on a society emerging from genocide and conflict, the threat of HIV in the mid-1990s was responded to, and as a result there are measurable declines in both risk behaviours and in the levels of HIV – the infection rate among pregnant women in Cambodia declined by almost a third between 1997 and 2000.

• The Philippines has kept HIV rates low with strong prevention efforts and mobilisation across society involving community and business organisations.

• Zambia’s focus on HIV prevention among youth and its efforts to involve business, farmers, schools and religion in the fight against AIDS have also shown success. In response to AIDS, young women in cities in Zambia have reported less sexual activity as well as increases in condom use and the age at which they first become sexually active. As a result, the proportion of pregnant women under 20 who were HIV-positive had fallen from 27% in 1993 to 17% by 1998.

• In the Mbeya region in Tanzania, falls in HIV incidence have come through a decade of sustained action. Building local skills and infrastructure has been a core part of this effort, along with generating political support and working through schools, health centres, churches, village committees and local businesses to deliver AIDS information and education, treat sexually transmitted diseases, deliver condoms, and provide community care for people with HIV.
Brazil provides a leading example of integrating commitment to prevention with comprehensive care. In 1994, the World Bank estimated that Brazil was heading towards 1.2 million HIV infections by 2000, but success in prevention in the second half of the 1990s kept the total down to 540,000. In 1996 Brazil established a legal right to free medication. The numbers of patients using antiretroviral drugs grew from 25,000 in 1997 to over 100,000 by 2002, and the number of AIDS deaths has fallen by 60%.

There are now widely accepted strategic approaches which are derived from these successful country experiences.

The international commitment to the AIDS response

There is also increased commitment to fight against AIDS on the part of the international community, including the United Nations, international development agencies and, increasingly, private sector organisations. Within the United Nations, increasing momentum is being led by the Secretary-General who has publicly declared that the fight against AIDS is a personal priority.

At the United Nations General Assembly Special Session on AIDS (UNGASS) in June 2001, 180 countries signed the ‘Declaration of Commitment on HIV’. All the countries adopted a series of benchmark targets in the HIV response, including 25% reduction in the level of HIV among young people in the hardest-hit countries by 2005, and 50% reduction in the proportion of infants infected with HIV by 2010. Countries also pledged to promote access to vital drugs and ensure a supportive environment for children orphaned by HIV. Such international statements often fail to result in the level of resource allocation needed for their fulfilment, but the Declaration of Commitment provides an important tool for advocacy. Since UNGASS, there has been an upsurge in country activity dedicated to meeting the targets set at the meeting. The establishment of the Global Fund to fight AIDS, Tuberculosis and Malaria (GFATM) will support countries to meet the pledges they made at UNGASS. The fund is a public–private partnership – its board includes business representation as well as non-government organisations and representatives of the communities directly affected.

Governments, corporations, NGOs and individuals have pledged large amounts to the Global Fund, representing a major increase in the international funds available for HIV prevention and care. The Global Fund announced its first round of grants in April 2002, a total of US$378 million over two years to 40 programs in 31 countries. There have been three subsequent rounds of proposals approved. Approximately 60% of the first two years of funding (totaling US$429 million) went to HIV programs. In 2003 the United States government also approved a greatly increased level of funding for responses to the epidemic.

Despite these new commitments there is still too little available to meet the needs for prevention and care for those infected and affected. UNAIDS estimates that by 2005 effective global responses will require about US$89 billion annually, with half of these resources needed in sub-Saharan Africa. About US$4.8 billion is required for prevention including interventions focussing on youth, workplace programs, mother-to-child transmission and condom distribution. US$4.4 billion is needed for palliative care, treatment and prophylaxis of opportunistic infections, support for orphans and antiretroviral therapy.
Global partnerships against HIV infection

A feature of effective responses has been the involvement of different partners. There have been traditional partnerships between governments and the community/non-government sectors. Some new creative partnerships have also emerged in recent years. Each partner has their own advantages which relate to the resources they can mobilise as well as the tasks and responsibilities they perform best.

- At the national level the expression of ownership and responsibility by governments needs to be accompanied by budgetary allocations. A clear expression of commitment has come from the African continent with the Abuja Declaration adopted at the Organisation of African Unity’s (OAU) special summit on AIDS in 2001. All OAU members pledged to allocate 15% of national budgets to health to help fight AIDS and related diseases.

- Bilateral donors can provide both funding and technical resources to support responses in low-income countries. Bilateral funding agencies, including AusAID (Australia), USAID (United States) and DFID (Britain), have increased their funding allocation.

- Multilateral organisations are well placed to ensure that internationally accepted scientific and technical standards are applied, and to help promote consensus on the effective approaches to complex and difficult social issues. In the case of the World Bank, this includes providing low-interest credits to low-income countries to use for the HIV response.

- Involvement by international NGOs, private foundations and business, is becoming increasingly important. The size, range and sophistication of business involvement in HIV prevention and care have grown over the past few years, but much more is needed. UNAIDS has developed agreements with a number of multinational businesses and international NGOs as partners in the fight against AIDS. Private foundations such as the Bill and Melinda Gates and the Rockefeller Foundations have become increasingly important partners in recent years.

Scaling-up responses

Many aspects of the global response have improved in the last few years, including:
- many examples of successful national responses to give us hope;
- stronger commitment by governments and the international community;
- more funding available;
- cheaper antiretroviral drugs;
- new partnerships committed to the response.

However, we need to translate proven approaches to full-scale national responses. The tools for effective responses exist. In the majority of countries around the world, there are detailed plans for dealing with the epidemic. There are communities ready to take action. In order to build success, increased financial investment needs to be matched with investment in developing the capacity of communities. Local capacity for prevention, care and support efforts need to be recognised, affirmed and strengthened.
References

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Chapter 3
Understanding HIV in your community: asking the right questions
by Rob Moodie and Tamara Kwarteng

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Introduction

In the previous two chapters, we provided a ‘global’ overview of HIV in the world. In this chapter, we move from a ‘global’ to a ‘local’ perspective and focus on HIV in communities. We also move from providing background information for understanding HIV to suggesting questions to ask when planning local HIV responses. This chapter is about gathering information to understand the needs of the community; this process, which is also referred to as the situation analysis, is essential for planning effective community action on HIV.

We present a set of questions as a guide for gathering information. You will not need to ask all these questions. You may need to wait to answer some of the questions; some of the questions may be answered during the project itself. Choose which topic areas are most important for your project. You may then decide to focus on one or two important questions in each section.
Community participation

Before starting to gather information, it is important to think about community participation and ownership of the project. Sometimes ideas for HIV prevention activities come from outside the community. This may occur as a result of concern from interested partner NGOs, or because there is money available in development aid budgets. Sometimes a community is unaware that they are at risk of spread of HIV.

The process of a community becoming awakened to the dangers of HIV and being motivated to act can take time. HIV can remain hidden to most in a community for a long period. The epidemic becomes visible when increasing numbers of people, especially young adults, become sick and die, and the links between the increased levels of sickness, death and HIV infection become more widely discussed and accepted.

 Communities are sometimes not aware of behaviours which increase the risk of HIV infection, or they may not be willing to admit that such behaviours take place. The situation analysis can be a time to encourage open discussion about these matters. If the information is collected by community members and presented to key decision makers, it can be a powerful way to get agreement on the need to act and the choice of effective strategies.

For responses that involve people or an NGO from outside the community, the information gathering process will also provide the opportunity to develop trust with the community. Use the planning phase as a time for learning about the community and about HIV and STIs. If possible, build HIV prevention and care activities into existing community development projects, so that you can build on the trust already established. In Chapter 6 we discuss ways of integrating responses to HIV into existing community activities.

Why do you need to gather information?

The spread of HIV, and the quality of life of those affected by it, are influenced by social, cultural and economic factors which vary from place to place. An understanding of these background factors will help program planners and communities to identify the most important areas for action. It will also help you in adapting the experiences of other countries and communities.

The quality of the information available at the time of planning will depend on what information already exists, and the time and resources you have to gather new information.

Once you have gathered information you need to analyse it to identify who is most vulnerable to HIV infection. You can also identify obstacles and opportunities to respond effectively to the need for prevention and care in the community.

BOX 3.1: COLLECTING INFORMATION

The decision about how much to collect should balance resources available, process (participation) considerations, the scope of the intended activity and the specific skills of the implementing agency. It may be useful to identify:

- information that is absolutely essential
- information that is useful but we could live without it
- information that would be nice to know, but that is all.

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1. Community may refer to one or many groups of people who share common identity on the basis of a particular factor or factors such as location, ethnicity, occupation, sexual preference and religion.
Learning about the community

Sexual behaviours and drug using behaviours are usually complex and often hidden. Before investigating these sensitive behaviours it is important to gain a broad knowledge of the community.

Useful national health, social and economic data is available in UNAIDS, WHO and World Bank publications and the UNDP Human Development Report. You can gather local information through rapid appraisal techniques that involve the community. We describe the methods that you can use to gather information in Chapter 4.

The information that you need to collect about the make-up of your community includes:

- demographic and socio-economic characteristics;
- local decision-making structures and processes, networks, interest groups, and elites;
- the health status of the community;
- existing health care, welfare and development services;
- relevant cultural beliefs and practices.

Demographic and socio-economic characteristics of the community

What needs to be answered?

Demographic data

- What is the estimated population of the community? What proportion of the population is female and what proportion is male?
- What is known about the age distribution?
- What is the geographic distribution of the population?
- How is the population expected to grow in the next five to ten years?

Socio-economic data

- What is the average family size, marital status and household structure? Does family size vary with season and migration?
- What are the education levels of the community?
- What is known about income levels? Is wealth distributed evenly across the community or are there large differences in household incomes and living standards?
- What are the main occupations of the community? How common is unemployment?
- Do employment levels vary by age, sex or ethnicity?
- Do people travel away from or into the community for work? How does this vary between men and women?

Where do you get the information?

Reports from the most recent census should contain the age, sex and geographical distribution that you need. District or regional planning departments will have specific local information on demographics, household economics, employment and migratory patterns. Check the information with community members, especially if it has been many years since the last census.

Understanding local decision-making structures and processes and gender relations

What do you need to know?

- How is the community organised? What social, family, ethnic, cultural, religious, language, labour, political or wealth groups make up the community?
• How do these groups differ in their access to political power, land, employment and services such as education, health and transport? Are some groups marginalised?
• How do the roles, status and power of men and women differ?
• Do women have the power to require fidelity from their men? Do they have the power to insist on condom use?
• Are women in a subordinate position within their families and communities? Do they have the means of independent economic support?
• Who are the formal leaders of the community? How are they appointed or chosen?
• Who are the informal leaders of the community? Are they leaders because of their wealth, gender, tradition, religion, or education?
• What is the effect of modern influences on traditional cultures? Are there two sets of power structures: traditional and modern? If so, are they in conflict or are they complementary?
• How and where do people gather to talk about issues of importance to the community?

Where do you get the information?
Discussions and interviews with members of the community should provide information about decision-making structures and processes. Note carefully the sources you use to collect such information – and possible biases in reporting. Some people may wish to minimise the differences between the majority and minority groups or be reluctant to discuss cultural practices.3 There may be government reports, or reports by UNDP and UNICEF about the situation of women. The most valuable information, however, is likely to come from women in the community, through focus groups and key informant interviews.

Health profile of the community
HIV is only one of a number of health problems faced by the community. A brief description of the major health problems will help to understand how HIV is placed among the health concerns of the community. It is also important to find out about the health care services available and how they are used by different members of the community.

What do you need to know?

Health status of the community
• What are the main causes of death (mortality)? Are there any estimates on how this varies according to age, gender, and place of residence?
• What are the main causes of illness (morbidity)? Is there any information about how this varies by age, gender, and place of residence?
• What are the levels of disability in the community?

Organisation and usage patterns of existing health and related services
• What is the estimated national per capita expenditure on health? Is there any evidence that it is different in your district or community?
• What types of health services are provided for women, men and children in the community?
• Who provides the services, for example, the government, religious or secular non-government organisations, private doctors, private pharmacies, traditional healers or street vendors?
• What proportion of care is provided by each of these categories?
• How accessible and affordable are these services?
• Who is using health services? Is there any information broken down by age, gender or location?
• What are the patterns of frequency of health care service use and what types of service are used?
• How satisfied are community members with the services?
• Do factors such as caste, class and race influence the distribution of and access to services?

Relevant cultural beliefs and practices about health
• What are the most important cultural beliefs, including religious, social, family and political beliefs, that influence use of health and development services?
• What are the major ‘folk’ illnesses in the community?

Where do you get the information?
The national health plan will provide information about per capita expenditure on health and services provided. The district or regional health plans are likely to provide more detailed local information about your community. Interviews and focus group discussions are useful methods to gather information about satisfaction of the community with the quality of health services and the reasons for choosing different types of health service, such as traditional healers, pharmacists, the hospital in town, or the local clinic.

Distribution and frequency of HIV infection and other sexually transmitted infections (STIs)
In many countries there is little reliable data on STIs, HIV, sexual behaviour and drug injecting behaviour. So the first step of the project may be the collection of baseline information. This need not be expensive or time consuming. You can use a variety of rapid assessment techniques, which we describe later in this chapter.

We have found that most people, whether in a remote village in Uganda or in the highlands of New Guinea, in suburban Abidjan or New Delhi, are willing to discuss their sexual experiences or drug using experiences if they are asked in a sensitive, private and confidential way. These are some of the questions we need to ask, and the reasons for asking them.

What do you need to know?
What types of STIs are most common?
• Ask which types of STIs are most commonly seen in clinics, hospital outpatient departments, by private doctors, and by pharmacists.
• How are STIs diagnosed or categorised? In areas with limited resources STIs are often diagnosed on clinical grounds without laboratory tests. Health workers may categorise them according to the presenting symptoms, such as urethral discharge, cervical discharge or ulcerative disease.
• What proportion of cases do local health workers believe are reported to the public health authorities?
• Are there any estimates of the incidence and prevalence of HIV and other STIs (see Box 3.2)?

BOX 3.2: UNDERSTANDING INCIDENCE AND PREVALENCE
• ‘Prevalence’ is defined as the proportion of a defined population infected at any given point in time. Prevalence is dependent on the number of new infections (incidence) and people leaving the infected pool (either through death or migration out of the sample area).
• ‘Incidence’ is number of new infections in a defined population in a given period of time (usually per year).
• What proportion of those who are estimated to be infected with HIV know that they are infected? A 2001 study estimated that less than 1% of the sexually active urban population in Africa had been tested. This proportion was even lower in rural populations. So HIV remains an invisible disease in many communities.

• What numbers and proportions of the community have AIDS? How many AIDS-related deaths have there been? Statistics on AIDS cases give an idea of the severity of the existing problem for health care services. The number infected with HIV suggests the future burden on the health care system. The ratio of HIV infections to AIDS cases is an indication of the age of the epidemic. Early in the spread of HIV in an area there may be many people infected with HIV, but few cases of AIDS. The ratio changes as years go by and more people infected with HIV become ill with AIDS. There may be no reliable statistical information from the community or region you are working in. In that case it may be appropriate to draw inferences from other similar regions where information is available.

• Who is getting infected? Is information available that is broken down by age group, gender, location, education level or occupation?

• Is there any information from specific population groups that are being tested for STIs or HIV infection such as pregnant women, STI clinic attendees, sex workers or truck drivers?

• Is there historical data that are able to show any changes over time in infection rates?

• Is the incidence of HIV or STIs increasing? If so, how quickly?

Where do you get the information?

Information about the number of cases of STIs and HIV can be collected in one of two ways. Most countries use some combination of both methods. The most common method is reporting to the health department by health workers when they encounter a new case. This type of notification usually underestimates the true number because many infected people do not seek treatment, and HIV testing is not always available to health care practitioners. Additionally, for many reasons, health workers often do not report the infections they treat. Another source of data is surveillance systems in which a large number of people are tested.

The national AIDS program staff will probably have the most up-to-date information on HIV and AIDS cases.

Local public health authorities, the local blood bank (if they screen for HIV, syphilis or hepatitis B), and doctors and nurses in STI clinics and hospital outpatient departments may have useful information about the types and distribution of STIs and HIV in the community.

Ask local government STI doctors and nurses, private doctors, researchers, pharmacists and unofficial medicine vendors about how STIs are diagnosed and treated.
Understanding sexual behaviour in your community

To develop an effective response to the HIV epidemic it is essential to understand patterns of sexual behaviour, and the social, cultural, economic, political and legal influences on these behaviours.

What differences do you note between the way that sex is discussed officially and publicly, and the ways that individuals, couples and families talk about sex in private?

All communities have ‘gatekeepers’ who influence policy decisions. These may be community and political leaders, religious leaders and NGO leaders. The discomfort of these ‘gatekeepers’ is often a more important reason for the lack of discussions about the realities of sexual behaviour than unwillingness of ordinary people to discuss these issues.

To learn about sexual behaviour it is useful to find out first what words or terms people use to talk about sex. In what social situations do people talk about sex, for example, when telling jokes, when men are together, when women are together, when married people are together?

Ideas about sexuality vary greatly from culture to culture. Remember that you will tend to think of sexuality in terms of your own cultural perspectives and biases.

You will need to find out about not only the dominant sexual cultures, but also about traditional and emerging sub-cultures. Examples of traditional sub-cultures include the hijras in India, the kathoey of Thailand, and the waria in Indonesia. Examples of emerging sub-cultures include sexual use of young men in southern African mining camps and urban dormitories, and previously unrecognised gay groups in many developing countries.

BOX 3.3: UGANDAN AIDS PROGRAM

In 1991 the Uganda National AIDS Control Program commissioned an evaluation of its information, education and communication activities. The evaluation found that the Government had been very open about the seriousness of AIDS in Uganda. Government policy had concentrated on raising awareness and prompting abstinence before marriage and fidelity in marriage. However, it had been unable to acknowledge the myriad traditional and contemporary influences on sexual behaviour. This led to people knowing more and more about the dangers of HIV, without having any means to either assess their own level of risk or to protect themselves when having sex. Since that time, however, the government, led by the President Yoweri Museveni, has been much more open about confronting the realities of sexual behaviour in Uganda, and as a result has been more effective in controlling the spread of HIV.
What do we need to know?

Some of the following questions may be relevant:
• What are the predominant cultural patterns and sub-cultural patterns of sexuality?
• Is migration into or out of the community a major influence on sexual networking patterns?
• How much does the ‘public’ discourse on sexual behaviour differ from the ‘private’ discourse?
• How much power do women have over their sexual relationships?
• What specific sexual activities increase or decrease risk of transmission of disease?
• How important is sex work for money?
• What do people know about STIs and HIV?
• What are common practices in relation to contraception and family planning?
• What changes in behaviour have occurred, and what further changes are likely to occur?

What part does sex play in people’s private and social lives?
• How important is sex to people? Why do people have sex?
Reasons might relate to desire for a child, love, clan, kinship, marriage, family or personal power, personal gratification, or cultural symbolism (rites of passage).
Understanding the meaning and associations of sexual behaviour in people’s lives helps us to understand what is needed to enable people to protect themselves from risk. For example, rituals that carry a risk of transmission might be changed so that the symbolism is kept but the ritual becomes safe. Widow cleansing refers to a practice in some sub-Saharan societies, where a male relative of the husband has sex with the widow soon after the death of the spouse. It acts symbolically both to cleanse the widow from any evil spirits as a result of her spouse’s death and to reinforce her as a part of the extended family. Because of the risk of HIV transmission many communities have decided to carry out the ritual in a non sexual manner.

In some parts of the Democratic Republic of Congo (former Zaire) it is believed that once a woman is pregnant repeated doses of semen are needed to form or ripen the growing fetus. This is one reason why the use of condoms is believed to be unnatural. This belief is based on ancient lore that the husband should take an interest in his wife if she is pregnant and not have sex with other women. Traditional healers now emphasise the need for repeated intercourse rather than repeated doses of semen to ripen the growing fetus. This means that condoms can be used following conception to reduce risks of HIV infection, if sero-status is unknown or if one partner is HIV positive.

What are the predominant cultural patterns and sub-cultural patterns of sexuality?
• When do young men and women start having sex? How much choice do young people have about this? How does it differ for men and women?
In many cultures sex before marriage is forbidden. Because of this, sex among young people becomes secretive. They often have little access to reliable information, to condoms or to contraceptive methods. Young women may have sex with ‘sugar daddies’ in return for ‘favourites’ in order to be able to continue their high school education.
• When and in what circumstances do people get married?
• What are the predominant cultural views of sexual relationships, for example, sex within or outside recognised marriage, sex between men and men, women and women, or sharing of spouses?
In Asia and the Pacific homosexuality is often defined as a Western phenomenon, yet many Eastern cultures have a rich tradition of homosexual poetry and art. Most cultures include some form of sexual behaviour between partners of the same sex.
• How and where do people meet sexual partners?
• How does sexual behaviour vary with age, gender, economic power, level of education and rural or urban living?

Among some cultures in sub-Saharan Africa the extension of clan influence may be far more important than love in the choice of marriage partners. So sexual fidelity to one’s partner may not necessarily be highly valued – despite contemporary church teachings.

• Are there cultural events that are linked to sexual relationships such as circumcision, rites of passage, naming of children or death of spouse?

Is migration into or out of the community a major influence on sexual behaviour?

All over the world a growing number of people move away from their homes to find work, including construction workers, miners, foresters, commercial sex workers and the military. Others, such as truckers, rural nomads, and sailors, have to travel as part of their work. This may result in new patterns of sexual behaviour, both for the partner who leaves and for the partner at home. This large-scale migration within countries increases the demand for commercial sex. The size of this migration is often underestimated. For example, in China, the size of the urban population is predicted to increase by 160 million between 1990 and 2000.

• Do men and women go away from the family or primary sexual relationship for extended periods of time?

• Are sexual sub-cultures, such as male-to-male sex in dormitories, sex work for money, gay and transgender sub-cultures, developing in urban areas?

• Are there military camps, ports or major construction works in the area?

• What are the major transport routes through the area? How many truck drivers or migrant workers pass through the area?

• Is there a tourist industry? If so, what types of tourists are there and where do they visit? What influence do the tourists have on local communities?

What is the public, as opposed to the private, discussion on sexuality?

• What forms of sexual relationships are socially acceptable? What forms of sexual relationships are not socially accepted? How common are these different types of relationships?

• What is the difference between the public perception of sexual behaviour and actual practice?

How much power do women have in their sexual relationships?

• How common is forced sex? How common is incest?

• Can women ask their partners to use condoms? Can women obtain male or female condoms? What are the barriers to women obtaining condoms?

• Who usually initiates sex?

In Papua New Guinea many men at some time participate in having sex with one woman and several other men, usually of the same language group. Often this is forced on the woman, but is not seen as rape in the legal sense, nor is it reported or condemned.

Are there specific sexual activities which may increase or decrease risk of infection with HIV?

• How common are sexual activities which increase risk? These include anal sex, dry sex, beating or traumatic sex, sex during menstruation, and sex during pregnancy.

• How common are sexual activities that decrease risk? These include non-penetrative sex, such as sex between the thighs, massage, mutual masturbation, and oral sex.

In some parts of the world, women try to dry their vagina before sex. This may be because they fear that men will think they have been unfaithful if their vagina shows normal sexual lubrication, or because of a belief that sex is more pleasurable with added friction. Wiping or douching the vagina, or inserting herbs or other drying substances may cause inflammation and increase vulnerability to infection with HIV.
In some cultures, men use penile devices (cock rings) that may increase the risk of damage to the vaginal mucosa.

In some places, such as Sri Lanka, inter-femoral sex (between the thighs) or ‘cupping’ is a common sexual practice that avoids the risk of pregnancy or STIs.

**How important is sex work for money or favours?**

- How is sex work defined locally? Is there an organised sex industry?
- Are women, men or children coerced or lured into urban sex work? Are there any other employment opportunities in their villages of origin?
- How is sex work organised? Who controls sex work? Do sex workers work in brothels, on the street, in nightclubs, for escort services or in hotels?
- What types of men visit sex workers? Are there times when they are more likely to visit a sex worker? For example, men might be more likely to visit a sex worker after a good harvest, after a fortnightly pay check, before their marriage or when their wife is pregnant or post partum.
- Is it common for women to have a sexual partner for money, goods or favours?
  
  *In some cultures sexual activity is often ‘transactional’, that is, it is expected that the woman gains money, rent or goods from her sexual partner. In these cases women do not think of themselves as commercial sex workers or prostitutes.*
- What are the types of sex workers in your community: female for male, males for males, males for females or transsexuals?
- What is the range of payment per client, and the range in the number of clients per day?
- Is commercial sex work legalised? Are commercial sex workers registered?
- Have commercial sex workers formed organisations?
- Are sex workers able to access appropriate health care services? What barriers do they face?
- Are health checks, HIV testing or treatment for STIs compulsory?
- Are sex workers exposed to inappropriate or dangerous practices in relation to STIs?

  *In some parts of Indonesia sex workers are subjected to regular injections of antibiotics, which promote resistant organisms and give a false sense of security.*

**What do people know and do about STIs and HIV?**

- What is the level of knowledge about transmission and prevention of HIV and STIs?
- Does knowledge vary from group to group?
- Do people perceive themselves to be at risk?
- Which individuals or groups of people are commonly perceived by others to be at risk of infection with HIV?
- What incorrect beliefs do people have about HIV?
- What do people do to protect themselves from HIV? How common is the use of condoms?
- How common is the use of lubricants? Do people use oil-based or water-based lubricants? Which lubricants are available and how much do they cost?

  *In a town in India police recruits responded to information about AIDS by making sure that they each had their own razor for shaving. But they did not change their sexual behaviour or start to use condoms.*
Is family planning common?

- What is the available range of contraception? Are oral contraceptives, injectable contraceptives, intra-uterine devices (IUDs), condoms, and/or female and male sterilisation available?
- Is information about how to recognise the time of ovulation available to women?
- What are the levels of use of these different methods?
- What are the traditional methods of family planning? How common are these?

What changes in sexual behaviour have occurred and what further changes are likely to occur?

It is important to understand the dynamic nature of sexual behaviour. Patterns of sexual behaviour change over time. Factors such as television and video, the Internet, economic development, the distribution of wealth, literacy levels, civil strife, and migration influence patterns of sexual behaviour.

Patterns of sexual behaviour have been changing very rapidly in China for example. There has been a great increase in sex before and outside marriage, and a greater recognition of homosexuality. Use of sex workers has increased and STIs have become more common. These changes have occurred with the opening of the economy and trade with other countries. The changes are greatest in the South of China, where economic development has been strong.10

How do you get the information?

The information required from the questions in this session should be explored through qualitative research methods such as focus group discussions with different members of the community and through key informant interviews. Participatory exercises from the field of Participatory Learning and Action (PLA) are especially useful to stimulate discussion of these sensitive subjects. These exercises include the ‘ten seed technique’, matrix ranking, mapping, and causal diagrams. They can be used within focus group discussions.

There are some useful books and articles by social scientists that help in understanding the history, attitudes and practices of specific sexual sub-cultures.11,12,13

A baseline knowledge, attitudes, beliefs and practices (KABP) survey can also establish the level of knowledge about STIs in the community. Repeats of the survey can be used to monitor and evaluate efforts to educate people about STIs and HIV. Of course people may not answer a questionnaire on such sensitive subjects accurately, especially if they feel their answers may not be kept confidential. Findings from KAPB surveys should always be interpreted with care.

Understanding drug injecting in your community

The use of illicit drugs (heroin, cocaine and amphetamines) is increasing around the world. Patterns in the production and use of illicit drugs have changed rapidly over the last decade, and continue to change rapidly. With regard to heroin, the changes in distribution routes and the availability of purer forms of the drug has led to preference to injecting of heroin over smoking opium in most countries.14

Injecting drug use is spreading to new countries, such as those in eastern Europe, Latin America and, more recently, to African countries. It is possible to minimise the spread of HIV among people who inject drugs. A study in over 80 cities has shown that HIV infection decreased by 5.8% per year in
the 29 cities with needle exchange programs and increased by 5.9% per year in cities without these exchange programs.\textsuperscript{15} In the US researchers estimate that HIV infection could have been prevented in between 4,000 and 10,000 people if they had had access to needle exchange programs.\textsuperscript{16}

Because it is illegal to inject drugs it is often difficult for countries and communities to admit openly that it occurs. It may be extremely difficult for those who inject to admit their drug use, or to seek information and treatment. This means that it is difficult to ask about the extent and nature of injecting drug use.

**What do you need to know?**

There are three major areas of inquiry:

- the extent of drug cultivation, production and transport;
- the extent and nature of drug injecting;
- the structural and social barriers to change.

**The extent of drug cultivation, production and transport**

- Are opium poppies or coca leaves grown in the area? Are amphetamines produced in the area?
- Are injectable drugs transported through the area?
- What is the ‘street’ price of drugs?
- Are drugs used to pay ‘in kind’ for transport and distribution of the drugs?

**The extent and nature of drug injecting**

- What is the estimated number of people who inject drugs? Is this increasing?
- What are the reasons that people take drugs?
- What is the estimated prevalence of HIV infection and the other blood-borne viruses, hepatitis B and hepatitis C, among those who inject?
- Are the sexual partners of people who inject becoming infected with HIV and other blood-borne viruses?
- What is the estimated number of people who are taking opium, cocaine or amphetamines by routes other than injection (smoking or by mouth)?
- Are people changing the way they take drugs?
- Is there a strong link between injecting drug use and sex work?
- Are there sub-cultures of people who inject drugs that develop according to sexual preference, labour or ethnicity?

*In Ruili county in Yunnan province on the China-Burma border injecting of drugs has occurred only over the last ten years or so. Young, poor, peasant men of one ethnic minority are now injecting because it is one-third the cost of smoking heroin. They inject in groups of about ten, using and sharing a needle with some intravenous line plastic tubing as a ‘syringe’.*

- What are the circumstances when people first begin to inject?
- What sort of drugs are being injected? How often on average (per day or per week) are these being injected?
- How do people inject? With what equipment? How many people do they share with? Where do they do it?

**BOX 3.4: CHANGES IN HEROIN PRODUCTION IN THE ‘GOLDEN TRIANGLE’**\textsuperscript{17}

The global production of opium in 1991 was 3,785 metric tons. It is estimated that 70% of this originates in the ‘Golden Triangle’ region of South-East Asia.\textsuperscript{18} (Bureau of International Narcotic Matters [US Department of State]. *International Narcotics Control Strategy Report* 1992, Washington, USDS.) In the period between the end of the second World War and the 1960s, opium was generally smoked unrefined in the Golden Triangle and heroin was unavailable. Most of the opium produced was exported for processing in laboratories in Bangkok, Hong Kong or Marseilles.\textsuperscript{18} Over the last two decades, however, heroin refinement laboratories have moved closer to the opium fields. This followed the closure of laboratories outside the Golden Triangle as a result of increased law enforcement pressure, improved laboratory techniques and the availability of cheap production chemicals. Consequently, in the 1960s abundant and cheap heroin became available for the first time in South-East Asian countries.

The patterns in drug transit also change constantly, according to geo-political and military circumstances. For example, heroin from the Golden Triangle was principally exported through Bangkok until the late 1980s, when the Burmese military cracked down on dissident ethnic groups involved in heroin.
• What efforts do people who inject make to avoid contamination? These might include:
  – avoiding sharing, carrying their own needles and syringes;
  – rinsing needles and syringes;
  – boiling needles and syringes;
  – using bleach or other locally available disinfectants to clean needles and syringes.
• How easy is it to get needles and syringes? How available is other injecting equipment?
• How available is bleach?
• How available is treatment for drug addiction such as drug substitution programs with methadone or buprenorphine?

The structural and social barriers to change
As with sexual behaviour, it is important to find out whether attitudes vary between the public, legal and ‘official’ position and the more personal family or individual attitudes.
• What are the cultural and political attitudes to drug injecting, and to those who inject?
• Those who inject may belong to sub-cultures or minority ethnic groups. What are the attitudes of their own communities towards those who inject?
• What laws are there that relate to:
  – the distribution of needles and syringes?
  – possession of drugs?
  – possession of drug injecting equipment?
• How are these laws implemented?
• What are the attitudes of the police towards those who inject?

How do you get the information?
Existing sources of information can help to answer many of the questions posed above – to discover the type, depth and scope of the injecting drug use problem in the community. These include the following:
• **Drug treatment programs**: can provide information about the numbers and characteristics of drug users who seek treatment and the drugs that are being used. They may also provide contact with drug users for in-depth interviews.
• **Health care facilities**: including hospital emergency rooms, mental health services, STI Clinics, dermatology clinics and primary health care sites. They may have information on the complications arising from drug use, and where those who inject live and gather to inject.
• **National AIDS organisations**: may have useful statistics.
• **Pharmacists and shopkeepers**: if they sell needles and syringes they will probably have had contact with drug users, and have information on how many needles and syringes they sell.
• **Police, prisons and other law enforcement**: can provide information on drug related arrests and the types of drugs seized.
• **NGOs**: may work with people who inject or may have come in contact with drugs through the services they provide such as primary health care or maternal and child health.
• **Traditional healers and religious workers**: may be dealing with drug users through traditional medicine and counselling, and are often consulted by families and friends of drug users.
• **Social scientists and medical researchers**: in universities or independent institutions, may have information from studies conducted with drug users or can provide information on particular patterns and behaviours.

There are several useful manuals to help you to conduct a rapid assessment on injecting drug use within a community.14,19,20
Blood transfusion and infection control

HIV can be transmitted to people who receive unscreened blood transfusions. When the equipment used to collect blood from donors is re-used without sterilisation HIV can also spread from one donor to another.

What do you need to know?

- Who is responsible for blood safety in the country? Where is blood for transfusion obtained? From volunteers, prisoners, army, family members or paid donors?
- Do hospitals have written guidelines with strict criteria for the use of blood transfusions? Do these practices vary between the public and private health sectors? Are staff trained in blood safety?
- Does ‘micro-transfusion’ occur? (Micro-transfusion is the practice of injecting small amounts of blood in the false belief that it will benefit the patient).
- What infection control practices do commercial blood banks follow to prevent transmission of viruses such as HIV? Who monitors these practices?
- Is blood for transfusion screened for antibodies to HIV, hepatitis and syphilis? Does the screening occur at all levels of the health care system, or only in the larger cities or in the private sector? What tests are used? Is the testing done before or after the blood is transfused? Are there any estimates for the percentage of blood donations that are screened for HIV?
- Are blood bank officials aware of strategies to reduce the cost of screening blood for transfusion?
- What are the infection control practices in the various health settings such as hospitals, clinics and health centres? What is the level of knowledge of health care workers about infection control? What are the barriers they face in implementing safe work practices and Universal Precautions? Are traditional healers and traditional birth attendants aware of the need for infection control in their practices?

Where do you get the information?

The local Red Cross, blood banks, and department of health, hospitals and health centres will be important sources of information about blood donation and infection control. It will also be useful to speak with blood donors about their experiences. Observation, and consultation with health care workers at all levels, will help to reveal knowledge, attitudes and practices in relation to infection control in health care settings.

The care of people with HIV-related illness

The health care system is an important element in the prevention of HIV infection as well as care and support of infected persons and their families. It is important to collect information about the capacity of the health care system to perform these roles.

What do you need to know?

- What health and support services are available for people with chronic illness; in the public, private and voluntary sectors?
- How much do people have to pay for health care, including medicines?
- How can HIV-related issues be incorporated into both the in-service and pre-service training systems for health care workers?
- Where are people with HIV-related disease being cared for? How far do they have to travel, and at what cost?
• At what levels of the health care service are diagnostic testing for HIV and for opportunistic infections available?
• Are there mechanisms in place for referral and discharge?
• Are drugs available for the prevention and management of opportunistic infections?
• Who has access to antiretroviral drugs? What criteria are used for treatment with antiretroviral drugs? Is monitoring available for those taking these drugs?
• What are the traditional patterns of care for people with chronic illness?
• Is there any support for those who look after people with HIV-related disease at home?
• How are the common symptoms of HIV infection being managed at home?
• What treatments are available for palliative care for the dying?

Where do you get the information?

The national health plan and district/regional health authorities may be useful sources of information about the capacity of health care services. Networks or groups of people living with HIV will be able to provide information from their own experiences of seeking health care. Qualitative methods such as key informant interviews, focus group discussions and observation with different levels of workers in health care services will help to build a picture of local capacity and training needs.

The political and religious context

When you plan HIV prevention and care activities it is important to understand and take into account the different political and religious beliefs of the general community, those who are particularly vulnerable to HIV, groups that are responding to HIV, and community and national leaders.

Differences in political or religious approaches between different organisations responding to the epidemic can lead to conflict or tensions. The religious and political environment can affect the success of HIV prevention and care activities.

In the USA, in the initial years of AIDS education campaigns, the government restricted the content of the HIV prevention messages produced by the Centres for Disease Control. This made the messages so difficult to understand that they became ineffective.

In Uganda in 1991 advertisements for the social marketing of condoms were withdrawn from the daily newspapers because of religious and political objections. Since then the political environment has changed significantly, as a result of continuing pressure from non-government and community-based groups, as well as from President Museveni himself. In addition religious institutions in Uganda have become very involved in the prevention of HIV as well as providing care for those infected.

What do you need to know?

• What are the overall goals and the broad directions of the national AIDS program?
• How do these national goals affect the specific local context in which the NGO is working?
• What are the predominant political perspectives in relation to HIV infection at the national, provincial or local level?
• What are the predominant religious attitudes and pronouncements in relation to HIV?
• How important are religious institutions as providers of care and information about HIV infection?
• What are the religious or political frameworks of organisations that work locally with groups who might be at risk of HIV infection, or that provide health or welfare services?
Where do you get the information?

The ‘National AIDS Strategy’ provides the goals and directions of the national program. If possible, conduct interviews with members of the major religious communities or their voluntary associations. Review of the correspondence and editorial columns in newspapers, and feature articles in national magazines, often help to reveal commonly prevailing attitudes. There may be information about religious opinion towards HIV and sexuality in the newsletters or leaflets available at churches or temples. Try to consult with voluntary groups or religious communities dedicated to caring for the ill and dying, and hold group discussions with members of their youth groups.

The first international conference on Religion and AIDS held in Senegal in late 1997 helped to show how agreements can be reached between church and state on messages that reinforce rather than contradict each other.22,23

What are the laws that relate to HIV and other STIs?

The development of a social and legal environment supportive of behaviour change is necessary for effective HIV prevention and care. An understanding of the current laws that relate to HIV and STIs will tell you whether the official response to people affected by the epidemic is punitive, or protective and supportive.

Next you will need to find out how these laws are interpreted and to what extent they are enforced. Some communities place more importance on law and legal rights than others. If the laws are enforced, how effective are they? Some laws make an impact on the transmission of HIV in unintended ways. For example, laws that criminalise behaviours (such as injecting drugs, prostitution, homosexuality) often simply drive ‘underground’ those people who practice these behaviours. Because the behaviours are then hidden, those who practice them have little access to education, information, and peer support for behaviour change. Similarly they have little or no access to the means to change behaviour, such as condoms, needles and syringes and bleach. So the law has the opposite effect to its intent and actually assists the spread of HIV.

Below is a list of laws that encompass eight areas relating to HIV infection. We have adapted it from the UNDP publication ‘Ethics and Law in Asia’.24 You will need to understand the major laws relating to HIV, sexuality and drug use when planning HIV responses. The list provides a guide to relevant laws, but does not comment on their appropriateness. The UNAIDS Guide to the Human Rights Machinery is a useful resource for this area of enquiry.25

What needs to be answered?

Public health

• Notification of HIV infection and/or AIDS: Are there legal requirements to notify government officials about individuals with HIV infection or AIDS? Are they reported with their full name and address or with a code? Is it a confidential system?

• Testing: Are there circumstances in which testing for HIV antibodies is mandatory: for example, for recruitment to the defence forces, for hospital patients, for pregnant women or for people applying for visas to enter or leave the country?

• Treatment: Is treatment compulsory for people with STIs? Is there legislation that protects people’s right to access health care treatment?

• Quarantine: Which infectious diseases are governed by quarantine and isolation laws? Is HIV included? Are these laws enforced?
Confidentiality

- **Confidentiality of HIV status**: Are there laws that forbid disclosure of information about people with HIV or STIs?
- **Partner notification**: Are there laws that require a person infected with HIV to tell their sexual partner that they have HIV? Is a medical practitioner or other health worker ever obliged to tell the partner?

**Discrimination and human rights law**

- **Discrimination**: Are there laws that prevent discrimination on the basis of health status (including HIV infection), gender, sexual preference, political views and religion?
  
  Do people with HIV receive appropriate medical treatment? Do they have equal access to employment, accommodation and other services?
- **Human rights**: What basic rights are enshrined in the country’s constitution or other laws? Are these laws effective in preventing discrimination?
  
  Is the justice system accessible to people affected with HIV?

**Women’s issues**

- **Participation**: Are there laws that promote equal participation of women in political and economic life?
- **Property rights**: Do women have the legal right to inherit or own property, particularly after the death of a spouse?

**Information law**

- **Rights to information**: Are these enshrined in law?
- **Obstacles to information**: Are there broadcasting, censorship or obscenity laws that prevent the dissemination of realistic messages about HIV, STIs and sexual and drug injecting behaviour?

**Families and carers**

- **Marriage, divorce, separation**: Are there customary laws and imported laws regarding marriage? What is the minimum age for marriage? Is polygamy recognised? How are marriages dissolved?
- **Non-consensual sexual intercourse**: Are there laws against rape? How is rape defined? Does the law acknowledge rape in marriage?
- **Termination of pregnancy**: Is induced abortion ever legal? Under what circumstances?
- **Children’s ability to inherit property**: Do children have the right to inherit property, if, for example, both parents die?
- **Care for orphans**: Is there legislation that protects and supports children whose parents have died?
- **Breastfeeding**: Has the WHO International Code for the Marketing of Breast-milk Substitutes been implemented through legislation?

**Prisons, custodial homes and welfare institutions**

- **Testing**: Are there laws for the testing and segregation of prisoners, drug users, prostitutes or others who are held by the state?
- **Information**: Do they have access to information about HIV or to condoms or clean needles?

**Workplace law**

- **Testing**: Are employees required to be tested for HIV, or for drug use, before or during employment?
• **Policies for infected employees:** Do policies exist for HIV infected people? What are these policies? Are people with HIV protected against dismissal? Are there confidentiality safeguards in the workplace?

**Criminal law**

• **Transmission offences:** Do laws exist that provide for offences of knowingly, recklessly or willingly transmitting HIV or other infections?

• **Sex workers:** Is prostitution illegal? Are there laws against living on the earnings of prostitution, or running a brothel? Can sex workers compel condom use?

• **Homosexuality:** Is homosexuality an offence? Is this law enforced?

• **Injecting drug use:** What are the laws relating to production, to trafficking and to possession of drugs, and to the paraphernalia used for injecting, such as needles and syringes, swabs, water and spoons?

**Where do you get the information?**

Staff of the national AIDS program will be important sources of information about the laws and policies relating to HIV infection and STIs. Social commentators such as lawyers involved in legal reform, members of political parties, journalists and researchers may also be key informants.

It is important to ask affected groups such as sex workers, men who have sex with men, those who inject drugs, and people living with HIV about their experiences in relation to the law. Have they been able to make use of the law to protect their rights, or have they found that the legal system, or the way that it is enforced, hinders prevention efforts?

**What is already happening? – identifying existing programs, services and resources**

Having spent time in understanding the determinants of the spread of HIV and STIs within your community, you need also to understand and analyse what has and is being done to respond to it. This helps you to avoid duplication and competition, and to learn what has worked, what has not worked, and why. It is important to ask questions that identify positive factors or strengths, as well as risk factors.

This review of the response will help to resolve the following questions:

• Do the responses tackle the roots of the spread of HIV in the community?

• Do the responses take into account the strengths, opportunities and obstacles?

Few, if any, organisations will be able to include all the necessary facets of HIV prevention and care in one project, nor is this necessarily desirable. Try to ensure that your community project is integrated and coordinated with other relevant initiatives, which may not be directly related to HIV.

**What needs to be answered?**

Find out **what services and programs are already available**, or are planned, and **how these actually work**. Find out who is providing these services and programs. They will usually include church or other religious groups; national, provincial and local government services; local and international NGOs; and international agencies such as UNAIDS, WHO, UNICEF, UNDP, UNFPA, and the World Bank. Does your country have a Country Coordinating Mechanism for the Global Fund?

It can be helpful to imagine the situation from the point of view of those who might need or be seeking information, peer support or services. For example, how would...
the following groups of people seek information, treatment and care: married women, mothers of small children, men who have sex with men, sex workers, people who inject drugs, and young women and men?

It is also helpful to visit and talk with local organisations and groups that contribute to the response to HIV. These discussions may reveal important gaps and opportunities. The following questions can help you to explore and assess existing responses.

**The enabling environment**

Are any groups working at community level to raise awareness and stimulate discussion and local action? Are people using participatory approaches, such as the ‘Stepping Stones’ program, that can help communities to explore and address social problems and attitudes that increase vulnerability to HIV? What organisations are working to address problems that underlie the spread of HIV, such as micro-finance schemes to alleviate poverty, literacy programs for woman, or skills training for homeless youth?

Have any organisations brought together workers in key sectors such as teachers, the military, police and youth workers?

**Education and information**

- How do different groups within the community learn about sexuality, about HIV and other STIs – from friends, family, school or health workers?
- What programs and resources are available for information and education in different settings, including schools, churches, health clinics, the workplace and in the press/radio?
- How do young people who leave school early learn about sexual health?
- Do any groups of refugees or displaced people have access to information about sexual health and HIV?

**Condoms**

- How easy is it to get male and female condoms? What is the availability, cost, accessibility and quality of condoms?
- What are the attitudes of service providers and community leaders to condoms?

**Access to health and social services**

- How can different groups of people get access to treatment for an STI? Who provides the treatment – trained personnel, untrained personnel or traditional healers?
- Are people examined properly if they have an STI? Are they treated with respect? Are they overcharged? Are the treatments appropriate and affordable, for example, so a full course of antibiotics can be taken?
- Is HIV testing provided? Is it confidential? Is pre- and post-test counselling available?
- Where are STI and HIV services located?
- Is there a home-based care program?
- How sensitive are health and other services to the needs of people with HIV?
- Who provides services for people with HIV? Consider the government, religious or secular non government organisations, private doctors both formally qualified and unqualified, pharmacists and traditional healers of different types.
• Are they special services or are they integrated with existing services such as primary health care, school education and welfare support?
• How accessible are these services? What are the opening hours and the attitudes and knowledge of staff?
• How is care provided for orphans?
• What types of activities do local NGOs and government agencies undertake?
• What resources do they have?
• What related services, such as family planning, sexual abuse, domestic violence and drug addiction treatment, are being provided?
• What is the quality of the services?
• Do they already, or would they like to incorporate HIV and STI prevention in their programs?
• Do the attitudes of family planning or health workers result in missed opportunities to contribute to HIV prevention?

In South Africa a study of teenagers seeking condoms at family planning services has shown that the workers discouraged the use of condoms because they believed that condoms were a poor choice for contraception. Young women seeking condoms felt intimidated at the clinics and were refused condoms.27

*Where do you get the information?*

Try to talk with a broad cross-section of the community to learn about the variety of activities and services. Consult widely to try to ensure that you do not miss organisations or groups that are active in some aspect of the response to the epidemic. Talk with representatives of HIV-positive people’s networks or support groups. Talk with provincial or district public health officials, who should have a good overview of activities, but also consult with government officials for other sectors, such as education, prisons, employment, tourism and welfare. Contact the UNAIDS Country Programme Adviser or the Chairperson of the UN Theme Group on HIV/AIDS to find out the UN system support to the national response. They should also be able to provide the latest country profile on HIV infection.
References


Chapter 4
Gathering information: answering the questions

by Rob Moodie, Tim O’Shaughnessy and Tamara Kwarteng

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Introduction

For many of us, research is something that other people do while we get on with practical tasks. Perhaps this is because research is often thought of as a specialised and difficult activity which is best left to the ‘experts’. Many of us, too, see research as something that happens at a special stage during a project, say during a ‘mid-term’ or ‘end-of-project’ evaluation.

In this chapter we want to suggest another view. Research should not be reserved for specialists. Research can and should be done by those who plan and implement projects, using straightforward processes and methods to collect information throughout the project cycle.

Give it a try and learn by doing. In addition to the advice in this manual, you can turn to other sources of assistance, such as experienced researchers and specialised manuals and websites.

You will need information for different purposes and for different stages of the project cycle. Before the project begins, collect data to help you plan the project and to monitor any changes that the project may help bring about over time.

During the implementation of the project, you will need data in order to monitor the project’s situation, evaluate performance and adjust the plan. You will also need to establish ways to record and store the data so that you can use it to inform decisions.

In this chapter we describe some common steps, processes and tools for you to consider.
The beginning

Your choice of information-gathering processes and methods will depend on answers to the following questions:

- **Who** is the information for and who will use the research findings?
- **What** kinds of information are needed?
- **How** is the information to be used?
- **When** is the information needed?
- **What** resources are available to collect the information?

Answering these questions will help you decide the kinds of information that are appropriate for your situation. There are no rigid rules for deciding on the design and methods for collecting information. Designs need to be based on resources, practicalities, methodological choices, and the creativity and personal judgments of the people involved.¹

The process of gathering information

The process of gathering information is important. Gathering information should establish links and trust with the community. This means consulting widely early in the planning stage of gathering information. Through this consultation the study team and community leaders can agree on how they will share the information from the research. The information-gathering process can also create a ‘space’ in the community where people are able to talk about sensitive issues. Here are some principles to help guide the process.

**Community participation**

When members of the community are closely involved in gathering information, they will better understand how they will benefit from the research. They will then be more likely to support the research and use the information effectively.

Community participation is also important for obtaining reliable information. People are more likely to speak freely to their peers. For example, young people are more likely to give honest information to peer researchers than to older people. Peer researchers are especially helpful in gathering information and views from people with high-risk behaviours. In many places sex work and drug use are illegal. It is important that people engaged in these activities trust those gathering information from them. Peers can establish confidence and trust more readily than ‘outsiders’ to the group.

**Study teams**

Whether you are collecting information for planning or evaluation purposes it is important to have a team of people working cooperatively. The team should include members of the community, in particular, members of the target population, such as...
as young people, sex workers and people who inject drugs. The roles and responsibilities of all team members should be clear from the beginning. If necessary, split the team to increase coverage.

It may be useful at the outset for the team to discuss among themselves their personal attitudes to sexual behaviour and preference, drug use and methods used to prevent and care for HIV and STIs. This will highlight differences in knowledge, approaches and values. Some of these differences may need to be reconciled or at least acknowledged in order to reach consensus on how to use the information.

If interpreters are needed, it is important to brief them well about the questions they will ask. They may need initial training or practice in asking about sensitive issues such as sex and drugs. Ask the interpreters to translate their questions back to you, to check the original translation.

Arrange to meet at planned intervals to discuss findings and progress made, and to talk about any difficulties and frustrations that arise.

**Ethical issues**

It is important that the process of gathering information does not cause harm to individuals or the community. Consider establishing a group from the community to advise on and monitor ethical issues, including ownership of the information, and approval processes for publication of the findings. You can avoid causing harm while gathering information by thinking through the following issues.

**Informed consent**

Before interviewing someone (either individually or as part of a group), it is important to get that person’s informed consent. Informed consent may be written or verbal, and means that the person being interviewed:

- understands that they are being interviewed (and that this is different from an everyday conversation);
- knows why they are being interviewed, what type of questions they may be asked, and what the information they give will be used for;
- understands that the interview will be recorded in some way, and knows how this will be done;
- knows who will have access to the information from the interview; and
- agrees to the interview of their own free will (and not because they have been pressured to do it by their boss, parents or friends).

The process for gaining informed consent will be different in each community. It may be unusual or even threatening to request written consent in some communities, but would be expected (and perhaps a legal necessity) in others. The consent process should be decided by the team in consultation with the community, before starting to collect information.
When using observation methods to gather information there are often practical difficulties in obtaining consent. Consultation with a community advisory group is helpful. In some cases it may be appropriate for the village or community leader to give consent.

Confidentiality
When people share their beliefs, thoughts and feelings about sensitive issues, it is important to keep this information confidential and to let the participants know that anything they say will be kept confidential. Ensure that all members of the team receive training in the importance of confidentiality, and have a chance to discuss problems that might arise. It may not be appropriate for team members from the community to be interviewers if they are likely to know the people that they are interviewing. Because some stories may be upsetting for local researchers it may help them to have an opportunity to ‘debrief’ with an ‘external’ member of the team after interviews or focus group discussions (FGDs). It can be stressful to keep upsetting or sensitive information confidential without the opportunity to share it.

Try to ensure that interviews take place in privacy. Confidentiality is also an important consideration when the team are writing up the notes from an interview. They should ensure that it is not possible to identify the sources of the information in the final report, especially in small communities where most people know each other. Notes from interviews and FGDs should be stored securely.

Providing information
Asking about issues in relation to HIV and STIs may stimulate questions from the participants. It is important that the interviewer or facilitator is able to answer such questions, or knows where to direct people for more information.

Supportive counselling
It is important to be aware that participants may be upset by an interview or group discussion on sensitive issues. Try to arrange a chance to talk afterwards, and let the participants know that counselling is available if they feel upset.
Methods for gathering information

The methods you choose to gather information for project design, implementation, monitoring and evaluation will depend on the time and resources available. The following methods may be useful:

- reviewing existing information from documents, databases, reports, books and media
- observation
- in-depth interviews
- focus group discussions
- ‘participatory learning and action’ exercises
- case studies
- questionnaire surveys.

Research methods may be quantitative or qualitative. Quantitative methods include questionnaire surveys of random samples from the population of interest, and observation using checklists. The results are reported as numbers, tables and graphs, and can be generalised for the study population from which the sample was taken. Qualitative methods, such as in-depth interviews, FGDs and ‘participatory learning and action’ (PLA) exercises are useful for gathering information about the range of knowledge, attitudes, and behaviours, and can be helpful in explaining quantitative survey results. The sample can be small and selected to be representative of groups of interest in the population. The findings are usually in the form of words and pictures. Neuman’s Social research methods is a useful guide to qualitative methods (see ‘Additional resources’).

When choosing methods it is helpful to consider whether some methods may be more culturally appropriate than others and whether there are ethical reasons to favour one method over another. It is also wise to cross-check information by using more than one method and gathering information from several sources. It is important to have advice from people with experience and knowledge of research methods when planning the gathering of information.

Box 4.2: Watch out for information overload

Information overload can be a major problem when gathering information, particularly when time is limited. Often you will have the dilemma of needing to talk with more people and needing to reflect on, and digest, the information you have already collected. You may need to see and ask less and understand more!
Reviewing existing information

The first step in gathering new information is to find and analyse what already exists. While there may not be many formal reports specifically about HIV in your community, there will usually be many published or unpublished documents that may provide valuable information. Some of the types of documents that you could review are listed below.

- **Published research articles**: These include studies of HIV and STI prevalence, reproductive health, and surveys of knowledge, attitudes, behaviours and practices. If you have access to the Internet it is useful to search the UNAIDS website, and the ‘Medline’ database which includes all the peer-reviewed health journals. The US National Library of Medicine ‘Gateway’ website automatically searches a collection of databases for you that include ‘Medline’ and AIDS conference abstracts. (See Appendix 2 for website addresses.)

- **Government reports**: National and provincial departments of health may have relevant information about HIV and other STIs and tuberculosis, as well as other important health issues. The most recent Demographic Health Survey (DHS) can provide much useful information about the composition of the population in terms of age, sex and health status. The local planning department may have demographic and socio-economic data. Labour and immigration departments may have information about mobile populations and mobile workers.

- **Publications from international and multilateral organisations**: You can get much useful national health, social and economic data from publications by UN agencies such as WHO, UNICEF, World Bank, UNDP, and UNAIDS, and international development agencies such as USAID. The UNDP Human Development Report and the annual UNAIDS/WHO Global Update of the HIV epidemic are useful sources of information.

- **Clinical records**: Patients’ records at health clinics may provide information about the pattern and frequency of STIs, contraceptive practices, pregnancies and health care seeking behaviour in different groups (such as gender, age, rural and urban). Clinic stock records may indicate what treatment is sought or given for STIs, contraception usage patterns and other behaviours. It is useful to review records for the preceding twelve months.

- **Unpublished reports and evaluations**: Sometimes students and others, including women’s organisations, private research groups, NGOs and the military, have carried out research or evaluations that may provide relevant information.

- **Mass media (print and electronic)**: Studying media such as news reports, editorials, radio talkback and letters is a good way to assess how the community sees the HIV epidemic. It can also help you consider issues relevant to the spread of the virus such as drug use. It can be worthwhile to contact journalists who have shown an interest in the subject matter.
Qualitative methods

Observation

Observation is a useful and often underused research method. Looking, listening and carefully recording your observations of events and behaviours provide valuable clues about what is happening. Observing the structure, leadership dynamics and lifestyles in a community is an important part of getting to understand that community. Observation is also very useful for confirming or challenging information from other sources. For example, in interviews, older people in a village may state that young women do not drink alcohol in their community. However, if young women have been observed drinking at the local bars or on the beach, then the information from the interviews could be questioned. Observation will also enable you to identify gaps in your information. You may observe a situation that your study team has not considered for investigation.

Observation may be casual (unstructured) or formal (structured). Casual observations can be made at any time. It is a good idea for team members to carry a notebook to write down observations and insights.

Structured or formal observations use a checklist as a guide. For example, after reviewing existing information or interviewing key informants, the team may decide to observe specific behaviours or activities, in certain places and at certain times. It is helpful to use standardised record sheets to write down what you observe and how often it occurs.

Observation can be done by members of a group – that is, someone observing the behaviours and interactions of their peers (an example of this could be an out-of-school young person observing the behaviours and interactions of other youth during night-time gatherings). This is known as ‘participant observation’. Observation can also be done by people ‘outside’ the group being observed (an example of this could be the same out-of-school youth observing the behaviour of businessmen at a local bar). There are particular strengths and weaknesses in each approach. People who are part of a group may not see the behaviour of their peers objectively and may have preconceived ideas about what they will observe. On the other hand, observers from outside a group may be unable to understand the context of the behaviours that they are seeing. This can lead to misinterpretations of the observations.

As with other techniques, information gathered through observation should be compared with that from other sources. This reduces the risk of placing too much emphasis on a rare or unusual observation.

(Much of this material is similar in nature to that in Chapter 5 of Protecting the future by Wendy Holmes and the International Rescue Committee.)

In-depth interviews

General information on community knowledge, attitudes, beliefs and practices related to HIV can be gathered from in-depth interviews with a range of community members. They might include village heads, teachers, monks, local government leaders and the heads of women’s groups. People whose occupations enable them to talk with a wide variety of people are also useful informants about behaviour and attitudes. They might include taxi or auto-rickshaw drivers, hairdressers, market stall holders and café owners. As well, members of groups perceived to be especially vulnerable, such as single young men, or sex workers, should be interviewed.

In-depth interviews can be useful for learning about sensitive matters, but only if the person trusts the interviewer. It may be
possible to get more in-depth information from interviews than from FGDs because one person is able to talk for a long time about a particular issue. However, you can obtain the views of more people more quickly using focus group discussions.

It is best to prepare a question guide or theme list with several members of the team. This should identify the main themes to ask about. It is also useful to think of additional probes. These are leading questions that the interviewer only asks if the point is not already covered in the conversation, in order to avoid suggesting answers to the person being interviewed.

It is best if the study team works together to prepare the question guide. Brainstorm a list of questions then sort the questions into categories or themes. Refer to Chapter 3 for ideas about the kinds of questions to ask about HIV in your community.

Interviewing is a skill that improves with practice. The role of the interviewer is to develop and maintain a sense of understanding with the person being interviewed, to guide the direction of the discussion, and to take useful notes during the process. Doing all of these things at once is quite demanding. In his book, *How to use qualitative methods in evaluation,* Michael Quinn Patton provides useful information about the in-depth interviewing process.

**Focus group discussions**

An FGD is an in-depth discussion in which a small number of people (usually six to ten) from a similar background (considering such factors as age, education level, gender and so on), discuss selected topics guided by a trained facilitator. The group dynamics in an FGD can draw out information that you might not think or know to ask about in a questionnaire.

During an FGD participants consider and respond to each other’s answers. It is not necessary for the group to reach agreement. The aim is to stimulate discussion which can reveal a great deal about knowledge, attitudes and beliefs. Participants often enjoy these discussions.

FGDs may be used:

- before a questionnaire survey, to make the questions appropriate and valid;
- after a questionnaire survey, to help to explain the results;
- to collect information about sensitive subjects that people may not answer in a questionnaire or interview;
- to pre-test messages in communication materials;
- during evaluation, to gather opinions, and to assess changes in knowledge, attitudes and practices.

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**BOX 4.3: TIPS FOR INTERVIEWING**

- Clearly explain the purpose of the interview to the interviewee. Ensure that the person has consented to be interviewed and understands that they can refuse to answer specific questions or stop the interview at any time.
- Treat the person being interviewed with respect. Keep in mind that it is a privilege and a responsibility to listen to another person’s experience.
- Establish rapport and a sense of mutual interest.
- Be familiar with the question guide. This will allow you to be flexible during the interview without missing important questions.
- Ask easy and non-threatening questions first; for example: ‘What kind of work do you do?’ or ‘Do you have children?’ Ask questions about attitudes or sensitive topics later in the interview.
- Ask truly open-ended questions. Open-ended questions allow the person being interviewed to take whatever direction and use whatever words they want. These questions avoid single word answers such as ‘yes’ and ‘no’.
- Avoid leading questions. A leading question is one that suggests an answer; for example: ‘You don’t use a condom, do you?’
- Ask one question at a time.
- Use probes and follow-up questions to get more depth and detail.
- Communicate clearly what information is needed and why that information is important. Let the interviewee know how the interview is progressing.
- Listen attentively and respond appropriately to let the person know they are being heard.
- Maintain neutrality towards the specific content of the answers. Remember that you are there to collect information, not to make judgements about the interviewee.
- Observe while interviewing. Be aware of and sensitive to how the person is affected by and responds to different questions.
- Tape-record whenever possible to capture full and exact quotations for analysis and reporting. Take notes to capture and highlight major points as the interview progresses.
- As soon as possible after the interview check the recording for malfunctions; review notes for clarity and record observations.
FGDs should take place in a venue that is comfortable, private and familiar to the participants, and where there will be few interruptions.

Choose participants for FGDs who are representative of your target population group. It is best if the groups are homogenous. For example, you might have different discussions for young women and young men, older men and older women. Discussion is generally more open with people of similar backgrounds.

For instance, it may be very difficult for a young woman to speak out openly, particularly about a sensitive topic like sex or HIV, in front of an older man.

The facilitator needs good group process skills to manage the discussion so that it is not dominated by one or two people and everyone in the group gets a chance to air their views. It is important to cover your chosen themes. One advantage of FGDs is that you can follow up or ‘probe’ interesting or unexpected answers. However take care not to get too sidetracked from the ‘road map’ of the question guide. Do not try to cover too much.

The facilitator should speak with the participants before the discussion to check that they understand the purpose of the discussion, to ask them to sign a consent form (if appropriate) and to explain that they are free to leave at any time if they wish to.

It is best to record the discussion on tape if possible. Obtain permission from the participants first. Ensure secure storage for the tapes afterwards so that they are not misused. Whether you record the discussion on tape or not, it is helpful to take notes of the proceedings. This includes taking notes about the atmosphere of the discussion, and the reactions of participants to different questions and statements.

There is no rule about how many focus groups to hold. Usually after a small number of discussions you will find that you start to hear the same range of views and themes and that more focus groups do not produce any additional information.

It is best if a small team undertakes the analysis by reading through the transcripts and identifying common themes and points of view. Care should be taken in the interpretation of FGDs. The responses may represent the views of the group participating in the discussion, but may not represent the views of the entire community. FGDs can only tell us the range of attitudes, knowledge and beliefs in a community. They cannot tell us how many hold a particular belief or attitude. Do not quantify the results.

FGDs have some weaknesses. An important one to be aware of is that if the participants know each other, it is not possible to guarantee confidentiality. Because of this, participants may be reluctant to speak freely and honestly about sensitive issues and the discussion may reflect attitudes and beliefs that are thought to be desirable rather than the actual attitudes of the participants. Combining FGDs with other information-gathering methods such as observation and in-depth interviews will help to cross-check the information you receive.
The following steps are helpful in planning FGDs:

1. Decide who will be appropriate participants.
2. Choose an appropriate venue or setting.
3. Prepare a question guide.
4. Prepare consent forms.
5. Train facilitators and note-takers.
7. Consider ethical issues.
8. Make a checklist of things to take.
9. Have a pilot discussion.

As with in-depth interviews, you can improve your skills by practising. There are also a number of manuals available about FGDs, including a very useful publication by Dawson, Manderson and Tallo, published by WHO.4

**Participatory learning and action exercises**

A number of ideas have been developed for stimulating discussion and recording information in communities which do not depend on literacy or knowledge of research methods. These methods aim to lead to action through raising awareness and stimulating discussion of responses to problems. They use techniques that present information visually. ‘Participatory learning and action’ (PLA), ‘participatory rural appraisal’ (PRA) and ‘participatory action research’ (PAR) are different names for related approaches that make use of these participatory techniques.

The PLA approach is a community development process that enables communities to define, evaluate and influence their economic, environmental, health and educational status. But these techniques can also be used as tools to help gather information in a participatory and inclusive way.

- **Mapping:** community members make a map together that shows the location of health facilities, markets, schools, clusters of bars and brothels, communication networks (including roads and bridges), social features (eg poor residential areas), and epidemiological features (eg areas of high or low STI incidence).5

**BOX 4.4: TIPS FOR CONDUCTING FGDs**

- Focus group sessions should not last more than 90 minutes, and there should be time for the participants to clarify any points with the facilitators.
- Try to ensure that the facilitators are appropriate for the group. Where possible, there should not be too much of an age gap between the facilitators and participants. Having facilitators of the same gender is also valuable, though not always essential.
- In the discussion, go from the general to the specific. It is wise to start with non-threatening topics – such as general likes and dislikes – before moving into sexual health topics, for example.
- Use secret ballots where necessary. For sensitive topics such as the age of sexual debut or condom use at the first or last intercourse, ensuring the anonymity of responses by using a secret ballot will help participants to give more honest answers.
- Use fictional stories. The facilitator could describe a scenario, for instance, where a boy and a girl meet. The participants then complete the story through their own discussion. Using fictional characters allows participants to talk about others while drawing on their own experiences as the frame of reference.
• **Seasonal analysis:** can be used by community members to show how food availability, movement of community members, workloads, wages, health status and other factors change during the year.

• **Timelines:** can help participants to understand the history of the community – religion, festivals, customs and beliefs, and major events – and the changes that have happened over time.\(^6\)

• **Decision-making matrix:** can help community members and organisations working with them to identify decision makers within families and the source of their power.

• **Body mapping:** shows through drawings how people understand the structure and function of their body – participants may draw around a member of the group to produce an outline.

• **Ranking:** using matrices or grids for comparisons or prioritising, for example, using the ‘ten seed technique’, showing what proportion of local people or peers have a particular practice, belief or behaviour.

PLA methods are often conducted in an informal way. When they are carried out in a public space community members are often keen to join in the discussion; thus a wide range of views can be obtained. Sometimes a group of people (such as women, or young men, or sex workers) are specifically invited to take part in PLA exercises. This is an example of purposive sampling, discussed earlier. Of course it is important to consider whether participants are representative of the general community. It is also important to consider how the time of day, the season and the setting may influence the type of people who are able to participate in the exercise. Check that you have been able to hear the views of women, older people, younger people and minority groups.

A good example of how these exercises can be used in developing a response to HIV is provided by the Mother Saradadevi Social Service Society, working in Oddanchatram, Tamil Nadu, India. The Society’s main strategy is the formation of women’s groups, to enable women to work together in order to have more say in the decisions that affect their lives.
Indigenous methods

A very important means of information gathering is through indigenous methods such as gossip, songs, poems, storytelling, and informal and formal group and community meetings. They may add a richness and depth that other forms of information gathering are unable to do.

BOX 4.5: MOTHER SARADADEVI SOCIAL SERVICE SOCIETY

Mapping

This exercise helped the women to learn what facilities were available in their areas, and also helped to motivate the women to form their own groups.

The women drew a map of their town or village on the ground with a stick or with powdered chalk, and then added features such as schools, temples, houses, hospitals and water pumps. Using neem or tamarind seeds, they then counted the number of men, women and children in their area and described the work done by each.

The exercise also enabled the Society to understand the lives of women in prostitution.

Seasonal analysis

This exercise helped the women understand how seasonal variations in their incomes affect their sexual vulnerability. In urban areas, during the festival months, the women earn a major part of their incomes from selling fruits, flowers and pictures to pilgrims. Between festivals though, many women sell sex to maintain their income.

In rural areas women earn enough during the months when there is plenty of work for both men and women in the fields. During the dry months from April to September, however, there is little agricultural work available locally, so the men migrate to the adjoining State of Kerala, where extra labour is required in the fields. The women are left behind in the villages, and many sell sex to sustain the household until September.

Timelines

The aim of this exercise was to help the women and the Society workers to understand the history of their village or town, their religion, their festivals, their customs and their beliefs. The process was useful in understanding the relationships between prostitution and caste, religion and local politics. The exercise led to much discussion that cleared up some misunderstandings about women in prostitution, and also helped to promote caring attitudes and better self-esteem among participants.

Changes to the women’s lives

In this exercise the women analysed the changes they had experienced in their lives through work, illness, family planning, child bearing and sexual relationships. The exercise was conducted in small groups of two to three participants to encourage the free exchange of information. These sessions laid the foundation for one-to-one discussions between animators and women in prostitution.

Through the exercise the women realised the underlying reasons for the spread of STIs and HIV, including the impact of male sexual behaviour, the influence of cinema and the role played by modern transport facilities. Importantly, they also understood that preventing an HIV epidemic would require the cooperation of the entire community, particularly of the men. This prompted many women to try to discuss HIV, AIDS and STIs with their husbands and other sexual partners, and to obtain treatment for their STIs. Many also began to persuade their husbands and other sexual partners to use condoms.
Analysing qualitative information

The analysis is best done by a small team. Prepare the data for analysis by transcribing tapes from interviews and FGDs, and make sure all the field notes are complete. If possible, type up the notes on computer. Make two or three photocopies of the text ready for the analysis.

Become familiar with the data. Read the notes carefully – then read them again. As you read the data, identify themes or categories of information that emerge and mark them in the margin of the notes page. An example could be the theme of ‘confidentiality’. It may become clear from talking to lots of people during the information-gathering process that lack of confidentiality is a common reason why people don’t use health services. People will describe confidentiality in many different ways: ‘I don’t trust them not to tell my husband’; ‘There are no secrets here’; ‘Everybody knows everyone else’s business’ and so on. However, all these statements would come under the overall theme of confidentiality, or the lack of it. You should also look for statements or beliefs that are different from the majority. Discuss with others why they might be different.

One way to group the statements is to write the topic headings or main themes as headings on large sheets of paper. Read through the transcripts or notes together, cut out what people say and decide where the comment or story belongs. It might belong in more than one category. Stick the quotes on to the large sheets of paper. If a new idea or point is made, write a new heading. In this way new themes come from what people have said.

When all the transcripts have been cut up, read through the ideas and points under each heading. Discuss the main points and findings and write a summary. It is useful to write down direct quotes that illustrate the points well.

This process can also be carried out on computer using a word processing program to cut and paste text under headings. The advantage of doing so on large sheets of paper with a small team is that the information is discussed and interpreted by several people. Those without computer skills can also understand the process of the analysis, and learn that they can do this again. Qualitative software programs such as Ethnograph and Nudist can be useful for large studies with many transcripts but are not necessary when information gathering to inform activities and projects, and tend to mystify the process.

The analysis and writing up stages often take as long as the data collection stage. Allow plenty of time. Try to find a quiet place where you can spread out your materials and focus on your analysis without any interruptions or distractions.

Capturing the findings of PLA exercises requires thought. A beautiful map may be drawn in the sand, illustrated with twigs, seeds and pebbles, but it will be more useful for planning if it can be copied on to paper. With other visual techniques such as matrix ranking and the ten seed technique, someone, preferably with a talent for drawing, should sketch the outcomes of the participatory work and make notes of what people say. The drawings and quotes can be used to illustrate a report of the findings. Capturing participatory exercises and discussions on camera or video might be a possibility, but this may inhibit people who are reluctant to be identified. Making a video requires relatively expensive equipment, electricity and someone skilled in filming and editing.

Discuss conclusions from the findings. What do the findings mean for your activities? The findings should help you to understand people’s attitudes, beliefs and practices. They should help you to understand the barriers to behaviour change and suggest ideas to help people to change risky behaviours. They should help you to decide how to develop effective messages.
Quantitative methods

Questionnaire surveys

The only reliable way of collecting quantitative information that is representative of the whole community is to conduct a ‘community survey’ or ‘population survey’ with a random sample. Do not undertake a community survey unless you have a team member who is familiar with proper sampling methods, questionnaire design and analysis.

Survey planning includes the following steps:
1. Gather background information.
2. Consult.
3. Define the study population.
4. Select an appropriate sample size and sampling method.
5. Design and pre-test questionnaire/s.
6. Estimate time needed and costs.
7. Consider ethical issues, including informed consent and confidentiality.
8. Select and train interviewers.

Sampling the population

To find out the frequency of certain characteristics in a population you do not need information from every individual. A random sample, if large enough, will give an accurate estimate of the frequency of characteristics in the population. The sample size will depend on the type of sampling strategy and on the likely frequency of what you are trying to measure. It does not depend on the size of the population unless the population you are interested in is small. The sample size should not be larger than is needed to provide an accurate estimate because this will add to costs and the time spent to complete the survey. Seek help from a statistician or an epidemiology manual to decide on an appropriate sampling strategy and to calculate the sample size.

Social survey methods: a fieldguide for development workers by Paul Nichols is a useful reference for conducting surveys. Epi Info is a statistical software program designed to help analyse questionnaire surveys. It is available free at www.cdc.gov/epiinfo/ along with a training guide.

The goal of a survey is to produce accurate statistics. But when we gather information it is easy for ‘bias’, or error, to affect our results. There are several possible sources of bias. The sample may not be representative of the whole population. The way you choose a sample and the size of the sample affect how well that sample represents a population. Some in the sample may decline to take part, or cannot be contacted. The questionnaire may include questions that are not clear. Different interviewers may ask the questions in different ways or in a different order so that they get different answers. People interviewed may be embarrassed or fearful to answer sensitive questions honestly, or they may not remember events accurately if asked for recollections over a long period. Errors may also occur when the results are tallied or entered into a computer.

Questionnaire design

Poor questionnaire design is a common cause of errors in surveys. The questionnaire should be based on preliminary interviews, observations and FGDs. The wording of the questions needs to be carefully tested in the community and revised accordingly. Survey personnel need to
be thoroughly trained in the use of the questionnaire. For a variety of HIV surveys there is no need to develop your questionnaire from scratch. There are many HIV questionnaires available that have been rigorously tested. You can adapt them to suit your circumstances. The Horizons Project, implemented by the Population Council, has developed an HIV Survey Library on CD-ROM called *AIDSQuest*. You can obtain this free of charge from the Population Council.

**Health facility survey**

Information on the quality of management of STIs and other relevant clinic-based services (such as health education) can be gathered through periodic ‘health facility surveys’. Trained observers use standard questionnaires and observational checklists to assess the adequacy of the diagnosis, treatment and education related to STI/HIV prevention provided by health workers. Protocols for health facility surveys are available from the World Health Organization.

**Presenting the findings**

Think about how you can present the findings in ways that different audiences will understand. Provide feedback to the communities that have provided information. The findings also need to be shared with other stakeholders such as local government departments, UN agencies, and other international and national NGOs.

Prepare a written report with a summary of the key findings, as well as the detailed findings from the analysis. The quantitative data should be illustrated with tables and graphs. Keep these simple. Illustrate the qualitative findings with direct quotes that convey the ‘voice’ of the people interviewed. Consider preparing a shorter community report in simple language that can be easily translated, using drawings and photographs. Remember to check for permission from the people pictured before you make copies. The community report can be a useful information and communication tool.

These reports might be distributed through community groups and buildings. Remember that your findings could well be relevant to workers in other parts of the country, or in the region. After seeking necessary approval you might consider putting the information on the Internet, or sending an article to a relevant journal or newsletter.
References


Additional resources

International Institute for Environment and Development. Participatory approaches to HIV programs. PLA Notes: 23; Sexual and reproductive health. PLA Notes: 37.


Chapter 5
The project cycle: planning HIV responses

by Tim O’Shaughnessy, Wendy Holmes, Karla Meursing and Mike Toole

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Introduction

In Chapters 3 and 4 we described ways of gathering information about the HIV situation in your community that may point to a need to develop a response. In this chapter we offer some suggestions to help organisations wanting to respond to the HIV epidemic.

Much aid from government and multilateral donors is in the form of projects. One definition of the term ‘project’ is:

A set of planned undertakings designed to achieve certain specific objectives within a given budget, project organisation and specified period … Projects remain the standard mode of operation because they cut complexity into bite-sized, manageable and fundable chunks.¹

A project goes through several stages. An idea germinates; it then passes through steps during a planning process when we increase our understanding of the context, the problems to be addressed, the objectives we aim to achieve, and how to select the appropriate way to act on the problem. It is then implemented, monitored and revised during implementation, and finally evaluated. The entire process from the first idea to the final evaluation is called a ‘project cycle’.

We can also think of this process as a ‘spiral’, because the project and the project participants never return to the same point. The project changes and moves on through the project cycle.

Funding agencies often support projects for periods of between one and five years. Three-year projects are common. Funding can be extended beyond the initial funding period in special circumstances.

We also talk about a ‘planning cycle’ because the sequence of problem and solution analysis, project design, implementation and evaluation should be followed by reassessment, redesign of project, and so on, in a cyclical manner. Planning, implementing, monitoring and evaluating are functions that continue throughout the project rather than existing as separate stages with a clear beginning and end.

As discussed in Chapters 3 and 4, the first essential step in the planning process is gathering information. The extent of information gathering before a project is planned will vary from one setting to another. In practice there are often pressures on the planning process caused by lack of time and resources. In some settings the results of detailed surveys are already available. If there is little existing information, it may be necessary to budget for a research-and-consultation phase in the project plan, which creates the opportunity and resources to gather more information and consult more thoroughly.

Chapter 3 also emphasised that the initial information gathering provides an opportunity to involve the local community and to build trust. This chapter continues the theme of promoting community participation into the next stages of the planning process.

In this chapter, we focus on the development of ‘project plans’ that can be submitted to government and funding agencies as ‘project proposals’. We hope that the suggestions in this chapter are also useful to organisations planning or undertaking projects that do not require external funding.

In recent years workers from a range of fields have contributed new ideas to improve the processes of planning, monitoring and evaluating. In ‘Additional resources’ we recommend several useful books and articles that provide more detail than we have room for in this manual.
The project cycle

The project cycle has three main steps, each consisting of a number of different activities (Figure 5.1). The first step is to **assess the context and analyse the HIV-related problem and responses** in your community. Other terms used to describe this step are ‘situation analysis’ and ‘needs assessment’. After completing the first step your community and/or organisation will have decided how to respond to the problems caused by HIV in your community.

The second step of the project cycle is the ‘planning’ phase. This is when you set out in detail the goal of your response (or project) and the strategies you will use to achieve your goal, all the way to the resources you will need in order to put your plan into action.

The third step is the ‘action’ phase when you implement the plan you developed in the previous phase, then monitor and evaluate it.

In the rest of this chapter we will focus on the first two steps of the project cycle. The action step – project implementation, monitoring and evaluation – is described in Chapter 14.

### Figure 5.1: The Project Cycle

**Assess context and analyse problems and responses**
- Assess capacity of your organisation.
- Consult stakeholders.
- Select indicators and targets.
- Analyse HIV-related problems and responses.
- Select priorities for action.

**Plan**
- Set goals, objectives.
- Design strategies.
- Select indicators and targets.
- Define outputs and activities.
- Identify inputs/prepare budget.
- Prepare implementation plan.
- Plan monitoring and evaluation.

**Act**
- Implement.
- Monitor and evaluate.

**Considering your response to HIV**

You will need to do many things before writing a project proposal, including:
- Review the capacity of your organisation.
- Consult with individuals and groups who may have an interest in the project.
- Analyse HIV-related problems.
- Consider responses and build support.
- Consider other options.
- Identify funds and other resources required.

This preparatory stage will help you to decide:
- what objectives your organisation could help the community to address;
- what activities your organisation could do to achieve these objectives;
- what population(s) the project should aim to reach;
- what geographical area the project should work in;
- what agencies the project should work with;
- who will carry out the project;
- what funding and other resources are required.
**Review your own organisation**

A single organisation cannot work with everyone, everywhere, doing everything. Most organisations have particular expertise and experience. Different organisations hold different social values. Before planning to include a response to the HIV epidemic in its work an organisation should review its strengths, weaknesses, opportunities and constraints.

Key questions to ask when you assess your organisation’s capacity to respond include:

- What is the purpose of our organisation? Why do we exist?
- What is the focus of our organisation and our work?
- What do we do well?
- What don’t we do well?
- What fundamental beliefs or values guide our work?
- What are we committed to?
- How can we make a difference?

It may become clear that your organisation’s existing activities already contribute in one way or another to lessening the impact of the epidemic. In Section 3, we emphasise the importance of integrating HIV prevention, care and support with other work.

You may decide to strengthen activities that the organisation already does. It is not always necessary to develop a new and separate HIV project. For example, an organisation may be managing an income-generating activity or micro-credit scheme. Offering this opportunity to single women or sex workers may contribute to prevention of spread of HIV and be tied in with providing information to women about HIV and STIs. An organisation that provides a palliative care service may provide training to volunteers in home-based care for AIDS patients. A literacy project can include HIV training for the project staff and use HIV-related materials in its classes.

When planning a project it is important to consider the capacity of your organisation to implement, monitor and evaluate the project.

If your capacity assessment reveals weaknesses or gaps, consider collaborating with another group that has strengths that your organisation lacks. The combined capacity may be greater than that of each organisation working alone. For instance, your organisation may require some technical support. It could help to form contacts with the local university or with an international organisation which may provide useful advice and support with planning, annual reviews and evaluation.

An organisation’s beliefs may influence its capacity to reach a particular target group. When an organisation that has affiliations with a particular ethnic group offers services to the general public, people from other ethnic groups may be reluctant to participate. A religious organisation may appeal to those of the same religion, but particular groups at risk of HIV infection may feel that their behaviour is judged to be ‘sinful’. This might make it difficult for an organisation to work with sex workers, those who inject drugs or young people who have sex before marriage.
Consider how the values of project staff will affect their capacity to undertake project activities. For example, staff may feel uncomfortable discussing sexual health and sexual practices with young people. Others may not discuss safer sexual practices such as mutual masturbation or condom use because they believe these practices to be immoral.

In reviewing the capacity of your organisation you should consider how your organisation’s values and beliefs might affect its HIV-related work. For example, its values may influence the staff’s view of the causes of the spread of HIV. A women’s group may view the low status of women as the most important cause of the spread of HIV. Christian and Muslim organisations may believe that HIV spreads because of immoral behaviour. A community development organisation may view poverty as the underlying cause of spread of the epidemic.

These beliefs may in turn influence what the organisation chooses to do and how it does it. For example, an organisation with strong human rights values may choose to undertake advocacy work. A religious organisation that places a strong value on caring for others may focus on a home-based care service.

An agency may fund a proposal that does not score well on every one of the above ‘experience and expertise’ questions. For example, an organisation with long experience in a particular setting may be in a good position to consult with the community about a new approach; or an organisation with experience in a particular field, such as education and empowerment of commercial sex workers, may succeed in an unfamiliar geographical setting.

**BOX 5.1: BEING AWARE OF FUNDING AGENCIES’ PERSPECTIVES**

When governments and funding agencies assess a proposal they consider how many people the project is likely to assist, how likely the project is to succeed and the probable costs and benefits. They also assess:

- the organisation’s ability to manage the proposed project;
- the organisation’s experience and expertise relating to HIV;
- the organisation’s experience and expertise relating to the project’s specific focus and method (eg delivering goods such as condoms, or delivering services such as training of health staff, or helping to build the capacities of communities to respond to HIV);
- whether the organisation has experience in the geographical setting of the project;
- the possibility of civil, political or military unrest or environmental disaster.

**BOX 5.2: IF YOU LACK EXPERIENCE AND EXPERTISE …**

If the project you are considering does not score well on each of the experience and expertise questions, you may wish to consider:

- planning a small project, and monitoring and evaluating its progress closely (ie a ‘pilot’ project);
- including the training of project participants in the project’s plan and budget;
- submitting the project as an HIV ‘capacity-building project’ where a key aim is to build the capacity of project staff and communities to plan, implement, monitor and evaluate HIV responses.
Focus on stakeholders

An organisation that considers expanding into a new area of need should identify and analyse the interests of other individuals and groups who may be affected by their plans. These people and groups are sometimes called the ‘stakeholders’ in a project. Examples of stakeholders might include someone who is infected with HIV, a leader such as a traditional chief, a health worker, a member of the community, a brothel owner or a local business person.

Some of the stakeholders may simply need to be informed about the project plans. Others could be invited to collaborate in the planning and implementation of the project. Some may be able to provide support or contacts, or cooperate in particular aspects of the project.

One way to identify potential stakeholders in the project and to analyse the roles they might play is to invite a small group of community representatives and relevant government officials to a consultation or planning meeting.

The questions about the local decision-making structures and processes, gender relations, networks, interest groups and elites in Chapter 3 are useful in this analysis. Other helpful questions include:

- Who are the main stakeholders in this geographical area? How are they likely to view the proposal?
- Who are the main stakeholders in the sectors (eg health, education, welfare) under consideration? How are they likely to view the proposal?
- Who will benefit, directly or indirectly, from the project? Who has an interest in this group or community?
- How do stakeholders view the underlying causes of the spread of HIV? What do they think should be done?
- How might stakeholders influence the project? What concerns might they have about the proposal? What expectations might they have?
- What is the best and most appropriate way to consult with stakeholders? For example, you might invite them to a consultative meeting, write them a letter requesting their comments or go to meet them personally to discuss the proposal and seek their support.
- Is there potential for stakeholders to play a role in the project as partners, collaborators, advisers or supporters? What might stakeholders be able to contribute to the project? How might stakeholders benefit from the project?
- How can you ensure that HIV-positive people are able to contribute to project planning, implementation, monitoring and evaluation?

Analysis of HIV-related problems

Identifying stakeholders and their possible roles in the project helps in the next step in planning.

Analysis of the issues raised by the HIV epidemic provides an important opportunity to engage the community in planning the response. In Chapters 3 and 4 we referred to the value of forming a local project planning team to assist with gathering information.

The same team can play a valuable role in developing the project plan or proposal. Such involvement ensures a wider view than just that of any one group such as government officials. It also helps to build the trust and support of the local community and makes it more likely that the project staff will be accountable to them. Such consultation takes time.

In addition to consultation it is important to read relevant reports and articles that describe and analyse the issues and possible responses. It is essential to read the national
government policy in relation to HIV infection and the prevention and care of sexually transmitted infections. It is also important to look at publications by organisations such as UNAIDS, UNICEF, the World Bank and UNDP about the country or area where you work. Organisations such as these usually work closely with the national government and will have a program of action in your country. These joint programs of action may give you ideas that you can explore during the planning phase.

Within a country there may be considerable cultural and socio-economic differences between regions and ethnic groups. While it is important to plan project activities that fit within the national AIDS program, your organisation’s analysis of the problem and the realities and priorities of the local community should guide potential responses.

Because HIV infection remains a hidden epidemic for many years, it is possible that early in the epidemic local people will not see the issue as a priority. However, activities needed to prevent transmission of HIV are often the same as those needed to address problems that are often seen as a priority by the community. These can include concern about teenage pregnancy, drug use by youths or limited access to health care services for treatment of STIs.

Problem tree exercise

A useful exercise when planning a project is to draw a ‘problem tree’ (see Figure 5.2). It is helpful to do this exercise with the project planning team and local stakeholders. Participants analyse the HIV-related problems in their community using the image of a tree’s roots, trunk and fruit. The trunk of the tree represents the problem being discussed, the roots represent the causes and the fruit symbolises the consequences. Developing a problem tree allows the participants to focus on a central problem, identify its causes and consequences, rank these factors and define objectives for an intervention. The problem tree also helps to create an overview of how problems relate to each other.

You can draw a problem tree at various stages in your planning process. A one- or two-day planning workshop to explore problems, responses and strategies is helpful.

Some of the information gathered during the situation analysis will be very useful for developing the problem tree. In fact, you might begin the problem tree planning exercise by presenting the findings of the situation analysis to the participants:

1 Ask participants to make a list of problems in the community, using the situation analysis information as well as their own experience. Write the problems on separate cards (colour A). Select one of the cards and tape it to the trunk of the first tree diagram.
2. Within the group, brainstorm about the causes of the problem being discussed. Write each cause on a separate card (colour B). Tape these to the root area of the diagram.

3. Now brainstorm with the group about the consequences of the problem. Again, write each answer on a separate card (colour C). Tape these on the branches of the tree.

4. The whole group examines and discusses the first problem tree. Then smaller groups can work on other problem trees, starting with another of the cards produced in the first step.

Aggregating the findings from the different problem trees can give an overall picture of the key HIV-related problems in the community.

Making a problem tree often stimulates discussion. When participants mention a problem, encourage them to describe how they see the problem and its possible causes and effects.

If you haven’t carried out the problem tree exercise before, you might like to practise with work colleagues first.

An example of a problem tree, generated with young people in Lusaka, Zambia, is shown in Figure 5.2 below.

FIGURE 5.2: PROBLEM TREE
Think about responses

There is a close relationship between analysing problems and developing responses. When a group discusses the causes and effects of problems they also begin to discuss possible responses.

Developing an objectives tree

The problem tree exercise can be used as the basis for developing an ‘objectives tree’.

Start the exercise by encouraging participants to think widely about possible responses to the problems. They do not need to limit the suggestions to objectives that the organisation can address by itself.

Developing the objectives tree takes less time than the problem tree, because each objective usually relates to a problem.

For example:
- The problem ‘food shortages’ becomes the objective to ‘improve the food situation’.
- The problem ‘increased/widespread HIV infection’ becomes the objective ‘to reduce the incidence of HIV infection’.
- The problem ‘high infant mortality’ becomes the objective ‘to reduce infant mortality’.

The more detailed and specific your problem tree, the more specific and useful will be your objectives tree. For example, rather than just naming ‘AIDS orphans’ as a problem you might specify some of the problems related to AIDS orphans, including:
- Many AIDS orphans are not properly cared for.
- Many orphans are leaving school earlier than non-orphaned children.

The related objectives might then be:
- to increase the number of orphans adequately cared for within their own extended families or communities;
- to reduce the school drop-out rate of orphans.

The next step is to identify who is doing what in relation to each objective in the objectives tree.

Write out your objectives cards again, and put them on the floor, table or wall. Underneath each one write the name of each agency responding to the objective and a brief description of what they are doing. Alternatively you could put the same information into table form. Encourage the participants to consider whether the current responses are sufficient and effective.

Next ask participants to identify where there are gaps in the responses, and where the responses are insufficient, ineffective or inappropriate.

It is now time for the participants to consider the big questions:
- What objectives could your organisation help to address?
- What activities could your organisation undertake to achieve these objectives?
- What population(s) should the project aim to reach?
- What geographical area should the project work in?
- What agencies should the project work with?
- How will you obtain funds for the project?
Considering different options for addressing the problems

The preparation of a problem tree and objectives tree can leave participants feeling overwhelmed. There may also be disagreements about what problems the organisation should tackle. At this stage it may be helpful to compare two or more options for a project proposal. This helps the group to compare options objectively and helps them to picture how they could respond to the problems in a practical and manageable way.

Encourage the group to choose one or more objectives for each option. Identify strategies or activities to achieve the objectives. Decide on an appropriate and feasible geographical area and target population for each option. Decide on agencies and stakeholders you might cooperate or collaborate with and where you might apply for funds.

You can use the following questions and criteria to assess the options:

• Is the option in line with key community priorities and needs?
• What is the likely impact?
• Does the organisation have the experience, expertise and values to manage the project?
• How does the option fit in with activities of other agencies?
• Is the option consistent with government policies?
• How will the local community feel about the option?
• What kind of resistance and/or support will come from the various stakeholders?
• What will each option cost and where will the funds come from?
• Are some options more likely to receive funds than others?
• Do some options look likely to deliver higher secondary benefits than others (benefits beyond the core objectives of the project)?
• How viable or sustainable is the option?
• What risks threaten the success of the option?

Before concluding the planning workshop, the facilitator or one of the participants should write up a summary of the major findings, agreements and recommendations.

Identify sources of funding

• What will it cost to implement your proposal? How will the proposal be funded?
• Will your organisation implement the project without applying for government or external funds? Many community-based organisations (CBOs) do just that. CBOs and their activities often rely heavily on donated funds, time, and labour from the volunteers who are the backbone of the organisation (see Chapter 14).
• Can your organisation implement the project with its own resources?
• If you wish to seek external funding for an HIV response, where will you turn? Who will you approach for funding? Who should you approach for advice?

You could start by approaching people you already know and trust for advice. You could speak to local leaders, including government representatives, and other local organisations.

It is worth speaking to international NGOs (INGOs) (such as Save the Children, Red Cross, World Vision, CARE, Médecins sans Frontières (MSF), and Oxfam) operating in your country, especially if they are already active in your area. Private voluntary organisations such as Family Health International, the Population Council and Population Services International carry out similar work. The Global Fund to Fight AIDS, tuberculosis, and malaria is providing funds for HIV activities to governments and NGOs. However, to access these funds your organisation should be a member (or affiliated with a member) of the Country Coordinating Mechanism.

Government and multilateral donors channel some of their overseas aid funds through INGOs. Consequently, INGOs have workers who are knowledgeable about the policies and funding guidelines of various government and multilateral funding agencies. In addition, INGOs may be looking for a local organisation as a ‘project partner’.
The precise roles and division of labour between local project partners and INGOs vary. The local project partner is involved in the more hands-on, day-to-day project planning, implementation, monitoring and evaluation.

Normally the INGO makes a contract with the funding agency and is legally accountable to ensure that the project operates consistently with the terms of the contract. In this situation, INGOs can be called the ‘contracting agency’.

Local organisations working in partnership with INGOs can ask them for assistance with planning, proposal writing, staff training, monitoring, evaluation, and so on.

INGOs act as intermediaries between the project and the funding agency. INGOs offer services to projects and to funding agencies to:

- assist project participants to plan, implement, monitor and evaluate the project;
- assist project participants to report back to funding agencies on the project’s performance and use of donor funds;
- be contractually responsible and liable to the funding agency in the case of misuse or theft of project funds.

TABLE 5.1: EXAMPLES OF FUNDING AGENCIES

<table>
<thead>
<tr>
<th>Types of funding agencies</th>
<th>Examples</th>
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<tbody>
<tr>
<td>Bilateral (government) aid agencies</td>
<td>Australia (AusAID)</td>
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<td>Canada (CIDA)</td>
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<td>Britain (DFID)</td>
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<td>Sweden (SIDA)</td>
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<td>Denmark (DANIDA)</td>
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<td>Germany (GTZ)</td>
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<td>USA (USAID)</td>
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<td></td>
<td>Japan (JICA)</td>
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<td></td>
<td>European Union (EU)</td>
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<tr>
<td>Multilateral organisations</td>
<td>WHO</td>
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<td></td>
<td>UNAIDS</td>
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<td>UNICEF</td>
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<td>UNDCP</td>
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<td>World Bank</td>
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<td></td>
<td>The African Development Bank Group</td>
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<td></td>
<td>Asian Development Bank</td>
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<td></td>
<td>The Global Fund</td>
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<tr>
<td>International aid agencies/Private voluntary organisations</td>
<td>Save the Children</td>
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<td></td>
<td>Plan International</td>
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<td></td>
<td>Oxfam/Community Aid Abroad</td>
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<td>World Vision</td>
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<td></td>
<td>Red Cross</td>
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<td></td>
<td>CARE</td>
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<td>MSF</td>
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<td></td>
<td>Family Health International</td>
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<td></td>
<td>Population Council</td>
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<td>Population Services International</td>
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<tr>
<td>Philanthropic organisations</td>
<td>Rockefeller Foundation</td>
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<td></td>
<td>Ford Foundation</td>
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<td></td>
<td>Wellcome Trust</td>
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<td>Bill and Melinda Gates Fund</td>
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<td>Clinton Foundation</td>
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Different funding agencies have different funding priorities and guidelines. They may favour certain geographical locations, certain topics and certain approaches. It is important to know about their current priorities. The knowledge need not necessarily change your plans but may influence the way you present the proposal.

Most grants from funding agencies do not cover the total administrative costs of running a project. You need to consider what resources your organisation can offer. These might include office space, equipment, labour or money.

Some funding agencies require the organisation to contribute a specific percentage of the total grant. This means that organisations sometimes need to raise funds themselves as a condition for obtaining a donor grant.

To increase the chances of obtaining funding you need to be aware of lessons learned about HIV prevention, care and support in other parts of the world. This will help to ensure that you plan a project that is innovative or based on approaches that are known to be effective.

Your application is also more likely to succeed if you frame your proposal according to a targeted donor’s specific guidelines and preferred format.

**Developing the plan**

It is a good idea to write down clearly what you want to achieve and how you plan to achieve it. This written plan provides a guide for action for your organisation and for the workers who implement the project.

A well-written plan can convince a donor that the proposed activities are worthwhile, carefully considered, appropriate to the defined problem and consistent with the donor’s funding guidelines. A good proposal can also convince the donor that your organisation is capable of carrying out its plan.

Here are some tips to consider before you start writing:

- Write the project plan so that those who will implement the project can readily understand it.
- Find out more about the guidelines of various funding agencies. Try to find a funding agency whose guidelines are most in tune with your proposal.
- Make sure that the project objectives fit in with the funding agency’s stated priorities and guidelines.
- You may wish to pick up and use some of the key words from the donor’s guidelines (e.g. ‘behaviour change communication’). Make sure you find out the meaning of any words you don’t understand.
• It is a good idea to write a brief initial letter of enquiry to determine whether the funding agency’s present interests and funds will permit them to consider your proposal.

• If the technology is available, use the Internet. Many funding agencies have home pages with useful information for prospective applicants. If your organisation does not have access to the Internet, it is worth trying to obtain access through a library or larger organisation to explore current funding opportunities. A list of Internet addresses of main funding agencies can be found in Appendix 2.

• Look through previous project proposals that have been successful.

• It is wise to follow the funding agency’s instructions and guidelines about the length, headings and format of project proposals. Some funding agencies simply provide the headings to be used in a project proposal; others specify the proposal’s maximum length, headings and even font size.

Components of a project proposal

When you develop a plan or proposal you look at the entire project and break it down into smaller parts.

Most funding agencies ask that proposals for funding be put into a format similar to the one in Box 5.3. You may find this format useful whether or not your organisation intends to apply for external funding.

Donor guidelines and manuals on project development or evaluation can differ in the terms they use. This can be very confusing! Some donors, for example, use the term ‘activity’ in place of ‘project’.

BOX 5.3: FORMAT FOR PROJECT PROPOSAL

• Summary of plan
• Statement of the problem: description and context of the problem to be addressed by the project
• Description of the way that the project responds to the problem:
  – Goal (also known as ‘development objective’ or ‘overall objective’)
  – Purpose (also known as ‘immediate objective’ or ‘project purpose’ or ‘project objective’)
  – Outputs (also known as ‘results’)
  – Activities
  – Inputs (also known as ‘resources’)
• Budget
• Implementation schedule or work plan.
• Assumptions and risks
• Sustainability
• Monitoring and evaluation plan
• Job descriptions
• Letters of support or agreement from collaborating organisations or partners
In the following section, we will try to explain each of the elements of a project proposal, and list the different terms used.

**Statement of the problem**

The project proposal should begin with a statement of the problem, its background and context. The proposal should show how the proposed project responds to the problems or needs in a specific region or community. Below are some suggestions to include in this description.

- The country and the specific geographical area the project will cover: if possible, include a map sufficiently detailed to locate the project.
- The nature and extent of the problem that the project will address: clarify how this need or problem fits in with the goals of the funding agency you have chosen.
- An analysis of the history and causes of this problem and who is affected by it.
- The group or population whose needs will be addressed by the project, including their gender, age, class and ethnicity.
- The strategies you will use to address the problem or need: explain why your organisation is qualified and well placed to address these issues in this particular country or region.
- Other related activities (if any) that are being conducted or planned by government, international agencies or other NGOs in the sector or area: show how the proposed project fits in with these activities. Funding should not duplicate existing or planned activities in the area.
- The ways in which the project’s objectives are consistent with government policies and strategies as well as with various UN programs. Back up claims by citing funding agency and government documents and joint documents of the government and organisations such as UNDP, UNICEF, UNAIDS or the World Bank.

**Defining the project goal**

Many funding agencies will ask you to describe the overall ‘goal’ or longer-term development objective that you expect your project to help to achieve. The project by itself would not be expected to achieve this goal during its lifetime. Also, other projects and processes are likely to contribute to it.

For example, a proposal ‘Youth and HIV in Province X’ had the goal:

‘Reduced incidence of HIV and other STIs in Province X and improved treatment and care of those living with HIV and STIs.’

In the above example, you will notice that the goal is written in as ‘reduced incidence’ rather than ‘to reduce the...’
incidence’. The Logical Framework Approach encourages planners to write their objectives in the past tense, as situations that have been attained.

You will also notice that the goal above merely indicates the general direction of the project rather than stating a precise, measurable target. Since the goal is a longer-term objective, not to be achieved solely by the project, it is not necessary to make it SMART by attaching measurable indicators and targets to it. We’ll have more to say about how to write SMART indicators and targets later in the chapter.

**Purpose**

Most funding agencies will ask you to describe briefly the situation that you expect to reach at the end of the project. This desired situation is the project’s ‘purpose’ or ‘immediate objective’.

For example, the proposal ‘Youth and HIV in Province X’ described its project purpose as follows:

‘Enhanced ability of youth groups in Province X to respond to the emerging risk of HIV and other sexually transmitted diseases across the prevention, treatment and care continuum.’

Once again, the purpose states a general direction. It is not measurable.

Funding agencies generally expect those managing the project to ensure that the project’s purpose is achieved by the end of the project.

Try to keep your project plan simple and clear. Where possible, you should name only one goal and one purpose for your project. Don’t be too ambitious.

**Outputs**

‘Outputs’ or ‘results’ are the specific, direct products of activities. For example, the proposal ‘Youth and HIV in Province X’ described some of the outputs as follows:

• improved HIV/STI planning capacity of youth groups in province;
• improved local research skills of youth groups in province;
• improved management, monitoring and evaluation skills of youth groups in province;
• Village Development Committees in project villages trained in HIV/STI prevention and care;
• HIV/STI response integrated into a community development project.

Once again, these outputs are directional rather than precise and measurable.

Most funding agencies are keen to assist local NGOs and community-based organisations to build their capacity to plan, implement, monitor and evaluate HIV

**BOX 5.5: EXAMPLE OF A PROBLEM STATEMENT**

The adult prevalence of HIV in Country Y is low (<0.05%). To date fewer than 637 HIV infections have been reported in a country with a population of five million. However, recent studies of HIV infection rates in some population groups suggest that there are about 1,500 people living with HIV in the country. Among reported cases men and women are equally infected, 50% aged 14–29 years and 96% heterosexually acquired.

Despite the low HIV prevalence, Country Y remains highly vulnerable to the spread of HIV due to the widespread presence of risk factors, including low usage of condoms. Country Y is a landlocked country surrounded by countries with much higher levels of HIV infection. In recent years, transportation and trade between Country Y and neighbouring countries has increased with the building of several highways, creating potential for the rapid spread of HIV. Also, there has been a rapid increase among young people in the use of illicit drugs, especially methamphetamines, which may exacerbate their risk of acquiring HIV and other STIs.

Studies conducted by young people about their risk and vulnerability to HIV found the following:

• Many young women and men are having sex before marriage, starting at the age of 15–18 years.
• Many teenage women are engaged in casual or part-time sex work which is negotiated in bars, tea shops, discos and other informal locations.
• Most young people – especially those in rural areas – have heard of AIDS but their knowledge is limited.
• Most young people are aware that condoms prevent HIV transmission but report that they infrequently use a condom and, if so, only with a sex worker.
• Many young men and women do not like using condoms.
• Most young people know where to buy condoms but it is difficult to purchase them outside of urban areas.
• The majority of young people who experience an STI do not seek treatment at a public clinic because of shyness and lack of confidentiality (urban areas) or distance from clinics and cost (rural areas).

Together with the information that 50% of new infections occur in young people, the situation analysis indicates clearly that there should be an increased focus on youth in the national response to HIV if Country Y is to avoid a major epidemic.

’Sslowly, slowly, the egg will walk.’

Keep in mind this old Ethiopian proverb as you design your project. Keep design realistic and achievable. It is better to start modestly and grow than to take on more than you can cope with.
responses. You can even make capacity building or training the purpose of the project. You may remember that the purpose of the ‘Youth and HIV in Province X’ project was described as:

Enhanced ability of youth groups in Province X to respond to the emerging risk of HIV and other sexually transmitted diseases across the prevention, treatment and care continuum.

Activities
Project ‘activities’ are the tasks necessary to achieve the specified outputs of a project. When you have defined the outputs, create a list of the main project activities for each output. Then explain briefly how each project activity relates to the output and why the proposed activity is the most appropriate way of achieving that output.

For each activity, explain what, where, when and by whom it will be performed. The description of each activity should be specific enough to clarify the need for all inputs and items listed in the budget.

Inputs
Project ‘inputs’ are the resources necessary to perform the planned activities. This may include personnel, advice, resources and materials, and money (e.g., salaries and renting of space and equipment). Project management staff are responsible for procuring these resources and using them effectively to implement project activities.

Here are some major project or activity inputs of the ‘Youth and HIV in Province X’ project aiming to develop youth capacity to respond to HIV:
- salary and on-costs for project manager (on-costs are all other costs associated with employing someone, such as insurance and sick leave costs);
- salary and on-costs for half-time technical adviser;
- salary and on-costs for six full-time research assistants for one year;
- equipment and running costs (including one four-wheel drive, one desktop and one laptop computer, three desks and chairs, one filing cabinet, fax, phone, Internet link and rent);
- materials for behaviour change communication;
- training costs (e.g., rent for training room, food and drink, daily expenses for participants, and training equipment such as overhead projector, transparencies and whiteboards);
- monitoring and evaluation costs.

In the project ‘budget’, the costs for obtaining these necessary inputs are specified. Stating the costs provides a baseline against which you can monitor and control expenditure.

Cost categories should include at least the following:
- project personnel costs – staff dedicated to the project;
- non-personnel costs – direct project inputs (e.g., materials, equipment, training costs);
- project support costs – communications, report preparation, costs for vehicles in countries where vehicles are essential to successful project management, and other costs directly attributable to the project;
- overhead costs – non-project staff support, office accommodation, utilities, audits, insurance, bank charges and office supplies.

Once you have specified the inputs needed, you can find out what they cost by asking agencies and suppliers in the area what they have paid for similar materials and services or where you might purchase these items.

Inflation will increase costs for each year of the project. You will need to estimate the likely rate of inflation and take this into account in your calculations.
Implementation schedule

The project ‘implementation schedule’ (or ‘activity timeline’) is a summary of the major project activities over time. For all project activities it specifies who does what, in which order and when. It is a very important tool for planning and monitoring the progress of the project. It helps to keep the project on schedule and to manage the project’s resources. When necessary, it can be adjusted during the implementation of the project.

Table 5.2 illustrates how to set out an implementation schedule or activity timetable in the form of a chart.

**TABLE 5.2: PRESENTING YOUR PROJECT ACTIVITY IN A TIME CHART**

<table>
<thead>
<tr>
<th>Major task</th>
<th>Responsible person</th>
<th>Year 1</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>July 2000 – June 2001</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Q1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>J</td>
</tr>
<tr>
<td>1 Inception phase</td>
<td></td>
<td>F</td>
</tr>
<tr>
<td>Recruit project coordinator and health educator</td>
<td>Project director</td>
<td></td>
</tr>
<tr>
<td>Establish project office and email connection</td>
<td>Project coordinator</td>
<td></td>
</tr>
<tr>
<td>Establish project coordinating committee</td>
<td>Project director and coordinator</td>
<td></td>
</tr>
<tr>
<td>Establish project information system</td>
<td>Project coordinator</td>
<td></td>
</tr>
<tr>
<td>Prepare detailed work plan</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

2 Improvement of STI/HIV planning capacity

| Training of youth union representatives in strategic planning |     |     |     |     |
| Situation analysis                                          |     |     |     |     |

Assumptions and risks

An important question to be answered in your project proposal is: ‘What has to happen for our proposal to work?’ In other words, what assumptions is your plan built on? Assumptions and risks are factors that are important for the success or failure of the project, but that lie outside its control.

In our example of the ‘Youth and HIV in Province X’ proposal it was assumed, among other things, that the National AIDS Control Committee would remain in its current role and that a specified number of staff would be seconded by the government.

The proposal should identify external risks that could prevent the proposed activities achieving their objectives or outputs. Try to give some assessment of the likelihood of the risk and how the project might cope if the risk eventuated. Examples of risks are deterioration of financial situation; civil unrest; natural disasters such as flood, earthquake or drought; and changes in political climate.

Sustainability

When we plan projects we hope that there will be longer-term benefits. Funding agencies, too, expect that project activities will be sustainable. A project is sustainable when local organisations or institutions are willing and able to work towards the project’s goal after external financial, managerial and technical assistance diminishes.

The following questions may help you to assess the sustainability of your project design:
• Is the project based on community needs? (including or especially women’s needs)
• Does the group or community that benefits from the project accept the objectives, approach, technologies and activities of the program?
• Is the intended group or community involved in planning, deciding, implementing and evaluating activities?
• Will the project improve women’s capacity and position?
• How will future activities arising from the project be funded? (eg from resources within the community, by cost-recovery or by another donor)
• How will mutually sustaining partnerships and networks be formed during the project?
• Does the project have the support of people in power?
• If the project does not have the support of people in power, how does it plan to win such support?
• Can the project be implemented and the project funds managed?
• How does the project plan to increase the skills and knowledge of the intended groups or communities?
• Does the project aim to build local capacity to plan, implement, monitor and evaluate HIV responses to ensure that community action on HIV continues after project funding ceases?

When projects that relate to HIV prevention, care and support are implemented in areas where the prevalence of HIV is high, it is important to recognise that it will be difficult to sustain activities when project funding ceases. This is because the impact of the epidemic, in terms of illness and death, will increase during the lifetime of the project. It is legitimate to acknowledge this. You can then describe how further funding may be identified, and how the situation of the population would be worse without the benefits delivered by your project.

Job descriptions
Some funding agencies may also require job descriptions and responsibilities for key staff. It is a good idea to prepare job descriptions for project implementers whether they are paid or not. Job descriptions can work as a record of understanding of what each worker should focus on and try to achieve.

Monitoring and evaluation plan
What is monitoring and evaluation? There are many different understandings and approaches to monitoring and evaluation. Our approach is summarised in Table 5.3.

| Monitoring | Monitoring is the regular and methodical process of gathering information throughout the project’s life in order to track the project’s performance against the plan. It also involves the gathering and reading of project data. |
| Evaluation | Evaluation involves: • analysing and assessing a project or part of a project; and/or • judging the worth or value of a project or part of a project; and/or • helping project participants to self-evaluate and improve their practices and the project. Rather than say that there is only one approach to evaluation, we can think of evaluation in a flexible way. **Formal evaluation** – the more formal, ‘special’ kind that can be done: • internally as self-evaluation involving project beneficiaries, other local stakeholders, project staff (eg annual review and planning workshops); or • semi-internally (including non-project staff from your NGO); or • externally (including external staff on evaluation team). **Informal evaluation** – the everyday assessment and discussion of project performance, strengths, challenges, effects and so on by project participants. |
Project proposals should include a plan for monitoring and evaluation. You could present the information in the format of Table 5.4 below. Monitoring and evaluation should be an integral part of your plan, even if funding agencies do not require them. They are essential as management tools, to tell whether your project is achieving what it set out to achieve or whether it needs to be changed.

**TABLE 5.4: WORKSHEET FOR DESCRIBING YOUR PROJECT MONITORING AND EVALUATION SYSTEM**

<table>
<thead>
<tr>
<th>What is monitored?</th>
<th>What information is needed?</th>
<th>Where to find the information?</th>
<th>When is information collected?</th>
<th>Who does what?</th>
<th>What resources are needed?</th>
<th>Cost?</th>
</tr>
</thead>
</table>
| **Management/ administration**  
Staff/personnel issues  
Vehicles  
Supplies | Name the source of information | For example: weekly, monthly, quarterly, annually | Name the key M&E players, their focus and functions | For example: computer, desk, office space, part-time bookkeeper, clerk | | |
| **Finance**  
Budget and expenditure  
Staff salaries  
Cash flow analysis | | | | | | |
| **Project**  
Progress towards objectives  
Problems  
Strengths  
Changes to plan  
Process  
Impact | | | | | | |

As you can see from Table 5.4, a project’s monitoring and evaluation system includes a project information system, people undertaking monitoring and evaluation, specific activities, equipment and funds to cover the costs.

It is important to document plans for monitoring and evaluation in the project proposal. Such early planning helps to clarify project objectives and creates a sense of accountability. It also makes it possible to reach agreement about the purposes of monitoring and evaluation activities. Once these are agreed, appropriate indicators, targets and evaluation methods can be chosen.

**Indicators and targets**

The monitoring and evaluation plan in your proposal should include a brief description of how progress towards the project’s objectives will be assessed. One way of monitoring the project’s progress towards objectives is to define measurable targets and indicators. A ‘target’ specifies the extent of change you expect as a result of project activities. An ‘indicator’ is a piece of evidence that shows how much progress or change has been made towards the target.

A target is a measurable standard that the project participants choose or are asked to meet. It can be expressed as a:

- **specific number** (eg 50 people trained as HIV peer trainers by the end of the first year of the project);
• **specific percentage** (e.g., 70% score on a test or 70% of participants score 50% or more on an HIV post-training test; 75% of people surveyed cite at least two acceptable ways of protection from HIV infection); *

• **numerical or percentage increase** (e.g., 20% increase in people surveyed cite at least two ways of preventing HIV/STIs; 20% increase in proportion of people surveyed report safe practices in their last instance of risk behaviour; 30% increase in proportion of people cite at least two acceptable ways of protection from HIV infection); *

• **specified standard on a scale** (e.g., 70% or more of participants surveyed rate the projects ‘behaviour development’ and ‘communication’ materials at least four out of five by the end of the project).

Indicators and targets should specify as far as possible:
• the quantity (how much?)
• the quality (what sort?)
• the target groups (who?)
• the time/period (starting when and for how long?)
• the place (where?).

Table 5.5 below shows some examples of how you can turn ‘directional objectives’ (general statements of direction for goal, purpose, outputs and activities) into ‘SMART objectives’ by specifying indicators, targets and sources of information.

### BOX 5.7: COMMUNITY RATING SCALES

Several types of community rating scales are possible. One is a community satisfaction ranking with the project’s performance, exemplified by the following:

4 Community members totally satisfied with the performance of the project (or of a component, e.g., behaviour change communication)

3 Community members mostly satisfied with performance of the project

2 Community members partly satisfied with performance of the project

1 Community members not satisfied at all with performance of the project

0 Community members do not know about the project.

---

1 Targets expressed as straight numbers or percentages (with no reference to the pre-existing situation) are called ‘attainment’ targets.

2 Targets expressed as an increase or reduction of a phenomenon compared with a baseline situation are called ‘comparative’ targets.
<table>
<thead>
<tr>
<th>Directional objectives</th>
<th>Indicator</th>
<th>Target</th>
<th>Source of information</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reduced incidence of HIV in Province X</td>
<td>Proportion of the general population in Province X newly infected with HIV between June 1999 and June 2002</td>
<td>Proportion of the general population in Province X newly infected with HIV between June 1999 and June 2002 reduced from A% to B%</td>
<td>Blood tests from a random sample of the population</td>
<td>Accurate and reliable information on HIV incidence in the general population is hard to obtain or estimate. Taking blood samples from a sample of the population is likely to be socially impossible.</td>
</tr>
<tr>
<td>Enhanced ability of government and NGOs in Province X to respond to the emerging risk of HIV and other STIs across the prevention, treatment and care continuum</td>
<td>Operational provincial HIV/STI/AIDS strategic plan produced by June 2000 and first phase implemented by June 2001</td>
<td>High-quality provincial strategic plan covering HIV/STI/AIDS prevention, treatment and care produced by June 2000 and at least 75% of the targets for the first phase achieved by June 2002</td>
<td>End-of-project evaluation team verifies existence of plan, assesses its quality and the extent to which the targets have been met</td>
<td>Directional Purpose Objective + Target = SMART Purpose Objective: This kind of purpose objective is appropriate for a project focussing on building local capacity to respond to HIV. Improving local capacity is highly valued by international aid donors. Production of a draft strategic plan could be an output of a training workshop on strategic planning. Production of an operational provincial strategy, requiring consultation and acceptance by the key stakeholders, is a purpose-level objective, not a simple product of a training workshop.</td>
</tr>
<tr>
<td>Improved HIV/STI/AIDS knowledge among project population</td>
<td>Proportion of project population citing at least two acceptable ways of protection from HIV infection increases between June 1999 and June 2002</td>
<td>Proportion of project population citing at least two acceptable ways of protection from HIV infection increased from B% to A% between June 1999 and June 2002</td>
<td>Survey of a random sample of intended population</td>
<td>Directional Output Objective + Target = SMART Output Objective: Improved knowledge can be seen as an output, that is, an effect or result of an activity such as training.</td>
</tr>
</tbody>
</table>

Indicators may refer to the ‘process’ of the project or to its ‘impact’. A process indicator may show what activities have been carried out, and how, such as number of volunteers who have participated in a home-based care workshop and participants’ satisfaction with the home-based care workshop.

An indicator of the impact or effectiveness of projects describes the extent to which objectives of the project were achieved. Examples of impact indicators are:

- changes in HIV-related attitudes
- HIV/STI-related risk behaviours
- trends in STI rates (e.g. gonorrhoea)
- increase in social support/community response.

It is worthwhile to spend time choosing appropriate and useful indicators. Indicators should be:

- valid – measure the condition or event it is intended to measure;
- reliable – produce the same results when used more than once to measure the same condition or event;
- specific – measure only the condition or event it is intended to measure;
- sensitive – reflect changes in the state of the condition or event under observation;
- feasible – the methods for collecting the data must be capable of being done;
• timely – the change that it measures occurs within a reasonable time of the project activity. For example, it may take a long time to achieve measurable behaviour change in a population, whether it is towards safer sex practices, safer injecting practices or reduced injecting drug use. A problem with the usual project life cycle is that evaluation usually takes place during and at the end of a project, but is not possible years after project funding ceases, when the long-term impact could be assessed.

### Choosing indicators, targets and evaluation methods

In order to develop a list of indicators and targets for your project plan or proposal, first ask the planning team to brainstorm about indicators for each objective (at the level of project purpose, output and activity). Next, ask the team to select the most useful indicators, making sure that they are valid, reliable, specific, sensitive, feasible and timely.

Resist the temptation to try to be comprehensive by putting down every indicator that you can think of. The project may start to sink under the weight of expectations. Select only those indicators that are likely to be influenced by project activities. Remember that the funding agency will expect you to measure all the indicators that you choose. In Sections 3 and 4, we include a selection of indicators that can be used to assess specific HIV responses.

If you set targets that are too difficult to achieve, the project team will become discouraged, and the local community will be disappointed. If baseline measures are available these can help the planning team to set realistic targets.

The findings of a baseline survey can also be helpful in deciding the feasibility of indicators. If something was difficult to measure in a baseline survey then it is not likely to be a useful indicator.

If a specific baseline survey has not been carried out, and you don’t have the time, resources or expertise to carry out such a survey, there are often other sources of information to measure changes against. These include a variety of routinely collected data from Ministries of Education, Health and Welfare, surveys carried out by other NGOs or academics, and the records of health and other services.

A plan for monitoring and evaluation should include the timing of evaluation sessions. This will be influenced by the implementation timetable. Practical factors, such as when staff and community can give time to evaluation, also need to be considered. For example, if you plan an evaluation at harvest time it will be difficult for the local community to be involved.

The plan also needs to include an estimate of the resources needed for evaluation, including technical advice and training.

It should include information about the frequency and format of reporting, and who will be responsible for reports. (See, for example, Table 5.4.)
References


Additional resources


Strategies for action

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## Chapter 6

**Community action: framework for responding to HIV**

by Mike Toole

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</tbody>
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Introduction

The direction of the HIV epidemic is decided within communities. People, not institutions, ultimately decide whether to adapt their sexual, economic and social behaviours to the threat of HIV infection. Communities play a crucial role in supporting individuals to adopt safer behaviours and to live positively with HIV if infected. Effective responses to HIV are in the first instance local: they involve people where they live and work – in their homes, neighbourhoods and workplaces. Community members are also indispensable for mobilising local commitment and resources for effective action. In particular, people living with HIV must play a prominent role in programs right from the planning stage, contributing their unique experiences and perspectives.

Community mobilisation against HIV/AIDS is taking place successfully all over the world. Community projects are as diverse as the peoples and cultures that make up these communities. Some are entirely ‘homegrown’ and self-sufficient, while others have benefited from external advice and funding. Some are based in religious centres, others in medical institutions, and still others in neighbourhood meeting places. Activities include public education, provision of care, and focussing on prevention and other goals.

In this chapter we describe a framework for responding, as a community, to the HIV epidemic. The central theme of the framework is the integrated response, addressing all aspects of this multi-dimensional problem. We describe the elements of the integrated response, with examples of how such responses have worked for different communities.
Framework for responding to HIV

The spread of HIV in a community is influenced by a variety of factors, ranging from individual risk behaviours to wider social, economic and political situations. The effects of the epidemic are also felt differently at different levels of the society. Effective responses to such a complex problem need to have multiple dimensions. An integrated approach is central to an effective HIV response. Such an approach addresses the individual causes as well as the wider health, social, economic, cultural, and political factors that influence HIV transmission. An integrated response also addresses the impact of the epidemic at individual, organisational and community levels.

Why do we advocate an integrated response?

The reasons for an integrated response become clear when we look at what is required to prevent the spread of the epidemic.

First, the community needs to know about HIV and how to protect themselves from infection. Second, to act on the information and knowledge about HIV and take steps to protect themselves, people need to have access to services and materials. These include access to:

- HIV testing facilities;
- counselling services;
- health care services, particularly for the treatment of STIs and the prevention of mother-to-child transmission;
- condoms.

Once HIV infection enters a community, people with the virus will become sick and need treatment and care. The natural history of HIV infection tells us that the need for treatment and care will increase with time. An integrated response will therefore need to include care and support services, including the treatment of opportunistic infections and, increasingly, the provision of antiretroviral therapy.

Of those infected with HIV, a large proportion are parents. Hence a consequence of increasing illness and death due to the epidemic is that large numbers of children are left without parental support. In communities with a significant HIV epidemic, the need to care for and support orphans and other dependents is an essential part of an effective response.

Effective community action will also need to address the underlying determinants of the epidemic in the community. These could include, for example:

- community action to ensure access to education for girls (a long-term strategy to reduce the vulnerability of women that arises from lower education and economic status);
- support to young people, who may be unemployed and/or exposed to the risks associated with drugs and alcohol;
- constitutional and legal reform and civil and human rights activism;
- social movements and land distribution.

An excellent example of an integrated community action on HIV is the Community Health Education Society (CHES) in Chennai (see Box 6.1). The different elements of the program have developed over time to meet the needs of the community as they are recognised. The program successfully integrates prevention, care, support and advocacy. CHES does not attempt to cover all aspects of the integrated response on its own. By developing strategic alliances and collaborating with other organisations, CHES has ensured that a comprehensive, multi-dimensional response to HIV is established in the community.
BOX 6.1: CHES – PREVENTION, CARE, SUPPORT AND ADVOCACY IN ACTION

Starting with care and support

As with many community responses to the HIV epidemic, the start of the Community Health Education Society (CHES) was almost an accident of fate: a member of the community is moved to respond to a desperate situation caused by the epidemic and does so. CHES began in 1993 when two children orphaned by AIDS were admitted to a hospital in Chennai (Tamil Nadu State) with severe jaundice. The children were HIV-positive. When they recovered from their illness, the orphanage where the children had been living would not take them back. Dr Pinagapany, who treated the children, took them home. However, it was clear that there were many children in a similar situation, so she established a shelter for people living with HIV in premises provided by the privately owned Raasi Hospital.

Doctors at the Chennai General Hospital began referring destitute children and HIV-positive women to CHES. Many of the women had been abused, and some had been sold into the sex trade. The residents of the shelter needed medical care and counselling as well as food and shelter. Raasi Hospital provided medical care and counselling services while relatives and supporters provided food and clothing to residents of the shelter. The children and illiterate adult female residents were able to learn to read and write in classes taught by a student volunteer. Other CHES workers provided lessons in mathematics, craft work and singing.

The first few years of CHES were precarious because the NGO depended entirely on gifts, small donations and volunteer work to support the needs of the residents of the ashram. CHES was unable to attract funding from national and international donors for providing care for people infected and affected by HIV.

Working on prevention

With a grant from the Tamil Nadu State AIDS Control Society, CHES began an HIV prevention program for female sex workers. Sex workers in the project area were invited to the hospital for free medical help. As the women began attending the hospital regularly to obtain treatment for various problems, mostly STIs, they learned how to use condoms. Those who were interested were trained as peer educators and condom suppliers.

Soon, some of the sex workers and brokers also became involved in caring for residents at the ashram. By caring for people with HIV-related illnesses, the virus became real to them. AIDS was no longer abstract, with a friend, a colleague or a relative affected. Some sex workers became full-time CHES employees, caring for the women and children at the ashram. In doing so, they earned a lot less money than they did when working as sex workers. Nevertheless, they preferred the change because, as one sex worker said: ‘I feel wanted and respected and feel I am part of a family. I cannot buy that with money, can I?’

Condom use in the project area increased to 63% in 1997 from a baseline of 7% two years earlier. During 1997 alone, CHES reached some 700 new entrants to sex work, 150 brokers and 2,400 clients with information about safe sex work; peer educators distributed 288,150 free condoms.

CHES conducts community education about HIV through street theatre. Volunteer male dancers dance to tunes from hit films with lyrics about AIDS. The main audience of these street theatre scenes are men, mostly teenagers. At the end of the performance, members of the audience are invited to CHES for further information, including counselling on safer sex and condom use. After training many continue their association with CHES as peer educators. In a very short time the community education program has reached an estimated 40,000 people with HIV information and education.

Family counselling

CHES is also playing a central role in re-uniting families torn apart by the tragedy of HIV, as illustrated by the story below.

After a relative attempted to poison Raghu, his wife Mala and their two children, they fled from their village in a remote part of Tamil Nadu to CHES. Raghu, Mala, and their eldest son, a three-year-old, were HIV-positive. The family settled at the ashram and Raghu was given a job as an office assistant. While they were at CHES, some of their relatives visited regularly and received
After about a year, the relatives asked Raghu and family to return to the village. The relatives’ fear of infection with AIDS through casual contact was clearly reduced by observing Raghu and family living, working and eating with others at CHES.

Home-based care
With support from the Tamil Nadu State AIDS Control Society, CHES has added home-based care to its many activities. The project reaches about 120 people living with HIV, mostly those who are too ill to come to the hospital. Staff and volunteers from CHES provide psycho-social support, medical advice and care in the homes of HIV-positive people. This helps prevent the onset of HIV-related symptoms and reduces the number of inpatient visits. The project runs a ‘Hope Club’, where HIV-positive people meet monthly to exchange experiences and learn about healthy living.

Advocacy
Advocacy on behalf of those most affected by HIV is an essential part of the work of CHES. They have used a number of strategies to promote community acceptance of stigmatised groups. For example, organising a beauty contest for transsexuals drew widespread media attention and promoted community acceptance. It also raised awareness among transsexuals about their vulnerability to HIV and encouraged them to become involved in prevention. CHES helped develop a self-help group for transsexuals, which will be registered as a society to enable them to improve their welfare and fight for their rights. As a positive step in this direction, CHES played a major role obtaining land for members of the self-help group. With financial help from the local Rotary clubs, the group will build houses for the members. There are also plans to help establish income-generating activities such as poultry farming to reduce the likelihood that transsexuals will resort to sex work.

CHES has also undertaken advocacy on behalf of female sex workers to prevent harassment by the police. They also assist women to look for alternatives to sex work when they request it. For example, some of the women take turns using a donated sewing machine that is kept in the CHES office. As one sex worker explained: ‘I can make about 700 to 800 rupees a month by sewing blouses. That way I can cut five or six clients and reduce my HIV risk.’

Networks of care and support
In order to deal with the diverse needs of its extended family, CHES has woven a web of symbiotic relationships with organisations that have skills different from its own. For example, CHES links its drug user clients to a clinic specialising in detoxification programs. In turn, the clinic obtains HIV counselling services from CHES. For HIV testing, CHES obtains HIV testing services from an AIDS service organisation. Destitute HIV-positive women are referred to CHES by The Banyan, an NGO which cares for destitute women; in turn, HIV-positive women who do not need institutional medical care are referred by CHES to The Banyan. For spiritual counselling CHES turns to a variety of Christian, Muslim and Hindu religious organisations.

The central role of HIV-positive people
The inclusion of people living with HIV in every aspect of the work of CHES places them at the centre of the response and helps to promote the fact that, without stigma and discrimination, they can live positively and contribute to the well-being of the community. As one ex-broker who is now a care provider expresses very well: ‘The fact that some of us have HIV and some do not does not preoccupy us. We feel like a family despite such minor differences because each of us understands what it feels like to be rejected, hunted or hurt by society.’

The bonds between prevention and care
The imaginary line between prevention and care is blurred at every level in each of CHES’s projects, whether it be the shelter for people living with HIV, the sex worker and client interventions, or the home-based care project. Each is an organic response to the growing needs of the other. The women’s support group looks after the children in the ashram. Brokers and clients from the community education project provide home-based care, including prevention counselling, for HIV-positive people. And HIV-positive members serve as counsellors in all the projects.

Source: Shreedhar (1998)
Integrating HIV responses into existing activities

As we have described in previous chapters, HIV is a complex problem, with many levels of causation. The epidemic also affects all aspects of life in the community. Long before HIV causes serious health problems for those infected, it can have many other negative consequences. The stigma and shame attached to the disease can isolate those infected and their families. Discrimination can lead to loss of employment and housing. In extreme cases people with HIV infection have been killed by neighbours simply because they are infected. The factors that affect the spread of the virus from one person to another also vary, ranging from individual health factors to cultural, socio-economic and even political issues.

A comprehensive response to a problem with such varied causes and consequences will of necessity have many aspects to it. In fact the very complexity of the HIV epidemic provides an opportunity for a diverse response. Part of the community response may be to try to reach different members of the community with information about the virus and how to protect themselves from infection. Another aspect of the response might be to mobilise the community to care for those who are sick. A response could also involve longer-term strategies for social change.

Most responses to the epidemic have been specially designed projects, some of which are multi-dimensional, although many have a single focus – HIV education. As our understanding of the epidemic has developed and deepened with time, it has become clear that stand-alone projects will never be enough to respond effectively to the problems caused by the virus. The epidemic is expanding rapidly in many communities and there is an urgent need to expand responses to it. One way to do this is to engage the involvement of different sectors of the society.
Integrating HIV prevention, care and support activities into existing programs provides an excellent way to expand the response to the epidemic. An important ingredient in an effective community response is the trust that develops between the community and those implementing the program. This trust is important in engaging the community in honest discussion about risk and vulnerability and developing solutions that work. An existing community-based program may have already established such a trusting relationship with the community. There is another benefit from integrating responses to HIV into existing programs such as adult education or safe motherhood. These programs are likely to be meeting the basic needs of the community; therefore, community members will more likely be more responsive in addressing the issues raised by HIV.

How can we integrate responses to HIV in our everyday work?

We will use several examples to demonstrate how different programs, groups and settings can include a response to HIV in their everyday work.

Primary health care programs

A primary health care or community health program can include responses to HIV in their ongoing work in several ways. Indeed, many are already doing so. With appropriate training, community health educators can:

• provide information about HIV to community members;
• counsel people about effective prevention methods;
• encourage people to go for counselling and testing, if they are worried whether they are infected;
• distribute condoms and show people how to use them;
• urge women and their partners to attend antenatal and postnatal services;
• help community members comply with treatment regimens.

Primary health care services can also be a frontline for diagnosing and treating STIs and TB.

Legal and advocacy services

There are laws in most countries that work against effective HIV prevention. For example, prostitution is illegal in many countries; women (and sometimes men) who sell sexual services are often harassed and arrested by the police. In some places carrying a condom is considered by the police as evidence of a woman’s intention to sell sex. This can discourage sex workers from having condoms readily available. For women who are not sex workers, the fear of being labelled as one also prevents them from buying and carrying condoms. Laws against the use of illicit drugs (e.g., marijuana and heroin) and against homosexuality also work against HIV prevention. In addition, people living with HIV in almost every country have suffered violations of their human rights, such as losing their job or home.

The legal profession can contribute to the HIV response by helping to change some of these laws and by defending the rights of HIV-infected persons in the courts. For example, a group of lawyers in Mumbai (formerly Bombay, India) became involved in HIV work when they represented a young man from Goa who had been jailed when he was discovered to be infected with HIV after donating blood. The Goa Public Health Act allowed anyone considered to be a public health threat to be placed in quarantine. The lawyers challenged this in court. Subsequently the Act was changed so that it was no longer mandatory to detain people with HIV. The work of the Mumbai and New Delhi Lawyers’ Collective is described in more detail in Chapter 14.
Religious institutions and places of worship – churches, mosques, temples

Religious institutions have a big influence on HIV prevention and care activities in many countries. The principal achievements of religious organisations – such as Christian NGOs, churches, parishes and hospitals; Buddhist temples and monasteries; Islamic institutions – have been able to mobilise volunteers to care and support people living with HIV. In many sub-Saharan African communities the health care system has been overwhelmed by the epidemic. Without the resources organised by the church-based organisations there would be no care and support services for HIV-infected people. There are many examples similar to the work of the Ndola Catholic diocese described in Box 6.2 below. Likewise, Buddhist monasteries in Thailand have been instrumental in caring for people infected with HIV particularly in the initial stages of the epidemic when there was little community-based care because of fear and stigma.

Although there is now hope that highly active antiretroviral therapy (HAART) will be increasingly feasible in developing countries, AIDS remains a death sentence for most. In these circumstances infected people have perhaps a particular need for emotional and spiritual support. Religious organisations fill a gap that exists for infected and sick people – that of responding to their spiritual needs and their fears of dying.

Religious organisations have played another more controversial role in the fight against HIV. In many countries they have been an obstacle to some prevention activities, in particular the promotion of condom use. Many religious leaders prescribe abstinence and mutual monogamy as the only HIV prevention messages despite overwhelming evidence that these behaviours are not always the norm. The fear of offending powerful religious constituencies has meant that many HIV prevention programs could inform people about the danger of the virus but not promote the use of condoms, the most practical way to prevent infection from sexual intercourse.

**BOX 6.2: THE NDOLA CATHOLIC DIOCESE – SUPPORTING AND ENABLING COMMUNITIES**

In 1991, nuns of the Catholic religious congregation, the Sisters of the Sacred Hearts, set up a small clinic in the office of the local Catholic Church, to care for the increasing number of people with HIV-related illnesses in two low-income townships on the outskirts of Ndola, Zambia. They soon realised, however, that many chronically ill people were unable to walk to the clinic and would have to be visited at home. This was a laborious, time-consuming job, which could be done only if local people were willing to become involved as volunteer health workers. Christian groups in Zambia have a long tradition of visiting the sick to provide emotional and spiritual support. However, given the negative public attitudes towards people with HIV at the time, it was by no means certain that many volunteers for this kind of work would be willing to come forward.

The sisters approached all the churches in the two townships asking for volunteers to visit the sick in their homes. The response was enthusiastic, and within three months the sisters had trained a total of 45 volunteers from the two townships. The AIDS support program has expanded since those early beginnings. By August 1998, more than 5,500 patients were registered with the program and well over 10,000 patients had received assistance from the program during the previous five years.

Source: Blinkhoff et al (1999)
In the absence of condoms, people do not necessarily abstain from sex or stay faithful to one partner. They may simply continue to have unsafe sex even when they know they run the risk of becoming infected or infecting others.

Strategies such as promotion of condom use and acknowledgement of homosexual relationships present religious institutions with some difficult ethical issues. Nevertheless, these can be resolved sufficiently to allow collaboration and compromise if addressed openly and with mutual respect. There are many examples of successful collaboration between religious institutions and secular organisations. Religious organisations promote HIV prevention based on their moral beliefs – monogamy and abstinence – while other organisations promote condom use. This arrangement only works if religious organisations do not condemn the use of condoms.

**The workplace**

Many companies have begun to invest in HIV programs for their employees. Workplace programs often involve training some staff members as ‘peer educators’ to talk to colleagues about the risk of HIV and to discuss prevention methods, such as condom use and safer sex. Some companies supply condoms directly to their workers, or work with public and private distributors to ensure that condoms are available and affordable. Since untreated STIs increase the risk of spreading and acquiring HIV, some companies have trained educators to talk about signs and symptoms of these diseases. Other companies ensure that STI treatment is available, either at their staff health facilities or from other health facilities.

There are many examples of successful workplace HIV programs. Forty Zimbabwean factories participated in a peer-led AIDS education program which included a condom distribution campaign. Compared with factories that were not part of the program, the action led to a 34% reduction in the number of new HIV infections among the employees. Another program in a large sugar estate in Tanzania demonstrated that treatment of STIs reduced the risk of HIV infection by 40%.

In addition to funding HIV prevention programs, some employers are now providing treatment, including HAART, to their employees, especially in southern Africa where HIV infection rates are the highest in the world. In 2000, the country’s biggest employer, the Debswana diamond mining company, realised after testing its 6,000-strong workforce that fully a third of workers aged between 24 and 40 were HIV-positive. With revenues of some $1.8B dollars a year, and skilled miners scarce, the company set up its own HIV/AIDS scheme. ‘We realised we had to do something

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**Box 6.3: Ten reasons to focus more on the role of churches in the fight against HIV in Africa**

In 2002, Strategies of Hope launched their newest publication, *Journeys of Faith*. At the launch Dr Lucy Steinitz from Catholic AIDS Action made the following points related to the role of the church in the fight against HIV in Africa:

- Churches reach further than any other institution in Africa. For example, Namibia is 95% Christian, mostly affiliated with mainstream churches, and prevention and outreach programs in just four denominations make it possible to reach 70% of the population.
- Churches fill a critical partnership role with the government, a role both groups recognise. For example, in Uganda both government and churches now preach the ABC (Abstinence, Be faithful, Condoms) approach to prevention. This combined approach has led to a delay in the average age of onset of sexual activity by young Ugandans, a phenomenon which has influenced the decline in rates of HIV infection in Uganda.
- In contrast with several church-based organisations, many national governments have been slow in providing leadership or new initiatives to fight against HIV. Churches have a level of flexibility that governments do not have.
- Faith-based churches fill a critical gap in the civil society of those countries where there are very few secular NGOs.
- Spirituality is very important to African people. The church is a good entry point for serious issues.
- Churches are already providing much of the HIV-related leadership, education and outreach in African countries.
- Church structures can sustain long-term community outreach, education and support. Churches are unlikely to go ‘out of business’ and therefore have the potential to support long-term change.
- Churches maintain moral authority and espouse values of compassion, care and youth outreach. People listen to church leaders.
- Churches possess a large reservoir of volunteers, local leadership and youth activists.
- Many African countries have ecumenical relations across church denominations, including several national inter-church AIDS initiatives.

Source: Lucy et al (2002)
fast because diamonds are the foundation of our economy,’ said Ms Tsetsele Fantan, director of the company’s program. She said Debswana agreed to provide free treatment for each infected employee and one legal spouse, while the government would provide treatment for other partners and their children.8

**Community organisations**

Community organisations such as women’s and youth groups and sports clubs provide opportunities for responding to HIV. Occasions that bring the group together can be used to provide specifically targeted HIV information. Additionally, the organisations can be mobilised as an important resource for prevention, care and support activities. In Chapter 14 we describe the work of KIWAKKUKI, a women’s group in Tanzania, in responding to the HIV epidemic in their community.

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**BOX 6.4: AN EFFECTIVE WORKPLACE RESPONSE – THE BOTSWANA MEAT COMMISSION**

In 1991, the Botswana Meat Commission began an HIV prevention and care program for its 1,500 employees. The program included:

- ongoing HIV education for all workers;
- provision of condoms from dispensers in toilets, changing rooms, showers and the workplace clinic;
- STI treatment for workers and their partners at the workplace clinic;
- HIV counselling for employees and families.

Applicants and workers undergo physical examinations but are not tested for HIV. Employees with HIV are given the same medical and other benefits as other employees with a disability. And, when fitness is impaired by HIV-related illness, HIV-positive workers are given less strenuous jobs until they are no longer able to work.

Source: UNAIDS (1998)9

**BOX 6.5: SOME STARTING POINTS FOR HIV EDUCATION, SUPPORT AND CARE PROGRAMS**

- Primary health care centres and programs, including antenatal and postnatal care clinics
- Maternal and child health programs, family planning services
- STI clinics
- Blood transfusion services
- Organisations of traditional healers
- Drug and addiction services
- Community development projects, such as micro-credit schemes
- Adult literacy classes
- Workplace, trade union and corporate education programs
- Sex industry groups
- Pastoral care teams – temples, religious organisations
- Women’s organisations
- Sporting events, teams and organisations
- Cultural events
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# Chapter 7

**Preventing HIV transmission**

by Tamara Kwarteng

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Introduction

Prevention works

The experience of Australia and some Western European countries demonstrated that it was possible to minimise the spread of HIV. In Box 7.1, we show that prevention has also been working in recent years in the low-income countries of Uganda, Zambia, Senegal, Thailand, Cambodia and Brazil. These successful national responses share some common characteristics:

- political leadership and openness about the threat of the epidemic;
- broad awareness of HIV and AIDS among the general population;
- open discussion of sex and a national commitment to sex education for young people;
- active involvement of multiple sectors of society (including civil society, religious leaders, and NGOs) in the response to AIDS;
- concerted effort to reduce stigma, and policy and legal changes to prevent HIV-related discrimination;
- availability of external assistance to finance, develop and implement effective prevention programs.

BOX 7.1: PREVENTION WORKS! – REAL-WORLD PROOF OF SUCCESS

The success of countries and individual programs in promoting safer behaviours and reducing HIV infections have been documented by UNAIDS and others.

Brazil has combined targeted prevention efforts, general awareness campaigns, universal access to antiretrovirals (ARVs) and other HIV treatments, and supportive policies to enhance the effectiveness of prevention and care initiatives. In addition to marked reductions in HIV-related illness and death, Brazil has seen significant declines in risk behaviour, reductions in new infections, and increased demand for VCT. National surveys indicate that condom use among IDUs increased from 42% to 65% from 1999 to 2000.

Cambodia embarked in the 1990s on a comprehensive national prevention program. As a result, between 1997 and 2000, HIV prevalence among pregnant women declined by almost one-third, and Cambodian males reported an increase in condom use; this trend was particularly striking among police and the military.

Senegal avoided the fate of many of its neighbours by implementing a multi-sectoral prevention effort as its epidemic was beginning to emerge. Although neighbouring countries now have HIV prevalences in excess of 5%, Senegal has managed to keep its level of infection under 2%. A key element to Senegal’s success has been the active involvement of civil society.

Thailand has perhaps the best-studied epidemic in a developing country. After experiencing escalating infection rates in the 1980s, Thailand initiated a comprehensive prevention program that included its 100% condom program targeting brothels, broad-based awareness efforts, the active involvement of multiple sectors of society, and strong human rights protections. The number of new infections has fallen from 140,000 new HIV infections in 1991 to only 20,000 in 2002.

Uganda, with strong and vocal support from the president, implemented a multi-component HIV prevention program that includes broad public awareness efforts, extensive condom promotion, and access to free voluntary counselling and testing. NGOs and organisations of people living with HIV/AIDS have played an especially visible role in Uganda’s national HIV prevention effort. Thanks to such multi-sectoral efforts to prevent transmission, HIV prevalence among pregnant women in urban areas in Uganda declined by nearly two-thirds between the beginning and end of the 1990s, and national HIV prevalence was cut nearly in half.

Zambia has in recent years initiated a multi-disciplinary national AIDS program in an effort to reduce the number of new infections. The program is showing some signs of success. HIV prevalence among pregnant urban women (ages 15 to 19) fell by nearly 50% between 1993 and 1998. HIV prevalence among pregnant women has also been steadily falling in Kigali (Rwanda) and Addis Ababa (Ethiopia).

Industrialised countries have recorded important successes in containing their own HIV/AIDS epidemics. By aggressively responding with prevention programs targeting men who have sex with men and injecting drug users, Australia contained a potentially serious HIV epidemic at a low level.

Individual projects have shown success within countries. Workers in Zimbabwean factories where peer education programs were implemented had a 34% lower rate of new infections than individuals employed in factories that had no peer interventions. In Cote d’Ivoire, peer education, combined with voluntary counselling and testing, has helped reduce prevalence among sex workers in Abidjan from 89% in 1992 to 32% in 1998.
Successful national responses and individual projects have taught us that to reduce vulnerability to HIV, individuals and communities need three things:

• the basic facts to understand the urgency of the epidemic;
• access to appropriate services;
• an environment supportive to changing unsafe behaviours or maintaining safe behaviours.

To prevent the spread of HIV there needs to be changes in sexual behaviour and in the behaviour of people who inject drugs. We discuss preventing the spread of HIV among those who inject drugs in Chapter 12. This chapter focuses on changes in sexual behaviour.

To reduce sexual transmission we need to explore and discuss knowledge, attitudes, and practices related to sex, and the influences on these. These discussions need to occur at national policy level and in communities. The epidemic of stigma, fear and discrimination that seems to accompany the spread of HIV also needs to be recognised and acknowledged.

Behaviour change communication (BCC) plays a vital role in this process and can set the tone for a compassionate and responsible response. BCC strategies can support a comprehensive prevention program and create a cohesive environment for behaviour change.

In the first part of this chapter we describe the various steps to develop and implement a communication strategy for individual behaviour change. Individual behaviour change is influenced by social and cultural contexts. In this chapter we present an approach for engaging the community in the process.

Behaviour change communications need to be complemented by supportive health and social services. Information campaigns have often been launched without considering the subsequent specific needs for local services. Behaviour change campaigns for HIV prevention will be ineffective without the appropriate health and social services necessary to translate information into behaviour change.

Supportive services include voluntary counselling and testing (VCT), condom distribution, and effective management of STIs. We describe how these services might be provided at community level to support behaviour change.

**Behaviour change: the basis of HIV prevention and care**

**Introduction**

Behaviour change is central to most effective responses to the HIV epidemic. Behaviour change is not a simple event that occurs in an individual’s life, at his or her sole discretion. We need to think of behaviour change as a process that takes time and often involves repeated attempts. When people try to change their behaviour they often pass through several stages.

• **Pre-contemplation:** the stage when a person has not begun to think about change or the need for change;
• **Contemplation:** when the person starts to think about changing his or her behaviour in response to some stimulus;
• **Preparation:** when the person prepares for change. This stage requires collecting information about the change, how to achieve it, and learning skills necessary to undertake the change;
- **Action**: when the person eventually changes his or her behaviour;
- **Maintenance**: once a new behaviour has been adopted, the person needs to practise to maintain the new behaviour. When the new behaviour becomes familiar and is practised without active thinking, then we can say that the behaviour has been maintained.
It is helpful for counsellors to be aware that people may pass through these stages more than once – but they never return to the pre-contemplation stage. At each stage in the process, people need information, emotional support and skills. Mass media and other channels can be used to get basic information to the target population. A person changes his or her behaviour in response to personal history and experience. Family and friends have a strong influence on individual behaviour, as do communities, religions and national governments.

It is easier for an individual to adopt a new behaviour if it does not conflict with the values of his or her community. However, we must keep in mind that the official view on sexual behaviour does not always reflect what most people believe (and practise). This ‘double standard’ often inhibits the open discussion of sexual issues. For behaviour change efforts to succeed, the necessary supportive services and commodities need to be accessible and acceptable.

Individual behaviour change

Behaviour change communication (BCC)

A comprehensive HIV program will include prevention, care and support services, community mobilisation and political support. Behaviour change communication can link these various parts together and contribute to the way in which individuals and communities deal with the underlying issues. It is important to see BCC as part of a broader program. Communication in an HIV program can be used for:

• **Community dialogue**: Stimulate community discussion on the underlying factors that contribute to the HIV epidemic.

• **Advocacy**: Ensure that policy makers and key opinion leaders take the epidemic seriously.

• **Providing information**: Make sure that people receive the basic facts in a language they can understand and using media they can relate to.

• **Reducing stigma**: All communication on HIV must incorporate a component dealing with the issue of stigma and attempt to influence the social response.

• **Promoting services**: All STI/HIV programs are developing services for prevention, care and support. Communication plays a vital role in promoting these services, which include STI diagnosis and treatment, VCT, support groups, networks of HIV-infected persons, orphans and vulnerable children, parent-to-child transmission prevention, clinical care for opportunistic infections, and social and economic support.

Guiding principles for behaviour change communication

Focussing

Interventions should focus on specific, well-characterised audiences. For example, sex workers might be an example of a specific audience. But when developing a BCC program for sex workers, the group may need to be further segmented and delineated through additional audience research, which may reveal discrete groups of sex workers who vary in their media habits, lifestyles, attitudes toward sex, or other variables. For example, among sex workers in Lhasa, the capital of the Tibetan Autonomous Region of China, there are significant differences between ethnic Tibetans and women from other parts of China. Strategies need to take these differences into account and employ relevant, meaningful, and effective approaches and/or messages for each segment of the target audience.

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1 This section on developing a behaviour change communication strategy is based on Franklin and Larivee, ‘Behaviour change communication to reduce risk and vulnerability in resource-constrained settings’.1
Skill development

Individuals must be provided with skills and devices/tools to prevent HIV. It is not enough to just communicate HIV risk reduction. BCC programs must ensure that skills are taught and support services are available so that individuals can act on the messages they see and hear. Activities might include condom use demonstrations at brothels; condom distribution to truckers; partner negotiation workshops at STI clinics; sexuality education for young soldiers; and/or treatment compliance aids for STI patients.

Support

A supportive environment needs to be created for HIV prevention activities. Individual behaviours occur within a social and cultural context; this context needs to be considered in any BCC activity. A supportive environment is also more likely to foster program sustainability. An example is attitudinal changes among key policy makers and opinion leaders. In Laos, the leaders of the national youth union were initially reluctant to promote sexual behaviour change among young people. However, after conducting a situation assessment in a number of districts they realised that many young people were engaging in unsafe sexual behaviour. They then led a process of developing a national youth strategy to prevent HIV and have made this an organisational priority.

Maintenance

BCC programs should include mechanisms that encourage the maintenance of preventive behaviours over time. Examples of appropriate activities include periodic follow-up and re-certification of peer educators; campaigns that include messages focused on maintenance; and annual meetings for organisations working in HIV prevention.

Monitoring and evaluation

BCC monitoring and evaluation indicators must be used to assess program implementation integrity and effectiveness. Although indicators will vary, it is crucial that they are in place and are relevant to the specific intervention. In addition to process indicators (such as number of training/education sessions held or materials produced/distributed) indicators of effectiveness must be developed. Examples include:

- an increase in grassroots participation in BCC campaign activities;
- more discussion of HIV/AIDS policy issues in legislative bodies;
- greater media openness about sexual issues;
- self-reported changes in ability to discuss safer sex options with partner(s);
- more business policies developed that protect HIV-positive workers from discrimination.

Steps in developing a behaviour change communication strategy

A practical approach for developing a behaviour change communication strategy involves the following steps.

Step 1: Identify problems and needs

A BCC strategy should relate directly to the overall goals of the HIV program and form part of an integrated response to the problems identified. The situation assessment conducted to develop the program (see Chapters 3 and 4) would point to the issues and problems that should be addressed by the BCC strategy. For example, the situation assessments of young people in Laos found that young people were starting to have sex at a young age, condom use was low, condoms were not available in most rural villages, and numbers of young women were negotiating sex for money in bars and restaurants.
Step 2: Identify and segment focus population

The problem statement will give an overall sense of the focus (or vulnerable) populations for the BCC strategy. Using the above example of problems defined in Laos, the main (primary) vulnerable population is young adults. Those who influence the primary population are the secondary audiences or gatekeepers. In this example, they include parents, youth leaders, village chiefs, religious leaders, politicians, and teachers. Within the primary population, there may be young people at high risk of infection, such as sex workers, people who take drugs, young soldiers and police, and men who have sex with men. When there are several focus populations, it is necessary to select the most important ones based on risk behaviours, political importance, and other factors. It is not possible to pay equal attention to all focus populations at the same time.

It is important not to identify vulnerable groups for BCC based on pre-conceived notions of sexual behaviour derived from other countries. For example, in many industrialised countries ‘gay men’ were a primary focus of BCC. However, in many developed countries men who have sex with men do not identify as ‘gay’ or homosexual and do not aggregate in particular locations or venues. Therefore, an alternative strategy is needed to access men who engage in this behaviour.

Step 3: Gather data about the focus population (Formative research)

Use existing knowledge, attitude, belief and practice (KABP) studies and behavioural surveillance surveys (BSS), as well as small qualitative studies to collect some information about the vulnerable group, as well as the broader community. The kind of information needed for the BCC strategy includes:

- perceptions of risk and risk behaviours;
- settings of risk behaviour;
- attitudes to preventive measures (eg condoms);
- key opinion leaders in issues related to sex and sexuality;
- structures and systems used by the focus population;
- hopes and fears for the future (this information will provide a hook for getting people’s attention);
- types of media they use;
- types of entertainment they enjoy;
- health-seeking behaviour (eg where do young people go to seek treatment of STIs?).

At this stage it is important to identify all key stakeholders who will be involved in making decisions about the BCC strategy.

Step 4: Identify behaviour change objectives

It is important to clarify the behaviour change objectives of the overall HIV program in order to make sure that the BCC strategy supports them. Basic behaviour change objectives may include:

- safer sexual practices – eg condom use, reduction in partners, postponement of first sexual experience;
- healthcare-seeking behaviour for STIs and tuberculosis (TB);
- promotion of VCT;
- blood safety – better practices, donor recruitment;
- drug compliance – for ARVs, TB medication;
- attendance at antenatal clinics;
- harm reduction for people who inject drugs, eg needle–syringe exchange, drug substitution;
- elimination of stigma;
- health worker attitudes and practices.
The formative research will identify specific behaviour change objectives for the focus population. Although behaviour change is the final outcome, it is helpful to identify smaller changes that can occur along the way. For example, if consistent use of condoms by the focus population (e.g., young men) is the desired outcome, the following smaller changes can be targeted and included in the design of messages:

- **knowledge** about risk and prevention methods and/or correcting specific misinformation – for example, rumours recently became widespread in some communities that circumcision acts as a ‘natural condom’ and prevents one from HIV infection. This is clearly not true and needs to be corrected through BCC;
- **attitudes** – for example, increasing perceived risk of HIV infection or changing the image of condoms;
- **behaviour changes that are precursors** to the ultimate change objective – for example, getting young men to remind each other to carry condoms when they go out drinking after a game of football.

It is important to be aware of and encourage incremental behaviour changes (the small steps) that mark the path to major behaviour change like consistent condom use.

**Step 5: Consult stakeholders**

It is important that all key stakeholders are involved in the development of a BCC strategy from the beginning. After information on the focus population has been collected and behaviour change objectives identified, hold a meeting with stakeholders to discuss the research findings and reach an agreement on the overall communication objectives.

**Step 6: Decide on the communication design**

The communication design describes the right approach to reach and get the attention of the focus population. The aim is to stimulate a demand for information, services and skills development, not just provide facts. The communication design will specify the overall concept, theme, key messages, and channels of communication for the effective dissemination of messages.

*Concept/Theme*

The concept or theme describes the general approach that the communication will use to attract attention and influence people such as fear, humour, or emotion. The concept or theme should fit in with the overall goal of the HIV program. We have learned about approaches to avoid. Because of the fatal nature of AIDS, it is tempting to try to frighten people into changing their behaviour. It is now commonly understood that messages which are too frightening are not effective. Fear may cause people to notice only part of the message or make people believe that the message does not apply to them. People may laugh off or deny a frightening message. Fear of AIDS together with ignorance can encourage misunderstandings about who is at risk and why. Fear may be one cause of the stigma attached to AIDS patients. Media campaigns which use positive messages have been shown to reduce stigma and discrimination against people with AIDS. Campaigns blaming one group are not effective either. Humour can reduce the tension that may arise when people discuss serious and sensitive topics.
Messages

A message is the carefully crafted information that you want the target population to receive. It is based on sound local information and designed to respond to the communication objective. The best communications are developed with the group who are to use them. Their participation encourages discussion, problem-solving, and innovative action.

Risk reduction messages must include a range of prevention choices. They must take into account the various circumstances of the people they are aimed at. For example, options for reducing the risk of sexual transmission of HIV include:

- celibacy;
- mutual monogamy with an uninfected partner;
- condom use (male and/or female);
- reducing the number of sexual partners;
- eliminating specific sexual practices such as ‘dry sex’ or anal intercourse.

Some groups believe that mutually monogamous heterosexual intercourse within marriage is the only acceptable form of sexual expression. These groups often criticise prevention messages that include other choices. Unless prevention messages recognise the realities of life for the particular focus population, they will have no effect. For example, a sex worker who is dependent on income from clients is unlikely to take advice to reduce their number of sexual partners. However, the option to use condoms to reduce risk of infection is likely to be more acceptable. In other words, if risk behaviour cannot be eliminated, it may be modified to decrease the chances of infection. Risk reduction is part of the wider principle of harm reduction (see Chapter 12).

Keep in mind that an audience may take a message literally. For example, in Thailand, the 100% condom campaign led to very high rates of condom use among men having sex in brothels. However, studies in the late 1990s showed that condom use was still low among men having sex with their girlfriends, casual partners, or other men. Therefore, the message may have to be modified as the norms of sexual behaviour change.

Pre-testing

Always pre-test communication concepts, messages and materials with a sample of the target audience to ensure that the message you want to send out is being received and having the desired effect on the target population. It is important to pre-test several alternative versions to compare their effect on the audience and to find out if people:

- agree with the information;
- find it easy to understand;
- personally identify with the message;
- find the materials attractive;
- find it offensive.

There should also be pre-testing with key stakeholders to ensure there is no objection.

BOX 7.2: THE ‘GRIM REAPER’ – CAMPAIGNING ON FEAR

The first national AIDS mass media campaign in Australia featured the Grim Reaper, a traditional symbol of death. The film showed a skeleton wearing a long black robe and hood, knocking down people with a scythe (an instrument with a large curved blade). No one – baby, child, man or woman – was spared from the assault. The message of the campaign was that the HIV epidemic was spreading remorselessly; that we are all potentially at risk of infection, and prevention is the only cure.

The campaign was very successful in making people sit up and pay attention to AIDS. It created intense public debate about sexuality. There were explicit newspaper and magazine articles about the risks of anal and vaginal intercourse, attitudes to condoms, and bisexual husbands. These were some of the good results from the campaign.

However, the ‘Grim Reaper’ campaign had some negative results. It created fear and great anxiety in many people about their past behaviour. After the campaign started, there was a tremendous increase in the number of requests for HIV antibody tests from people who were considered to be at low risk of infection.

Many AIDS educators were critical of the campaign because they believed that it undermined their efforts to change people’s behaviour. AIDS educators had worked hard to promote the belief that everyone has the power to stop the transmission of HIV infection by adopting particular forms of behaviour. They argued that the underlying message in the ‘Grim Reaper’ film was that no one had the power to resist and death was inescapable.

In summary, the ‘Grim Reaper’ campaign used fear of death to create personal awareness of AIDS. The strategy worked to get AIDS on the national agenda and encourage debate on issues related to the epidemic. However, the strategy also created great anxiety in people and made people feel powerless to prevent infection.

Communication channels – getting the message heard

Effective information and education for HIV prevention depend not only on developing clear and appropriate messages but also on making sure that the messages are heard. How you deliver the messages depends on the audience you want to reach (see Box 7.3). Some ways that selected audiences can be reached include mass media, print media, folk media, video, film and slide shows, peer education, and special events.

Different media have relative advantages and disadvantages and are best used at different times during a campaign to achieve different communication objectives.

Mass media

Mass media channels of communication include radio, television, newspapers, and magazines. Mass media can potentially reach more people than any other method of communication. For example, if you hand out brochures on prevention at a clinic, you can reach every person who comes into the clinic. But, if you take that same information and put it into a radio, television or newspaper announcement, you can reach thousands of people who may never come to a clinic. Mass media methods can create awareness of HIV infection and increase knowledge in a very short time. The accuracy and completeness of the information can be assured and media can give the facts authority. Mass media campaigns can create the environment for more focussed messages. At later stages of adopting a new behaviour, the audience is less interested in media authority than in the opinions of those close to them. Mass media campaigns can also place AIDS on the national agenda and promote public involvement and debate, especially if popular role models, such as sports stars, are involved.

If mass media is being used, it is important to know which radio and TV programs and stations reach the focus population. It may not be cost-effective to use the national radio station if that population is youth who only listen to FM music stations.

Print media

Print media include:
- publications for reading such as pamphlets, brochures, leaflets and cartoons;
- materials for display, such as posters, calendars, and wall charts;
- materials for use with individuals or groups, such as flip charts, and picture cards.

Cartoons can introduce humour into a frightening and embarrassing subject. This can defuse panic and anxiety and help people to get the problem into perspective. Strip cartoons or stories are particularly popular with young people who cannot read well. Strip cartoons can show folk heroes acting powerfully against HIV, or tell stories of ordinary people who are finding ways to cope with the problem.

Like mass media communication channels, leaflets are useful for raising public awareness; however, unlike those channels which rely on the spoken word, printed materials are not useful when the audience is illiterate.

BOX 7.3: ESSENTIAL ELEMENTS OF HIV PREVENTION MESSAGES
- Messages are most effective when they are directed towards a specific population group.
- The content of the message is more effective when it is clear and exact.
- Suggestions for behaviour change should reflect the ‘real life’ situations of the populations to which they are directed.
- The group to which the message is directed should personally identify with the message.
- Messages should be pre-tested with the audience for whom they are intended before they are produced for distribution.
Printed materials are a popular communication method because:
- they can reach many people;
- they remind the reader of essential information and can be shown to others at home;
- the written word has authority.

**Folk media**

Folk media include story telling, role play, drama, puppetry, songs, dance, and mime. There are several advantages to using the folk as a medium of communication for prevention of HIV infection:
- In most societies in the world, people find it easier to understand and relate to the spoken word than to print materials. Using the spoken word becomes even more relevant when the audience is illiterate, as is the case in many sub-Saharan and Asian countries.
- Experience with campaigns suggests that people need more than a list of facts and directions to take action. The facts need to be placed in a context which involves people in a personal way, which enables them to experience, at least secondhand, the reality of AIDS in their lives. Folk media can achieve this reality and involvement in a way that is rarely possible through print materials.
- Folk media enable people to discover privately what information is relevant to their lives without feeling accused or threatened.
- It is much easier to be explicit about sensitive subjects such as sexuality and human anatomy through puppetry or actors.
- Folk media have been used for educational purposes for generations in most societies in the world. The necessary skills are available in the community and people understand and relate to familiar media.

Street theatre is a popular form of communication used in many settings (see Box 7.5). In rural areas with no television, they can serve as a major form of entertainment in the community. It is important to provide an opportunity for discussion with the audience after the performance. For example, since 1992 Wan Smolbag Theatre, meaning ‘One Small Bag’ in Bislama (the language of Vanuatu), has been producing plays and even videos on the risks and prevention of HIV. In 2003, they traveled to Papua New Guinea to help train local drama troupes to put on HIV-themed street theatre in the local Pidgin English.

Religious sermons may be an appropriate and effective means of communication on HIV prevention and stigma reduction. Imams in Indonesia have been broadcasting on this topic from mosques and minarets for many years. In Thailand, the Sangha Metta Project was initiated by monks themselves in response to the need for Buddhist monks to have a more active role in HIV prevention and care. Taking the Buddha’s teachings as their inspiration, monks concluded that a core aspect of the response to HIV and AIDS was ignorance about the condition among both the sufferers and the general public. Local religious leaders should be consulted about their potential role in delivering BCC.
BOX 7.5: STREET THEATRE PROVOKES ATTENTION TO HIV MESSAGES

Bienvenida gets out of a white car at the far corner of the intersection and slinks across the street in her leopard print mini-skirt and four-inch heels. As she approaches, a group of men sitting on their motorcycles offer her shy smiles of greeting.

The conversation begins slowly. The men, all middle aged, speak with Bienvenida about the weather, the people passing on the street and the increasing price of gasoline for their motorcycles. Ten minutes pass before she begins her negotiations. ‘Do you like what you see?’ she asks. All the men agree they do.

As they argue over who will leave with Bienvenida, another woman yells across the street to her, ‘Bienvenidaaaa, is that you?’ Ingrid shouts. ‘Bienvenida, what are you doing on the street tonight?’

‘Go away,’ Bienvenida says, ‘I’m doing business. Stay away from us.’

The men stare curiously at the persistent Ingrid, who joins the happy group.

‘You shouldn’t be out tonight,’ Ingrid argues. ‘I saw you at the clinic last night. You have gonorrhoea! You shouldn’t be working.’

The group of men now stand silent. They stare at Bienvenida, waiting for an answer.

‘I got treated last night!’ she says. ‘What I have won’t hurt these men. You’re strong, healthy men, aren’t you?’ She cozies up to one of them. ‘We can have fun tonight, you and I.’

Ingrid frowns and asks, ‘Did you at least bring your condoms?’

‘CONDOMS!’ says one of the curious group of men. ‘I never use condoms. They ruin all the fun. I’m healthy and I only choose healthy-looking women.’

‘See,’ says Bienvenida, ‘I don’t need to worry here. Now go away. We don’t want you here. We are having fun on our own.’ A grunt from the group of men around her signals their agreement.

‘But it doesn’t matter how someone looks,’ counters Ingrid. ‘Anyone could have an STI, or even worse, AIDS! Condoms are the only way to protect yourself during sex. Anyway, Bienvenida, you aren’t cured of your gonorrhoea yet. You should be home taking all your medicine and not out on the street tonight.’

‘Leave us alone!’ one of the men says to Ingrid. As she turns to cross the street, flinging a last warning over her shoulder, a man named Joselin comes barrelling past her.

‘YOU!!!!’ he says, pointing a finger at Bienvenida. ‘YOU’RE THE ONE! YOU gave me an STI! YOU gave me this horrible disease. I gave it to my wife, and now she’s not speaking with me! It’s YOUR FAULT!’

Joselin grabs a surprised Bienvenida and begins to shake her. When one of the men jumps to her defence, he turns and says, ‘Don’t have sex with her. She is unclean. I didn’t use a condom and she gave me this uncomfortable disease. My wife will never speak to me again!’

‘Don’t have sex without a condom,’ Joselin says as he walks away. ‘The same thing can happen to you.’

‘You better leave now,’ one of the men tells Bienvenida. ‘There is no business for you here until you have taken care of your STI.’

Ingrid pulls an embarrassed and confused Bienvenida across the street and around the corner with her. There Bienvenida, Ingrid and Joselin hug each other to celebrate another successful ‘provocative theatre’ intervention on the streets of Santa Domingo.

After several minutes of debriefing, the trio return to the stunned but good-natured group of men and explain that they are actors from an organisation that works to prevent HIV/AIDS and STIs. The men ask the actors many questions. Before leaving, the performers distribute condoms and comic books and other educational materials.

Source: Family Health International
Peer education

Peer education or peer facilitation can be described as the process of recruiting and training ‘peers’ (ordinary members of a focus population) to undertake, on a voluntary basis, educational and other activities among their fellows. It is the cornerstone of all interventions with vulnerable populations. Peer educators, or peer facilitators/leaders, can play an important role in reaching specific groups by modelling safe behaviours, stimulating community discussion and providing referrals to appropriate services.

Peer education occurs in a variety of settings and includes many different activities such as:

- factory workers giving HIV prevention talks in the cafeteria during lunch hour;
- women from a women’s group making house-to-house calls to distribute leaflets and talk with housewives;
- out-of-school youth organising video and information shows for other young people;
- military personnel counselling new recruits;
- students meeting in dormitories to demonstrate correct condom use;
- sex workers discussing STI treatment;
- politicians, bureaucrats and community leaders talking together – eg about supportive government responses to the epidemic.

In all cases, non-professional teachers – peer educators – are talking to, working with and motivating peers.

Peer education can take place on a street corner, at a social or sporting club, in a bar, on school grounds, in a home, in a church, at a bus station, in a factory, or any place where people feel comfortable.

Regardless of where they take place and who is targeted, all peer education programs have certain elements in common:

- They use trained people to assist others in their peer group to make decisions about STI and HIV prevention through activities undertaken in a one-to-one or small group setting.
- Motivation for peer education works best if rewards can be maintained. Sometimes the rewards of the work are enough; in some circumstances, rewards such as food, free condom supplies, free access to health services, or small allowances are given.

Benefits

Peer educators may have several roles, such as disseminating information, distributing condoms, or supervising ‘directly observed short course therapy’ for tuberculosis patients (DOTS). They may be able to incorporate their HIV awareness messages into their daily work and activities. They may also play the role of facilitators in community group discussions. Peer educators may be given resources to develop their own ideas. They may be able to reach large numbers of people through extensive informal networks.

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Being a peer educator can increase confidence and self-esteem, encourage a sense of ownership of the program, and provide useful skills to refugee volunteers. Peer educators can also play a useful role in advocacy work, since they become aware through their work of the needs of their peers.

Support
Although a peer education strategy is relatively inexpensive it does need to be adequately resourced if it is to be effective. A system for coordination, supervision and support needs to be established. Peer educators need to be well trained in one-to-one health education and counselling so that they feel equipped to provide support if needed. They need to be able to refer people with problems or illness. For example, if women peer educators raise the awareness of other women about the need to get treatment for STIs, they need to have somewhere to refer them when they do complain of symptoms. It is important not to exploit volunteer peer educators or treat them as though they were paid workers. Peer educators can keep logbooks to keep a record of their contacts with community members.

Constraints
Community members who are outgoing or have useful skills are often recruited for many roles and become overburdened. Peer educators often face difficulties which lead to frustration and high turnover:
- lack of time of community members who are struggling to survive;
- lack of space to meet;
- lack of interest of many who feel that AIDS is not a big problem for them;
- lack of community structures through which to work;
- mobility;
- diversity of cultures and language;
- lack of literacy.

Peer educators often gain status from their role, but in some settings adolescent girls trained as peer educators have been stigmatised by their families and communities. Knowledge about sex and reproduction is often hidden from girls until they marry. Some may believe that these young girls have acquired their knowledge through experience rather than through training and so they may be rejected. It is important that these peer educators remain associated with and supported by the program team. The subject matter of training should be broad so that public perception is not that peer educators have been trained only in sex. For example training in child health could usefully be included in the ‘curriculum’ for young peer educators. Youth peer educators might be linked with adult peer educators for support.

Encouragement
Encouragement for peer educators might take the form of T-shirts, practical help, for example with sewing classes, schoolwork or small cash allowances. Motivation can be maintained by putting peer educators into contact with other peer educators – perhaps through an electronic mailing list. The opportunity to attend a conference and meet other peer educators can provide great encouragement and enable them to see the significance of their role in a wider context.
Creating an enabling environment

Factors that influence the social environment

Most behaviour change is affected by factors within the social environment. Some factors are barriers to behaviour change. Enabling factors positively influence behaviour change. The factors that contribute to an ‘enabling environment’ or are barriers to change may be social, cultural, legal, political and religious/spiritual. They include the following:

Social factors

Male same-sex behaviour provides a good example of how social and cultural attitudes can be a barrier to behaviour change. In societies where male homosexuality is taboo, men who have sex with men are more likely to marry, but continue to have sex with men in secret. It is likely that the men may not see themselves as homosexual. In some cultures, it is not uncommon for some heterosexual men to have sex with other men before they get married on occasions when they do not have the opportunity to have sex with women. Since these men do not identify as ‘gay’ they will not frequent openly gay venues and miss out on any BCC that is aimed at gay men. These groups of men (and their wives) will be vulnerable to HIV because they are unlikely to be reached by safer sex programs developed for men who have sex with men.

Religious factors

Religious beliefs, in particular Islam and Christianity, greatly influence behaviour. In some cultures, religious prohibitions affect what can be discussed. If sex outside marriage is viewed as a sin, then it becomes difficult to discuss the issue, even though everyone may know that it is a common practice. Women may feel that they cannot even discuss their husband’s infidelity, or strategies to reduce the risk that results, even with other women.

Legal factors

Laws that prohibit certain behaviours or seek to control them with punitive measures can work against behaviour change. For example in places where sex work is illegal, sex workers may be arrested or harassed for carrying condoms, making it difficult for them to practice safer sex with clients. On the other hand, where sex work is legal but regulated, sex workers have found it easier to hold HIV education sessions, talk to one another openly, and support each other’s efforts to change the unsafe sexual behaviour of clients.

Stigma and negative attitudes

It is important to reduce stigma about being HIV-positive for a variety of highly practical reasons. In places where stigma is strong, asking a partner to practice safe sex may be seen as an admission that one is HIV-positive, or having doubts about the partner’s infection status. In such a situation, many people will choose not to use a condom, even if worried about their own or their partner’s health.

Strategies for creating an enabling environment

Community action is a key element in creating or modifying an enabling environment. All communities have some existing capacity to address problems. The strategies for creating or modifying an enabling environment aim to assist communities to develop their problem-solving capacity further. They build on:

- previous experience, skills and knowledge within the community;
- the ability to develop new understandings of old concerns;
- the ability to develop the capacity to address new concerns, by learning for others who already understand those concerns.
Structured community discussions

Structured community discussions provide opportunities for men and women to better understand each other’s perspectives and problems, and have been found to be effective in altering HIV risk behaviours.

In 1995 the British NGO, ActionAID, produced the Stepping Stones training package which helps communities to develop communication and relationship skills. This is part of a series of publications called Strategies for Hope, now published by Teaching AIDS at Low Cost. The package was designed for use in sub-Saharan Africa, but it has also been successfully adapted for use in Asia, North and Latin America and Europe. It includes a manual for trainers, and an accompanying workshop video. The package aims to enable individuals, their peers and their communities to change their behaviour – individually and together – through the ‘stepping stones’ which the various sessions provide. Evaluations suggest that one of the most useful features of the Stepping Stones process is that the participants are divided into four small groups of 10–20, by age and gender: older men, older women, younger women, and younger men. All the groups are brought together for occasional sessions.

The aim of Stepping Stones is to enable women and men to describe and analyse their relationships and other experiences and to develop solutions to the sexual health problems and risks that they face in the course of their daily lives. The materials enable people to explore issues that affect sexual health including gender roles, money, alcohol use, traditional practices, and attitudes to sex and death. The process can be used in existing HIV projects and in general development projects which plan to introduce an ongoing HIV component.

Stepping Stones is based on the following important principles:

- The best behaviour change strategies are those developed by the community members themselves.
- Peer groups need their own private time and space to identify and explore their own needs and concerns.
- The process of self-analysis leads to greater self-awareness and self-respect, and this enables people to practise more assertive behaviour.
- The expression of our own needs leads to awareness of the needs of others, respect for others, better communication and care.
- Behaviour change will be more effective and sustained when the whole community is involved.

The sessions use a participatory approach of adult learning through shared discussions. The exercises are all based on people’s own experiences. Role-play, drawing, and songs enable everyone to take part. Literacy is not needed. Participants discuss their experiences, act them out, analyse them, consider alternative outcomes, and then rehearse these together in a safe, supportive group. This approach may also be helpful in challenging cultural practices that increase risk of spread of HIV such as ‘widow cleansing’ when a dead man’s brother has sex with his widow.

In some communities workshop sessions have been organised on a weekly basis, so four or five months are needed to complete the course. In other communities sessions have been held every afternoon five or six days a week, so that the course is completed in only three weeks. It is important to bear in mind that in the safe environment created in the peer group sessions people may say more than they usually would. When these things are shared with the other groups the person may feel ashamed or embarrassed. Sometimes a woman may say something in a community meeting that gets her into trouble when she is alone with her husband. It is important that facilitators are well trained. In several different countries the Stepping Stones process has resulted in greater openness and reduced stigma and fear.
Engaging religious leaders
The example from Senegal in Box 7.6 shows clearly how behaviour change programs for religious leaders resulted in their support for HIV interventions.

Overcoming stigma and discrimination with involvement by people infected with HIV
The visibility and openness of people living with HIV is essential for reducing stigma. With appropriate support, people infected with HIV can play a central role in overcoming stigma and discrimination. Strategies for participation are described in Chapter 9.

BOX 7.6: CREATING AN ENABLING ENVIRONMENT IN SENEGAL – MUSLIM AND CHRISTIAN LEADERS PREACH TOLERANCE AND SOLIDARITY

Religious leaders have an enormously important role in Senegalese national life. Their support for HIV prevention activities was vital if the activities were to succeed. And it was clear that religious leaders wanted to be involved in this important area. An Islamic organisation, Jamra, approached the national AIDS program to discuss HIV prevention strategies. Although initially rather hostile to condom promotion and some other aspects of AIDS prevention, the group became an important partner in a dialogue between public health officials and religious leaders.

To understand the needs of the religious constituency, the government supported a survey of Muslim and Christian leaders. The survey found that religious leaders felt they were poorly informed about HIV, and wanted more information to enable them to give clear guidance to their followers. They also specified what they were prepared to support. For example, they were reluctant to support condom use between unmarried youngsters, but were prepared to support it within marriages. In response, educational materials were designed to meet the needs of religious leaders. They focussed in part on testimonials from people living with AIDS – the human face of the epidemic, often hidden where prevalence remains low.

Training sessions about HIV were organised for Imams and teachers of Arabic, and brochures were produced to help them disseminate information. AIDS became a regular topic in Friday sermons in mosques throughout Senegal, and senior religious figures addressed the issue on television and radio. In March 1995, 260 senior Islamic leaders gathered for a conference on AIDS. The result of the conference was clear support for AIDS prevention efforts. The religious leaders declared that HIV was not a divine retribution for immoral behaviour. They supported the rights of people living with AIDS, including the use of condoms to prevent HIV from spreading within marriage if one partner is infected. And they stated that everyone should have access to full and accurate information about HIV and AIDS.

Among Christians, there was substantial resistance to AIDS prevention at first. And yet Christian organisations are important providers of health services in Senegal, and AIDS clearly threatened to become a major health issue if it were not prevented. Led by a Catholic NGO, SIDA Service, the churches gradually developed a more supportive outlook on prevention. They provided important counselling and psycho-social support, and frequently referred those in need to alternative providers where they could not meet needs, for example, for condom provision.

Every bishop in the country attended a conference on AIDS. Again, the result was a consensus that AIDS prevention was an important national activity.

The moral support for HIV prevention given by religious leaders allowed secular and health authorities to work productively in providing education and specific prevention services.
Voluntary counselling and testing (VCT) and psycho-social support

Introduction

The vast majority of people living with HIV in low-income countries do not know they are infected. This weakens efforts to respond effectively in resource-poor settings.

One of the results of a campaign to raise awareness is that people may want to know if they are infected or not. Although there are many benefits to knowing one’s status, testing can have negative consequences in communities where people with HIV are stigmatised. No one should be forced into being tested. The decision to take an test should be entirely voluntary.

Voluntary counselling and testing (VCT) is the process by which an individual undergoes counselling to enable him or her to make an informed decision about being tested for HIV. Voluntary testing, with appropriate pre- and post-test counselling, has become an important part of HIV prevention and care programs. Studies have found that people who test positive tend to reduce behaviours that can transmit the virus.

VCT can help direct HIV-positive people to relevant care and support services, such as treatment for tuberculosis, opportunistic infections and STIs, family planning, treatment with antiretrovirals, and prevention of mother-to-child transmission. The role of VCT in prevention of MTCT is discussed in greater detail in Chapter 10. Knowing and accepting one’s HIV status enables more informed planning for the future, including for one’s dependants. VCT can also help to reduce stigma and secrecy surrounding HIV infection and AIDS.

Barriers to VCT

VCT services are becoming increasingly available in resource-poor settings. However, many people are reluctant to be tested. Problems with coping, stigma, rejection and discrimination, human rights abuses and lack of perceived benefit are barriers to people getting an HIV test.

Problems with coping

A positive test result can come as a great shock and be very difficult for a person to cope with. There is often a big difference between knowing a test result and accepting it. Some people deny the result even when they are near death. People diagnosed with HIV may experience anxiety, depression, fear, stress and suicidal feelings. Counselling can help a person accept the test result and to cope with his or her concerns.

Stigma, rejection and discrimination

People are afraid of HIV in many places. Infected people may be rejected by their family or community. Many experience discrimination and violence. Fear of rejection or stigma is a common reason for declining testing. Education and awareness in the community, as well as linking testing with ongoing care and support services, can reduce stigma and may contribute to wider acceptance of VCT. Women with HIV are particularly vulnerable. Some women have lost their homes and children, or have been beaten and abused when their HIV status becomes known. It is important to consider how to protect and support vulnerable women when developing VCT services.

Lack of perceived benefit

If treatment, care and support services are not available or inadequate, people may not see any benefit in knowing that they are infected. Linking VCT with comprehensive care and support services and improving acceptance of people with HIV infection in the community can reduce this barrier to testing.
Mandatory testing

Many people are tested for HIV without having any choice or find it difficult to refuse to be tested. This process, called mandatory testing, has been applied to:

- sex workers
- military recruits
- injecting drug users
- migrants
- refugees
- visa applicants and international travellers
- students and scholarship recipients
- pregnant women
- patients in health facilities
- people being treated for STIs
- people planning to marry
- job applicants.

Mandatory testing has no advantages over VCT, violates human rights, and has several disadvantages:

- Testing without informed consent or counselling does not help people change their risky behaviours to prevent HIV transmission to others.
- Testing without counselling and follow-up can be devastating for those who test positive. There are many reports of people who had no idea that they were being tested, committing suicide after finding out they were HIV-positive.
- Mandatory testing may lead to a false sense of security. For example, health workers may not follow infection control procedures if all patients are tested for HIV. This is dangerous because patients who test negative may be in the ‘window’ period.
- Mandatory testing in health care settings, such as antenatal clinics, may lead to mistrust by clients and discourage them from seeking health care.
- Insisting on testing new employees or military recruits will not ensure that they are HIV free as they may acquire HIV infection during their employment or military service. It would be better to use the resources to offer care and support to those with HIV and provide comprehensive HIV prevention and education programs for employees.
- The need to provide evidence of a negative test result has led to anecdotal reports of health workers selling negative certificates to untested people.

The counselling process

HIV counselling is a confidential dialogue between a person and a counsellor. Counsellors need to have the skills and personal qualities for the job. Their role is to listen and ask questions and to provide relevant information, practical suggestions, and emotional support.

The voluntary counselling and testing process consists of pre-test, post-test and follow-up counselling. The process of counselling can be adapted to suit the needs of the clients – be they individuals, couples, families and/or children.
Pre-test counselling

Taking a test is a very serious matter for individuals. Not only is the result important for the person but it will also have implications for their partner, their family, their employment, and, in some countries their life insurance. Pre-test counselling is carried out to help a person decide whether or not to be tested for HIV. Pre-test counselling aims to:

- provide information about HIV/AIDS and risk behaviour;
- assess whether a person might have been at risk of HIV infection;
- provide information about the test and how it works;
- explain about the window period (see Chapter 1);
- explore the possible advantages and disadvantages of taking a test;
- discuss the implications of a positive test result for relationships, employment, and future health;
- explain how confidentiality will be maintained;
- assess the person's ability to cope with a positive result, including the emotional and practical support available to them;
- explore the possibility of sharing their test result with their partner, a friend or close relative;
- provide information about services available to people with HIV;
- discuss the implications of a negative test result and prevention of HIV infection;
- give the person enough time to consider whether or not to take a test;
- obtain informed consent, if the person decides to take a test.

In some places, counsellors have found it useful during pre-test counselling to ask a person why they want to take a test and what they expect the result to be. This can help the counsellor see how the person will cope with the result.

The client must be given adequate time to ask questions and digest new information. Where same-day testing is used, clients should be given adequate time to think in the pre-test session.

Some people will defer testing at this stage and return later after discussing the test with their partner, relatives or friends. When a client has a steady partner, he/she may prefer to return with the partner to be tested together. This approach is beneficial because it allows couples to make decisions together about safer sex.

In some countries, group or community counselling has been used to inform people about the HIV test and the implications of being tested. However, group counselling is not appropriate for people to make decisions. Decisions should be made in private and confidential situations, to ensure that there is no pressure put on an individual.

**BOX 7.7: WHO SHOULD BE A COUNSELLOR?**

Counsellors need to be:
- informed about HIV
- good listeners
- warm and caring
- able to explain things clearly
- trustworthy and credible
- non-judgemental
- emotionally stable
- able to keep information confidential
- able to respect the rights and dignity of others
- able to talk and hear about sensitive issues such as sexuality, death, violence, and divorce
- familiar with the client’s socio-cultural environment and circumstances
- aware of and sensitive to gender issues.
Post-test counselling

Whatever the result of the test, each individual must be counselled appropriately after the test. The two main aims of the post-test counselling sessions are to support the person who has been tested and reduce the spread of HIV. Post-test counselling does both by discussing the result, sharing information and encouraging safer sex. The topics of discussions will depend on whether the test result is negative or positive. In some circumstances, post-test counselling sessions only last a short time. However, because of the emotional consequences associated with giving an HIV test result, it may be necessary to allow up to 60 minutes for post-test counselling for some people.

Counselling for a negative result

Although a client will be relieved to receive a negative test result, the counsellor needs to explain that, because of the window period, this may not necessarily mean that the person is not infected with HIV. The counsellor should suggest the person consider returning for a repeat test after three to six months. It is also important to discuss the HIV status of sexual partners. If this is unknown or positive, the counsellor should suggest the person consider returning for a repeat test. The emphasis on counselling is to show empathy and give people some measure of hope of staying well and living a normal life.

Counselling for a positive result

There is no right way to tell a person that they have a positive result. It depends on the individual and the culture – everyone reacts differently. Some may cry; others swear; some remain silent. The emphasis on counselling is to show empathy and give people some measure of hope of staying well and living a normal life. The following suggestions can help counsellors when the result is positive:

- Give results simply, clearly, and gently.
- Allow time for the result to sink in.
- Discuss the meaning of the result with the client.
- Give emotional support and help the client to discuss how they will cope, including identifying what support is available at home.
- Discuss the personal, family and social implications – including whom, if anyone, to tell.
- Refer the client, where possible, to a community support organisation and for follow-up care and counselling.
- Explain how the result will be kept confidential, so that no one else will know, unless the client chooses to tell someone else.
- Discuss who the client may want to tell about the result, risks to sexual partners, and how to tell their partner.

Box 7.8: Post-test counselling and behaviour change

My peer group was a bad influence. At age 15, we engaged in smoking, drinking and sex. My parents were worried and convinced me to attend a seminar on AIDS. I wanted to get tested, but was afraid. I went to AIC (AIDS Information Centre) three times but couldn't find the courage to get beyond the gate. Eventually I got tested and was relieved to find out I was HIV-negative. I was eager to know everything about AIDS and the counsellor helped me to feel free to ask all my questions. I joined the Post Test Club (PTC) and this changed my life. Here I have found many new friends living healthy lifestyles. Most people think PTC is only for those who are HIV-positive, but PTC gives me support to maintain my HIV-negative status. I am busy with the drama group and spend my free time with other members, playing board games and attending educational talks. I will wait now to have sex until I am married. I am trying to set an example for young people in our community, and my brothers and sisters. We are 15 all together. Our community leader often asks me to tell my story at community meetings. Troubled youth seek my counsel. A lot of students in secondary school engage in high-risk behaviour, like I did. I make a special effort to reach out to these young people.

Source: UNAIDS (June 1999)

Box 7.9: Finding out you are HIV-positive – the benefits of post-test counselling

'I was raped. The doctor suggested that I go for an HIV test. So they tested me at the hospital. The result of the test was negative. Then they said I should return in six weeks for another test. The second test was positive. When they told me I sat there silently. I couldn’t talk. I couldn’t do anything. It took some days before I could say, ‘This has really happened to me and I can’t go back.’

I think what really helped me was the counselling. I joined a support group and it gave me strength to cope. Counselling says you must keep it confidential and you mustn’t share it, but I think this is not good because spiritually a person can’t cope.'

Source: Lawson (1997)
• Explain how the client can take care of their health, including advice about diet, exercise, rest, avoiding infections and when to seek advice.
• Tell the person where to get treatment and care.
• Discuss the responsibility to protect others – ask about risk behaviour, and discuss how they might change. Provide information about safer sex and condoms.

It is often very helpful to have a follow-up session after a few days, when the client has had time to reflect on the implications of the test result and can discuss future plans, needs and follow-up.

**Follow-up supportive and problem-solving counselling**

Some people will require ongoing counselling and support after learning their HIV status. People turn to different sources of ongoing support. Women often turn to female relatives and men to male friends and relatives. Church-based and religious groups provide spiritual support. In sub-Saharan Africa, many people seek the help of traditional healers who can work closely with counsellors and health workers in providing ongoing support and care for people with HIV.

The most common concerns expressed by people who test HIV-positive in resource-poor settings are medical. People worry about becoming ill and not having access to medical care. Many have seen friends or relatives suffer painful, undignified deaths, and fear the same would happen to them. Other common concerns include the need for material support, especially for widows who care for orphans and sick dependants.

The aim of follow-up supportive and problem-solving counselling is to help people reach decisions to enable them to cope with their problems.

**Confidentiality**

Confidentiality and anonymity are among the most problematic issues in HIV testing. An individual’s test result should always be private. In practice, especially in a small town or village where everyone knows everyone, this may be impossible to guarantee. However, without the promise of confidentiality, people who feel that they may be infected will be unwilling to be tested.

The approach adopted by the Chikankata program (Zambia) is to promote the idea of ‘shared confidentiality’. The person is informed of the diagnosis in confidence, but encouraged to share this information with family members or, on rare occasions, a close friend. In this way the psychological burden of coping with the consequences of diagnosis is also shared.

**Partner notification – advantages and dilemmas**

Confidentiality means that the person who conducts the test tells the result only to the person tested. However, sometimes an HIV-positive person chooses not to tell their sexual partner. This poses a difficult ethical question for the person who arranges the test. Whose rights are paramount? Does someone with HIV have the right not to inform a spouse or sexual partner of their HIV status? Does the spouse have the right to know?
The main arguments in favour of partner notification are described by Jackson (1992):
- The partner of someone with HIV may or may not yet be infected. However, over time the risk of infection is very high unless condoms are properly used all the time. The partner has the right to know the information as it may be life saving.
- The partner has the right to know that she or he may already be infected and to seek a test and treatment as needed.

The arguments against partner notification include:
- Patient confidentiality must be upheld, and if this is not guaranteed, some people will be deterred from seeking treatment.
- Giving the partner information in the absence of any other support merely creates anxiety and conflict and may do nothing to reduce sexual risk, particularly for women. The story in Box 7.10 illustrates some of the difficult problems associated with testing women for HIV.

The issues of partner notification and confidentiality related to HIV antibody testing are difficult and will probably remain unresolved for some time. One way of overcoming the partner notification problem is to counsel and test couples together. Couples who are both HIV-positive can support one another in decisions about fertility, care and other issues. When one partner is positive and the other is HIV-negative, they can discuss how to reduce the risk of transmission.

People who come for pre-test counselling could be invited back with their partner, so that the decision about testing is made together. Couple counselling provides a safe place to discuss difficult issues and it can be easier if both partners have an HIV test at the same time.

**The testing process**

Diagnosis has traditionally been made by detecting antibodies to HIV. Over 100 different kinds of HIV tests are currently available worldwide. The most commonly used HIV-antibody testing method is the enzyme-linked immunosorbent assays (ELISA). More recently rapid tests have become available. Some of these tests can be performed in less than 10 minutes. Others require 30 minutes to two hours. Rapid tests can be carried out by staff with no formal laboratory training. This removes one obstacle to expanding VCT services to rural areas and in small sites where laboratory facilities are not available. HIV testing strategies are discussed in more detail in Chapter 1.
The availability of rapid tests means that people can find out their HIV status in a few hours. Experience from the AIDS Information Centre in Uganda shows that the majority of clients prefer same-day service (see Box 7.11). However, the use of simple/rapid tests could also lead to results being given to people who have not had the chance to think through the implications. Some VCT services that use rapid tests advise people to go away and think for a few hours after pre-test counselling, to decide whether they really want to go ahead.

**Setting up a VCT service**

**Assessing the situation**

Voluntary counselling and testing is the main entry point for care and support services. NGOs in many countries are already providing VCT services. With the plans to expand access to ARVs (both for treatment and prevention of mother-to-child transmission) in many countries, there will be an increasing need for more NGOs to provide VCT. It is important that NGOs are well-prepared before they include VCT services in their program. The following questions can help NGOs assess their capacity and readiness to provide VCT.15

**Technical capacity**

- Is there a regular, reliable and sufficient supply of HIV tests?
- Is there an appropriate testing strategy, including confirmatory testing of positive results?
- Are high-quality testing and laboratory procedures in place to ensure accurate results?
- Are quality control systems in place to identify and correct technical and clerical errors?

**Staff capacity**

- Are experienced health staff available who can take blood samples and who are trained to follow universal precautions?
- Can adequate training for counsellors be provided?
- Are enough trained counsellors available to provide pre-test and post-test counselling?
- Is there capacity to provide support to health workers and counsellors?
- Are there laboratory staff trained in how to carry out the tests?

**Capacity for treatment and care**

- Is medical treatment (management of opportunistic infections and HAART) available for people diagnosed with HIV?
- Can people who are diagnosed with HIV be referred for care and support?
- Is there family or community support for people with HIV?

**Administrative capacity**

- Is there adequate space for confidential counselling and testing?
- Does the capacity exist to maintain proper records and systems to ensure confidentiality, and to make sure that people are given the correct results?
- How will the quality of counselling and testing services be monitored?
- Can supplies, transport and storage be ensured?
- Is there a system for safe handling and disposal of contaminated needles and syringes?
**Financial capacity**

- Are there enough funds to set up services, including training and improving laboratory infrastructure?
- Are there enough funds to cover recurrent costs, such as purchase of tests and any additional staff salaries?
- Are there enough resources to run a comprehensive program that includes education, follow-up counselling, care and support?

**Steps involved in setting up a VCT service**

1. **Raise awareness in the community about VCT**

   Awareness in the community about the benefits of an HIV test is essential for VCT services to be accepted and used. The methods described above, in the 'Individual behaviour change' section, for informing and educating the public, such as outreach programs, health talks in clinics, and IEC materials are all appropriate for raising community awareness about VCT. In particular, outreach activities have been shown to strongly influence the utilisation of VCT services. It is important to direct IEC materials and awareness-raising efforts about VCT to specific groups such as young people and couples, and for vulnerable populations such as people who inject drugs and sex workers.

2. **Choose the model and site of VCT service**

   VCT is carried out in various settings, including free-standing sites, hospital services, NGOs within hospitals, health centres, private sectors, workplace clinics, youth and school health services, services for vulnerable groups (sex workers, prison populations, refugees, people who inject drugs, etc) and blood transfusion services. Different models may suit different communities. Factors such as community perception of confidentiality within health care facilities can influence the choice of VCT model. It is important to involve the community in a participatory planning exercise to determine the acceptability and model of the VCT service proposed.

3. **Select and train counsellors and supervisors**

   Training of counsellors should ensure that they:
   - have thorough knowledge of HIV infection and AIDS;
   - are familiar with the logic and content of pre-test and post-test counselling processes;
   - have the skills to break bad news and contain the immediate and mid-term consequences;
   - are able to work with families in crisis;
   - are able to discuss taboo topics such as sex, death and bereavement;
   - are able to identify and manage psychological consequences of risk recognition – anxiety, depression, suicidal thinking, grief etc;
   - have information to link with local community resources in ongoing care and support.

   Courses for counsellors may be intensive sessions or involve regular seminars on a part-time basis. Experience has shown that role-playing, active participation in discussion, feedback and case study examples are essential to assist trainee counsellors in identifying and working through the key issues that arise in counselling management.

4. **Establish system for record keeping and ensuring confidentiality**

   Clients may be seen by different counsellors for pre- and post-test counselling and ongoing emotional and health care. A system must be in place to ensure that health care workers who need access to test results and case notes have it, while ensuring that confidentiality is not breached.
5 Choose a testing strategy and train laboratory staff in HIV testing

Your initial situation assessment will identify any gaps in the skills of laboratory staff. Once you have chosen the testing strategy, ensure that the laboratory staff have the skills to do the tests. As discussed previously, the availability of rapid tests reduces the need for highly skilled laboratory staff.

Quality control should be given a high priority. All sero-positive tests should be confirmed before a definitive result is given. It is important to monitor stock and ensure the quality of testing is of a consistently high standard.

6 Establish a system for procurement and secure storage of test kits

A system for supply of both HIV test kits and reagents and consumables such as syringes, gloves, vacutainer bottles, disposable pipettes should be organised. Regular supply, secure storage, distribution and accounting must be ensured.

7 Set up or establish links with post-test services

VCT clients who test HIV-positive may need medical care and emotional support to cope with their status. Those who test negative may also need access to some form of ongoing support to remain negative. VCT service providers can organise some of the post-test services themselves. They can also serve as a gateway to other service providers, such as health care providers and community organisations involved in HIV and AIDS care and support. Being able to offer support, especially to those who test positive, is an important part of VCT services. One popular strategy is to support the establishment of a Post-Test Club (PTC). Some PTCs are set up mainly for clients who test HIV-positive and are intended to give emotional support. Others welcome people who tested negative to attend so that they may discuss strategies and acquire skills to help them remain negative.

8 Secure adequate and long-term financing

If your VCT service is successful, there will be greater demand from the community. It is therefore important to ensure long-term funding before services are started. Estimates of the cost of VCT in developing countries range from US$8 to US$29 per client. In poorer countries heavily affected by HIV, it is unlikely that VCT will soon become affordable by all people. VCT services provided by NGOs are usually financed through grants or subsidies from national governments or international donors. In lower-prevalence or middle-income countries, such as those in South America and Asia, partial or full-cost recovery may be an option. Social marketing of VCT services has been tried in some countries.

9 Establish monitoring and evaluation

Building in self-assessments, monitoring and regular evaluation is an important tool to enhance the quality of VCT. The quality of VCT counselling determines the outcome. Poor quality counselling can result in misunderstanding and even resistance to change. Strategies which can be used for monitoring and evaluation include:

- Undertake a baseline survey and situation analysis at the beginning.
- Use a ‘service-tracking sheet’ to monitor the use of the service.
- Counsellors collect a variety of client data during pre- and post-test counselling, including personal data, general HIV and AIDS knowledge, medical history, risk behaviours, beliefs related to VCT, and intentions to change behaviours.
- Ask clients to fill in an anonymous exit questionnaire about the service.
Possible indicators for a VCT service are shown in Table 7.1 below.

<table>
<thead>
<tr>
<th>Indicator</th>
<th>Means of measurement</th>
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<tbody>
<tr>
<td>Proportion of people accepting VCT among those invited for VCT</td>
<td>Review of VCT records</td>
</tr>
<tr>
<td>People returning for test results among those tested</td>
<td>Review of VCT records</td>
</tr>
<tr>
<td>People sharing results with partner</td>
<td>Interview VCT clients (by counsellors)</td>
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<tr>
<td>HIV-positive people accessing care and support services</td>
<td>Interview of clients and families</td>
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<td>Quality of counselling provided</td>
<td>Observation of counselling sessions</td>
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<tr>
<td>Satisfaction of clients with service provided</td>
<td>Focus group discussions</td>
</tr>
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<td></td>
<td>Survey of clients</td>
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</tbody>
</table>

**BOX 7.12: KEY ELEMENTS OF VCT**

HIV testing for individuals should only be carried out if the following essential requirements can be met:

- **Pre-test counselling** – given before HIV testing.
- **Post-test counselling** – provided after the test result is known.
- **Informed consent** – given so the person being tested has a clear understanding of what the test involves, the advantages and disadvantages of testing, the implications of a positive or negative result and agrees to be tested.
- **Confidentiality** is assured – ie information about the person is not passed on to anyone else without that person’s permission.

**Condoms**

**Introduction**

The correct and consistent use of condoms during sexual intercourse is very effective for preventing the transmission of HIV, other STIs and pregnancy. Studies with couples where one partner is infected with HIV and the other is not have shown that with regular sexual intercourse over a period of two years partners who consistently used condoms did not become infected with the virus. Even if both partners are already infected with HIV, using condoms prevents exposure to different strains of the virus and to other STIs and therefore benefits the health of the individuals.

Condoms are relatively cheap and generally have no side effects. Nevertheless, objections from religious groups and other society ‘gatekeepers’ make condom promotion one of the most contentious issues in HIV prevention. This is a challenge that NGOs involved in HIV prevention projects have to be prepared to meet. Other prevention activities such as behaviour change communication, improved STI management, and needle-exchange programs can be seriously undermined if good quality condoms are not available at affordable prices to those who need them. Promoting and distributing condoms is essential for preventing sexual transmission of HIV and should be an important strategy for all effective prevention and care programs.
Types of condoms

Male condoms
The male condom is a thin sheath made from latex that is used to cover the erect penis during intercourse. It is cheap, widely available and highly effective if used correctly. Because latex is soft, male condoms have to be used carefully in order not to break or tear them. To ensure safe usage, the following principles are important:

- Men should have the right size of condoms. Condoms that are too small for the size of the penis are more likely to break. On the other hand condoms that are too big may slip off during intercourse.
- Water-based lubricants such as K-Y Jelly or saliva should be used, because oil-based lubricants such as Vaseline, body lotions or cooking oil will damage the latex of the condom and cause it to break.
- Condoms must be stored properly. Condoms stored in a hot place may tear during use.
- Condoms that have expired should not be used because they are more likely to tear.

Female condoms
The female condom is a soft, strong sheath made of clear polyurethane plastic, with a flexible plastic ring at each end. The plastic ring at the closed end is used to help insert and keep the condom in place against the cervix. The ring at the open end is slightly larger and remains outside the vagina, covering both the woman’s external genital area and the base of the man’s penis.

Because of the polyurethane used to make it, the female condom is both strong and durable. It is less likely to break or leak than the latex which most male condoms are made of, and causes few allergic reactions. Sex with the female condom feels more natural than with a male condom because the polyurethane transmits heat. However, some people complain about excessive noise during intercourse. Special storage arrangements are not needed because polyurethane is not affected by changes in temperature and dampness. It can be used with oil-based and water-based lubricants.

Using the female condom will require the agreement of both partners in most cases, but it does give a woman more control. Since it can be inserted several hours before intercourse, it can provide protection in situations where consumption of alcohol or drugs may reduce the chances that a male condom will be used.

Several studies have been conducted in different parts of the world to assess the acceptability and effectiveness of the female condom. In Vietnam, an acceptability study carried out in Hanoi during 2000 found that 320 of the 428 women who tried the female condom said they would continue to use it provided it was free or affordable. Sex workers showed the strongest preference for the product, with 84% saying they would want to keep using it.

The biggest barrier to the widespread use of the female condom at the moment is the price. The market price in low-income countries in 2003 was between US$2 and $3. This is much too high for the populations who are most likely to benefit from it. To make the female condom more affordable, UNAIDS has negotiated with the manufacturer, the Female Health Company, to sell the condoms to public sector agencies in low-income countries for 58 US cents. However, even this lower price is not within the reach of those who need to use them. It is hoped that as the demand for the female condom increases, the price will be reduced further.

It is possible to reuse the female condom, although the manufacturer does not recommend that at present. WHO does not recommend or promote the reuse of female condoms.
Obstacles to effective and widespread use of condoms

Although they have been shown to be effective in preventing HIV and STI infection, there are many obstacles to the widespread use of condoms. It is important to understand the obstacles in your community so that you can develop strategies to overcome them. Some of the common obstacles are described below.

Social and cultural beliefs and attitudes

Some societies associate condoms with infidelity and immoral behaviour and have religious or cultural rules that restrict or stigmatise condom use. A common argument put forward for disapproval of condom use is that sexual intercourse is only expected to take place within marriage. Since married couples would want to have children, it is not necessary or indeed desirable for them to use condoms. Unmarried couples should not be having sex and therefore do not need condoms.

In cultures where ejaculation of semen into the vagina is considered to be a vital part of the sexual act, using condoms is not regarded as ‘manly’.

Lack of awareness about HIV and STIs and effectiveness of condoms

People, particularly youth, may not be aware about the seriousness of HIV and STIs and the effectiveness of condom use in preventing the sexual transmission of these diseases and avoiding pregnancy. Other people may not believe that condoms can prevent HIV/STIs and pregnancy.

Personal reluctance to use condoms

Regardless of the culture, many people simply do not like condoms because they spoil the enjoyment of sex. People may be reluctant to use condoms because they believe they reduce pleasure or are uncomfortable. If someone does not know how to put on a condom or has had an unsatisfactory experience (such as a condom breaking), he or she may be reluctant to use condoms in the future. Some women also fear that the condom will get lost inside them.
Difficulties in obtaining condoms
People may be discouraged or prevented from buying condoms, even when they are willing to use them, because they may be too expensive or not available from a convenient place. Young people are often too embarrassed or shy to ask for condoms especially in small towns and villages. Vending machines have the advantage of allowing people to purchase a condom anonymously.

Lack of control over condom use
Women (and sometimes men) often do not have the power or negotiation skills to insist that their sexual partner use a condom. Sex between men in certain situations may be opportunistic, or reflect power relationships, such as in prisons, which inhibit the use of condoms by the ‘active’ partner.

Desire to have children
Consistent condom use prevents pregnancy, which is a problem for couples who wish to have children. In some cultures, pre-marital sex is the norm until a young woman becomes pregnant – a signal that the couple must marry. Using condoms may interfere with such traditions.

Implications about lack of trust in a partner’s fidelity
Sometimes, people consider condoms to be relevant only for casual or commercial sex situations. When a relationship becomes regular or formal (as in marriage), and involves strong emotional bonds, asking a partner to use a condom suggests a lack of trust about the partner’s fidelity. Wives may know that their husbands have sex outside marriage but cannot suggest condoms for fear of abuse or rejection. Men may use condoms when they are away from home (e.g., migrant workers), but not when they return. If their wife has had sex in their absence, they risk being infected.

Poor quality or design of condoms
Inadequate manufacturing standards, improper storage conditions and poor handling by users can lead to breakage, leakage or slippage of condoms during use. The importance of good quality condoms to the effectiveness of HIV prevention programs is illustrated by this true story in Box 7.13.

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**BOX 7.13: EXCERPT FROM PROCEEDINGS OF A WORKSHOP FOR PEER EDUCATORS OF A PREVENTION PROJECT FOR FEMALE SEX WORKERS**

... About three minutes into the introduction, an older woman sitting in the front of the group suddenly interrupts and begins to speak. Then she stops and reaches into her blouse, taking out a folded handkerchief. She places it on the floor in front of her and carefully unfolds it. Everyone is silently watching. Inside the handkerchief is a folded newspaper, which she proceeds to unwrap. Lying in the centre of the newspaper is a small cellophane bag which she opens. She reaches inside and pulls out a used condom. She holds it for everyone to see. The condom is tied in a knot at the top and has brown fluid inside it. ... Suddenly it dawns on us that the brown fluid is blood. The semen has blood in it. As she holds the condom she explains that the condoms they are given by the project are no good. They break. She says, ‘This is what happened yesterday after I left here (the workshop). What happens if this gets inside of us? What good is this project if this is what happens? Unless we get good quality condoms, this project isn’t worth anything...’
Strategies for promoting and distributing condoms

To increase the use of condoms in a community, we need to overcome the obstacles outlined above with a range of strategies that include information and education to change behaviour and attitudes, training in sexual health and human sexuality, teaching negotiation and condom use skills. Strategies are also needed to make condoms available to people when they need them and to overcome social, political and religious barriers in the community.

Overcoming social, political and religious objections

Like other HIV prevention programs, condom promotion is much more successful when the social, political, and religious leaders are not against it. In the past many religious denominations, in particular the Catholic Church, have been reluctant to support the use of condoms to prevent the transmission of HIV and other STIs. These negative attitudes towards condoms from religious organisations are changing. An article in the Vatican’s official newspaper in April 2000 said that condoms might be permissible for containing the spread of the AIDS virus. The article does not endorse condoms, but tolerates their use as part of a comprehensive HIV education program where the primary emphasis is on moral behaviour. In Uganda, a dialogue between the Islamic Medical Association and Muslim religious authorities resulted in a statement that education and the responsible use of condoms was both acceptable within Islamic teachings and necessary to defend communities against HIV.

In general, it is a good idea to present condoms as one of several options to prevent HIV and STIs, including delayed start of sexual intercourse, reduction of number of sexual partners, abstinence, and mutual fidelity. It is possible to reach agreement with different groups in the community to promote the prevention options that fit with their own values without speaking out against the other options. The Zaire condom social marketing program occurred under such conditions. The government provided supportive leadership as well as free television broadcasting time. In addition, religious leaders agreed not to speak out against condom use.

If members of the community are worried that the availability of condoms may increase promiscuity, you can point out that several studies have shown that this is not the case. Consulting widely and involving the members of the community in planning a condom promotion and distribution program is vital for gaining support. Groups which may be opposed to condom promotion need to be identified and engaged in open dialogue on HIV prevention early in the planning phase.

Promoting condoms to increase demand

Well-planned education campaigns can make condoms more acceptable to the community and thus increase the demand for them. Information and education campaigns should aim to persuade people that condoms work, that they are easy to use and that it is acceptable and normal to use them. Messages that using condoms demonstrates care and responsibility and provides peace of mind should also be promoted. It is vital to make people aware of the importance of using condoms consistently.

All the methods previously described for increasing awareness and knowledge about HIV infection – television, radio, counselling, peer education, performing arts etc – can also be used to raise awareness of the availability and benefits of condoms.

A method which has been used successfully in many countries to create demand for and increase the use of condoms is ‘social marketing’. Social marketing is the application of private sector marketing techniques to the sale of products such as condoms which fulfil a social objective. The demand for condoms is increased through vigorous advertising and public promotion. The condoms are carefully packaged and
A name that is easily recognised is chosen by market research. They are sold at low, affordable prices through every available retail outlet and through dispensaries, pharmacies and health centres. A very successful condom social marketing program in Zaire is described in Box 7.14. Social marketing of condoms was so successful in Thailand that the government was able to reduce its budget for condom distribution through the public health system by 60% in 1997, just five years after the 100% condom campaign was launched.

Another strategy for increasing demand for condoms is ‘narrow casting’. With this approach, information about condoms is directed to specific population groups through highly selective use of radio and strategic placement of posters and stickers. For example, stickers and posters could be placed in brothels, STI clinics, family planning clinics, hotels, saunas, taxis, etc. The narrow casting approach is particularly useful in places where there may be religious or political opposition to promoting condom use through the mass media. The strategy allows the promotion of condom use for people with high-risk behaviours or in places where risky sexual or drug injecting behaviours may occur.

**Teaching skills in condom use**

It is important that people, particularly men, feel confident that they can successfully put on a condom before they have to do so. Teaching people how to use condoms properly also reduces the chance that they will break or slip off when used.

It is important to teach people **not** to open a condom packet with their teeth or sharp objects because of the risk of damage. It is also important to stress that only water-based lubricants should be used with male (latex) condoms.

When teaching people, encourage them to feel the condom. If they have a concern that condoms reduce sensitivity and therefore pleasure they can be reassured by feeling the thinness of the rubber. They can blow up the condom like a balloon or put about 300 ml of water into it to show that the rubber is strong.

All condom packages should include instructions about how to use them. Nevertheless, it is helpful if people (men as well as women and girls) can practise several times. Wooden penis models or bananas are often used to show how to put on a condom. These demonstrations can be done in one-on-one sessions or in group education sessions. Community HIV educators from a Mozambique NGO, OMES, conduct condom demonstrations after every group education session in market places or bars, before distributing condoms to those present. The demand for condoms after these demonstrations is always very high.

Finally, the skills training should include teaching couples how to introduce condoms to their partners without causing conflict.

**Procuring and distributing condoms**

It is essential to ensure that the condoms you provide are of good quality. People’s trust in condoms to protect them from HIV and STIs will be jeopardised if they use poor quality condoms that break.
In any condom promotion program, understanding the circumstances and preferences of a specific population is vital. Consider all the different groups in the community who may need condoms and how best to reach them. Such understanding will help you to decide whether your program will distribute condoms free of charge to sell them to consumers.

Condoms should be freely distributed to community members who cannot afford to buy them. People may be discouraged from using condoms by even a small charge. For example, in 1995 female sex workers working at the port of Makassar in Indonesia charged 500 Rupiah (approximately US$ 0.25) per session. Cheap condoms cost about 200 Rupiah. Women in this situation are unlikely to be persuaded to spend 40% of their income on condoms. Under some circumstances, there are no alternatives to free distribution of condoms.

Free condom distribution, combined with information and skills building, has proved effective in HIV prevention campaigns, especially among groups whose behaviour may put them at increased risk of infection. Condoms can be distributed free of charge in a variety of settings including health centres, workplaces, youth centres, schools and colleges.

In Thailand, for example, free distribution contributed to making condom use the norm in commercial sex. Between 1994 and 1996, the Thai Government procured 150 million condoms and distributed them free through STI clinics and other health centres.

It has been argued that selling condoms, rather than giving them away, has three benefits:

- The value of condoms is raised in the consumer’s mind. Several studies have shown that as long as the price of condoms is affordable, they will be bought even when they can be obtained free. Information from the Zaire social marketing program indicated that people were more likely to use condoms if they bought them than if they had obtained them free of charge. Similarly, some clients of sex workers in Songkhla (Thailand) preferred to buy their own condoms rather than use those provided free of charge by brothels.
- Local merchants are more likely to stock and sell condoms because of profit incentives, thus increasing distribution.
- The profit from sales can be used to make the condom distribution self-sustaining — in theory.

Social marketing programs have been used to make condoms widely available at cheap prices. Socially marketed condoms are found in both traditional retail outlets such as pharmacies and drugstores and non-traditional points such as bars, coffee shops, brothels, beauty parlours, workplaces, petrol stations, and bus and truck terminals. One advantage of having distribution outlets in hotels and bars is that they are likely to stay open longer than the average pharmacy or health centre. It is especially important to have outlets in places where sexual transactions might be negotiated.

Social marketing of condoms can also be done through community-based distribution where non-professional sales agents are recruited from among groups in the general population such as self-help cooperatives, women’s associations and itinerant salesmen who travel to remote areas (see Box 7.15). The individuals receive basic training in IEC and sales and are usually rewarded financially from small margins on their sales. This approach is increasingly chosen as a means of reaching geographical areas and socio-cultural groups that are difficult to access.

**BOX 7.15: KEY ELEMENTS OF CONDOM PROMOTION AND DISTRIBUTION**

- Strategies to overcome social, political and religious objections to the promotion and use of condoms in the community
- Information and education program to change behaviour and attitudes to condoms
- Effective promotion to make condoms acceptable as well as fashionable
- Teaching skills in condom use and negotiating skills
- Reducing prices and improving distribution through social marketing
- Good quality condoms
TABLE 7.2: POSSIBLE INDICATORS FOR CONDOM PROMOTION AND DISTRIBUTION

<table>
<thead>
<tr>
<th>Indicator</th>
<th>Means of measurement</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of outlets distributing condoms</td>
<td>Observation, review of documents</td>
</tr>
<tr>
<td>Knowledge of correct condom use</td>
<td>Survey</td>
</tr>
<tr>
<td>Number of condoms distributed per month per capita</td>
<td>Distribution records</td>
</tr>
<tr>
<td>Increase in use of condoms with last sexual intercourse (with regular partner/with non-regular partner), among specified groups</td>
<td>Survey among specified groups</td>
</tr>
<tr>
<td>Change in attitudes towards condoms</td>
<td>Focus group discussions</td>
</tr>
</tbody>
</table>

Management and control of sexually transmitted infections

Introduction

The World Health Organization estimates that over 300 million people are infected each year with the five main curable sexually transmitted infections (gonorrhoea, chlamydia, syphilis, chancroid and trichomoniasis). The majority of those infected are in low-income countries. It is much easier for a person with one of these infections to infect or be infected by HIV when they have unprotected sex. This is because the STI creates additional entry points for the virus or helps the virus to make more copies of itself.

Apart from increasing the risk of HIV infection, STIs cause a great deal of harm when left untreated. Their effect on women is particularly severe. It has been estimated that in urban populations of sub-Saharan Africa, STIs are responsible for about 17% of ill-health (burden of disease) suffered by women of child-bearing age. Infection with gonorrhoea or chlamydia usually causes a discharge in men, but often shows no symptoms in women. Since women are not aware they are infected they do not seek treatment and the infection can spread through their womb to the fallopian tubes and ovaries to cause pelvic inflammatory disease (PID). This can make the woman infertile. In sub-Saharan Africa, half of the cases of infertility are caused by STIs.

The link between STIs and HIV infection has focussed renewed attention on control of STIs in low-income countries. The diagnosis and treatment of STIs is inadequate in many parts of the world. Many individuals with symptoms of STIs – especially young people – seek care outside formal health services. This may be due to shyness about revealing their condition, lack of availability of formal health services, unwelcoming attitudes of staff, or inability to pay for the treatment. In many countries in Asia and sub-Saharan Africa, it is common to buy antibiotics from private pharmacies and unlicensed drug vendors. It is quite common for people with STIs to take insufficient amounts of drugs to cure their infection. This practice is contributing to the development of antibiotic resistance.

A study of health-seeking behaviour for STIs was conducted in Bali, Indonesia. People were able to nominate more than one source of treatment. The study showed that approximately 50% seek treatment from private doctors, 50% ‘self treat’ from pharmacists or street vendors, and less than 10% use the formal government health care system.

Control of STIs is now recognised as one of the most effective interventions available to reduce HIV transmission. A study of community-based management of STIs in the Mwanza region of Tanzania showed that the number of new HIV infections was cut by 42%. However, another intervention, based on mass treatment of STIs with antibiotics in Rakai, Uganda, did not reduce the number of new HIV infections. This suggests that
efforts to treat and control STIs are more likely to reduce HIV infections if they form part of broader comprehensive HIV prevention program.30

**Strategies for preventing and controlling STIs**

The aim of STI control programs is to reduce the rate of new infections using a combination of strategies that fall into two broad categories. One group of strategies aims to prevent people from becoming infected with STIs in the first place. They include encouragement of safer sex practices such as abstinence, monogamy, non-penetrative sex and the consistent use of condoms. The second group of strategies aims to successfully treat people who are infected. It includes efforts to encourage people to seek treatment, to diagnose and cure STIs early.

People with STIs seek treatment from a wide variety of services and individuals, both medically qualified and otherwise. They include:
- formal public health care services such as STI clinics, hospital outpatient clinics, primary health care centres, maternal and child health centres, family planning clinics;
- informal or private sector service providers such as private doctors, nurses and midwives, pharmacies and drug stores, traditional healers and street drug vendors.

Often people with STIs will attend formal health services only after alternative treatments have failed.33,34 The quality of STI diagnosis and treatment provided through these diverse services varies enormously. Nevertheless, it is important that effective services be available in a range of settings so that different members of the community can use them. For example, providing STI services through maternal and child health clinics will enable women to have asymptomatic STIs diagnosed and treated without fear of stigmatisation. However, men might be more comfortable going to a private doctor or pharmacist. Young people may be too shy to attend a primary health care centre and would prefer to see a doctor or nurse at the youth centre, for example. Sex workers may prefer to use night clinics located near sex work venues.

Strategies for preventing and controlling STIs in the community should also aim to improve access to information and appropriate treatment for people who use the informal sector. It is essential to have initiatives to enlist the support of private doctors, pharmacists, street drug vendors and traditional healers for sexual health promotion and appropriate management of STIs.

Comprehensive management of STIs should include:
- accurate diagnosis;
- effective treatment of STIs with drugs;
- education on:
  - the nature of the infection
  - the way it is transmitted
  - taking the medicines prescribed
  - reducing risk of future infection
  - proper use of condoms
  - the need for all sexual partners to be treated
- providing condoms and instructions on use;
- providing information about treatment of sexual partner(s);
- follow-up examination (if convenient to the patient and service provider) to assess the outcome of the treatment.

**BOX 7.16: PHARMACISTS’ ROLE IN MANAGING STIs IN GHANA**

In Ghana, private sector pharmacists are acknowledged by the government to be the preferred option for people seeking treatment for STIs. They have longer opening hours and are perceived by the public to provide a confidential service. Customers would usually describe their symptoms to the pharmacists who sell them presumably the correct dose of the appropriate drug. There are no restrictions on the sale of antibiotics without prescriptions.

An operational research project was conducted in the Greater Accra Region to improve the STI management services provided by pharmacists. Private pharmacists were trained to diagnose STIs according to the symptoms presented and provide appropriate treatment. The pharmacists also provided individual counselling and health education to clients in private space on the premises.

Evaluation of the project showed that the pharmacists were effective in the management of STIs, particularly in the management of urethral discharge. Referral of customers with genital ulcers to laboratories and medical practitioners was recommended.

Accurate diagnosis and effective treatment

Traditionally, the diagnosis of STIs relies on laboratory tests. Simple microscopy can be used to identify gonorrhoea (using a gram stain) and trichomonas. More sophisticated laboratory facilities can detect syphilis through blood tests and gonorrhoea and chlamydia by the culture of swabs from the genital area. New DNA tests enable STIs to be diagnosed from urine or tampon specimens.

Due to the scarcity of laboratory facilities in many low-income settings, WHO has developed a ‘syndromic’ approach to diagnosis and management of STIs which does not require laboratory tests. The syndromic system classifies the pathogens responsible for the main STIs according to the cluster of syndromes they produce. Health staff then use a flow chart to guide them in the antibiotic treatment of the syndrome they have identified. For example, for the syndrome ‘vaginal discharge’, they treat gonorrhoea, trichomonas and chlamydia.

Syndromic management of STIs is simple and can be implemented at the primary health care level. It avoids unnecessary return for laboratory results and treatment can be given at the first visit. However, it is not useful for the management of asymptomatic patients who are mostly women. Syndromic management may lead to over-treatment in some patients (i.e., patients taking medicines for STIs they do not have) – especially in cases of vaginal discharge – because the diagnosis is not specific enough.

Despite these shortcomings, syndromic management currently offers the best means of delivering STI care in settings where laboratory services are lacking or too expensive. Effective syndromic management requires a well-functioning primary health care system, well-trained and supervised staff and a regular supply of effective drugs (see Box 7.17).

Some people in the community may not be able to afford the drugs they need to treat their STIs. They may either not buy the medicines at all or may be tempted to buy only part of the dose they actually need. Social marketing can be used to provide STI drugs cheaply, in a similar way to its use for condom promotion and distribution. Social marketing of pre-packaged STI treatment kits has been introduced successfully into Uganda by the Futures Group. The kit contains the antibiotics ciprofloxacin and doxycycline, condoms, partner referral cards, and patient information.
Educating and counselling the patient

Treating someone for an STI provides an excellent opportunity to educate them about the nature of the infection, its consequences, and how to prevent future infections. If the patient is not educated he or she is at a higher risk of becoming re-infected and/or spreading the infection to his/her partners.

Counselling relates more to issues of anxiety and coping with the infection and its social consequences. Counselling can help patients decide about how to inform a partner or spouse about the STI diagnosis. It can also help the patient learn about and come to terms with complications such as infertility or chronic infections such as HIV, genital herpes and warts.

In a busy clinic there is often little time for a doctor to provide comprehensive health education. This may best be done by a trained health educator, nurse or counsellor, in a separate room during one-on-one discussions. A busy STI clinic in a large hospital in India established links with local NGOs to counsel STI patients. The hospital provided a room for counselling, and trained volunteers from the NGOs in counselling techniques. This arrangement was beneficial for the hospital, whose health staff did not have the time to provide adequate education. It also benefited the NGOs, whose volunteers acquired much-needed skills that they could use in their own work. Most importantly, it was beneficial for the clients.

It is important to reinforce key education messages by giving patients an information leaflet, which should be designed in a way and translated into languages that are easy to understand and relevant to them.

Condom promotion and supply

STI consultation provides an opportunity to promote and supply condoms, as patients should be open to understanding their usefulness in preventing future exposure to infection. The health care worker should explain how a condom works, how it should be used, and use a penis model to show how to put it on.

The clinic should supply some free condoms and indicate where more can be acquired either at the clinic or at various distribution points in the community.

Contact tracing and partner notification

Contacting or notifying sexual partners of STI patients, persuading them to go for treatment, and treating them promptly and effectively, is an essential part of comprehensive STI management. Notifying the partners helps to:

• protect those that are not yet infected and prevent those that are infected from spreading the infection;
• avoid the re-infection of first patient;
• reduce the level of asymptomatic infection in the community.

Contact tracing is always difficult and needs to be handled carefully. It is important to pay attention to the social and cultural circumstances in the community in order to avoid undesirable outcomes, especially for women who may be rejected or physically harmed. Because women often have no symptoms when they have an STI, it is particularly important to try to contact and treat the female partners of male STI patients.

Health workers need to be properly trained to undertake partner notification in a sensitive and confidential way.

Partner notification should be guided by the following principles:

• no coercion – treatment of patients should not be delayed until partners are brought forward;
• confidentiality;
• accessibility of partners;
• no bad consequences for the index case and/or their partners (e.g., danger of domestic violence).

The methods that can be used to contact and notify partners are:

• **Patient referral or passive partner notification:** The health care worker asks the patient to tell his/her partner(s) to come for examination and treatment. They do not ask for information about the partners. The patient may be given contact cards or referral slips to give to their sexual partner(s). In some places, the health worker gives the patient medicines to give to their partner.

• **Health care worker referral or active partner notification:** The health care worker obtains the names and contact details of sexual partners and tries to contact them by visiting, mail, or by telephone.

• **Patient and health care worker referral or contractual notification:** Health care worker and patient agree on the strategy beforehand; the patient will look for the sexual partners and if failing to have referred anyone after a certain period of time, the health care worker will actively look for the partners.

**Clinical follow-up**

It may be difficult for patients in some settings to return for follow-up; however, they should be encouraged to do so, especially if symptoms persist. If the STI is not cured, the health care worker can find out why this is so. The patient can be given the original treatment again if the treatment failure was because they did not take their medication as prescribed. A second line of drugs can be prescribed if the first medication was taken properly but failed to work. The patient may also be referred to the next level of care.

**Case reporting and surveillance**

The data from the STI service provider can provide valuable information for the health care workers themselves as well as for district health management. Case reporting and surveillance can be organized in the following ways:

• Through the routine health information system (HIS), which tracks the main consultation diagnoses. The HIS form can be redesigned to capture the syndrome diagnosis categories. Summarized reports, consisting of weekly or monthly tally sheets, will provide the number and distribution of STI syndromes treated by age group and sex.

• Selected sentinel sites may be asked to keep a separate patient register book for STIs. Only absolutely essential data should be collected, such as patient name or identification number, sex, age, residence, syndromic diagnosis and treatment given and whether condoms were provided. A separate column should be used to enter such follow-up date as date of return, clinical observation, and partners treated. These registers can form the basis of discussions with the supervisor during patients’ regular visits. Some simple data can be extracted from them and analysed by the health worker. Such monitoring indicators can become targets and act as a motivating factor.³¹

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**BOX 7.19: KEY ELEMENTS OF STI CARE**

- The setting of STI care must be accessible and acceptable to the target population — this includes staff attitudes, the location, and opening hours of the service
- Accurate diagnosis (syndromic and/or laboratory) and effective, affordable treatment
- Integration of STI care into primary health care, including MCH and family planning
- Information, education and group and individual counselling for disease prevention and treatment compliance
- Ensuring the patient’s contact(s) are evaluated and treated
- Preventing infection by promoting the use of condoms
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Additional resources


Chapter 8
Care, treatment and support

by Tamara Kwarteng

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Introduction

In many parts of the world where the HIV epidemic has been spreading for a decade or more, substantial numbers of people have been infected long enough to be falling sick and dying. This is particularly true of southern and eastern African countries such as Botswana, South Africa, Zimbabwe, Mozambique, Swaziland, Zambia, Malawi, Tanzania, Kenya and Uganda. Many countries in South and East Asia and the Pacific – including India, Thailand, Myanmar, Cambodia, Papua New Guinea (PNG), and parts of China – are also witnessing large increases in the number of people with AIDS. Providing care and support for infected and affected people will therefore constitute an ever-increasing part of efforts to limit the impact of HIV infection.

While prevention remains essential to the AIDS response, care rather than preventive activities is often of greater concern, interest and visibility to the community. This is particularly true in places with high HIV infection rates, where many adults and children are sick and dying from the disease. The credibility of AIDS responses will increasingly be judged by the quality of care they offer. The support and care of HIV-positive people is thus not only a human rights obligation, but is vital to maximise the impact and success of prevention activities. Programs that focus on prevention alone, without any care and support component, will be seen as a partial response and may lose credibility and support.

The needs of affected individuals, their families and communities are diverse and complicated. To be able to cope successfully with HIV, people living with the virus must have access to a wide range of treatment, care and support options provided across a continuum. This continuum should cover individuals’ changing needs as their condition develops and progresses through the various stages of HIV infection.

In this chapter we describe the ‘continuum of care’ approach to providing comprehensive care for people living with HIV. Because of the important role of NGOs in providing home-based care, we pay particular attention to the key aspects of home and community care.

There has been a dramatic decrease in the cost of antiretroviral drugs in the past three years. This has raised hopes that it is feasible to improve access of people from resource-poor settings to these drugs. The chapter includes some of the current debates about the use of antiretroviral drugs in resource-poor countries.

In countries that are severely affected by HIV, the proportion of orphans aged under 15 is tripling or quadrupling. Large-scale systems for protecting and managing orphans are still developing. NGOs have been involved in some of the most innovative approaches to date. The chapter concludes with a discussion of strategies for orphan care in resource-poor settings.
Care and support needs of people living with HIV

The care and support needs of people living with HIV vary a great deal over the course of their illness. In the early stages of the infection many people are physically healthy but may need counselling and emotional support to help them cope with the stigma associated with HIV in their communities. As the disease progresses and the immune system becomes weaker, medical interventions are needed to prevent or treat opportunistic infections and HIV-related illnesses. At the late stages of the disease, the emphasis of care and support may shift to palliative care (i.e., providing pain relief, and spiritual and psychological support to someone who cannot be cured to enable them to die with dignity). Many infected persons and their families also need financial and social support to meet basic needs such as food and shelter. At all stages of the disease, there is a need for information and materials to prevent further transmission of HIV.

A comprehensive care and support system for people living with HIV that responds to their various medical, psychological, social and financial needs includes the following:

- accessible voluntary counselling and testing services;
- prevention and treatment of tuberculosis (TB) and other infections;
- prevention and treatment of HIV-related illnesses;
- provision of antiretrovirals;
- palliative care;
- prevention and treatment of sexually transmitted infections (STIs);
- prevention of further HIV transmission, through existing prevention strategies (behaviour change, use of male and female condoms);
- family planning;
- good nutrition;
- social, spiritual, psychological and peer support;
- respect for human rights;
- reducing stigma associated with HIV.

The different elements of comprehensive care need not come from the same institution but can be provided through networking with other services, institutions, NGOs and community organisations. A great deal of consultation, coordination and collaboration is needed to ensure that all aspects of comprehensive care complement and strengthen each other. If there are good links between hospitals, clinics, community and home, then people living with HIV are referred to the appropriate level of care when needed and are not discharged without any support. The idea is to have a continuum of care to help them and their families cope effectively with the virus.

As Figure 8.1 shows, people living with HIV should be able to access care at several points along the continuum—from voluntary counselling and testing services, health (primary, secondary and tertiary care) and social services, to community-based support and home care. Formal health care services may refer clients to community-based care organisations, which in turn may refer clients to health care services. Within a catchment area, different organisations and institutions should form partnerships so that an effective referral system between voluntary counselling and testing services, hospitals, and health centres and home care services can be established. Community groups and NGOs are essential links in the continuum of care.

**BOX 8.1: PARTNERSHIPS FOR CARE – AN EXAMPLE FROM CAMBODIA**

The Home Care Program in Phnom Penh is a good example of how partnerships can be established between different institutions and organisations to provide comprehensive care to people living with HIV.

Nurses from eight government health centres teamed with community workers from five local and two international NGOs. Each Home Care Team was made up of a nurse from the government health centre and three NGO staff members. In their catchment area each team established strong links with community leaders, traditional healers and members of Buddhist temples. After intensive training, each Home Care Team in turn trained community volunteers in different aspects of comprehensive care. Referral systems were established between the Home Care Teams, health centres, referral hospitals, and the three government-run voluntary counselling and testing centres.
Home and community care

Since the beginning of the epidemic, the care of people with HIV in their homes, by family and community members, has been an important and essential part of the response. This has sometimes been from choice, but all too often it has been because hospital care has not been possible. As the epidemic grows, the demand for hospital beds increases. In many resource-poor settings, patients with terminal diseases may be discharged to make room for others. Increasingly, family members will have the responsibility of caring for patients, often with limited information, equipment and access to drugs and other necessities.

There are several advantages of good home care, one of the most important being that the sick person can remain in familiar surroundings with loving family members (see Box 8.2). Unfortunately, in some cases people living with HIV are neglected in the home and hidden to avoid stigma on the family.

Home and community care programs have been established almost everywhere the epidemic has appeared – from the richest to some of the poorest countries. NGOs, community-based and faith-based organisations

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**BOX 8.2: ADVANTAGES OF HOME CARE**

- Good basic care in the home allows the ill person to be as active and productive as possible.
- Family support for the sick person is strengthened.
- Very sick or dying people often prefer to stay at home, especially if they know they cannot be cured in hospital or receive any further benefit from inpatient care.
- Sick people are comforted by being in their homes and communities with family and friends around.
- Relatives are able to carry out other duties (eg work, child care) more easily if the sick person is at home rather than in hospital.
- Home care is usually less expensive for families than hospital care.
- Home care can help to relieve the pressure on hospitals so that staff can give better care to those who really need to be in hospital.
- Home care offers opportunities for educating families and communities about HIV prevention and can help remove stigma.
- Home care can be an effective entry point for support to the survivors of the sick person, especially the widowed spouse and orphaned children.
have been at the forefront of home and community care. Their programs have provided us with some valuable lessons about caring for people living with HIV in a variety of settings. Some of these are described below.

Work to overcome stigma
It is difficult to provide quality care in the home if family members are afraid of the disease and/or ashamed to have an HIV-infected person in their home. As people’s knowledge and understanding increases, their attitudes towards caring for persons with HIV-related disease are likely to become more positive. Overcoming fear and stigma by increasing awareness in the community is an important part of a home care program.

Sometimes the process of providing home care can help to reduce stigma. Family members and neighbours can become less fearful of the disease when they see health care workers or volunteers visiting and caring for a person with AIDS. Families of people living with HIV who are not receiving home visits may overcome their concerns about confidentiality and stigmatisation by accepting home visits.

Inclusive services
It is best if a home care service is available to all those in the community who need it, rather than for AIDS patients alone. Making services inclusive reduces the risk of stigma.

Provide training and support to carers
Even when family, friends, and neighbours are willing, caring for people at home still presents problems. Very few of the people giving this care have ever had any training in looking after sick people. Many of them will be concerned about their lack of knowledge and skills. They may also be concerned about becoming infected. Providing training to carers is an important part of a home and community care program.

Involving the community
Home care relies on two strengths that exist everywhere in the world: the family and the community. Involving community members in a home care program is important for overcoming stigma. Community involvement is also essential for establishing a sustainable program. Community members can contribute to a home care program in several ways:

• As volunteer caregivers, they are usually the most important resource of the program. Most volunteers tend to be women and many are recruited through local religious institutions.
• They provide food, clothing, and money (e.g. for rent) for chronically ill people who are unable to earn a living.
• They support children whose parents have died of AIDS, either by taking them into their own families, or (in the case of households headed by teenagers) assisting them in practical ways.

Involving men
Home care generally means additional work for women of all ages. This burden might be reduced if men became aware of women’s workloads and the importance of mutual support. Of course, this will not just ‘happen”; therefore, organisations supporting home and community care need to consciously involve men in the planning of these services and ensure that they have clearly defined roles. This could include traditional male roles such as making home improvements and repairs.
Types of home and community care

Many successful types of home care have been developed in different settings, including the following:

- **Hospital outreach services:** These involve health care workers (most often a nurse and counsellor) travelling to the home to provide care. A major drawback of this model of care is that it can be very expensive per client served, with much of the budget being spent on transport for the mobile care team.

- **Community-based services:** These are usually provided by NGOs, community organisations or religious organisations. These services, which rely on volunteers, tend to be cheaper to run and provide wider coverage.¹⁹

- **Home care teams:** These teams are based in particular localities, consist of health care workers (usually nurses) and community health workers or volunteers. The health care worker provides training and backup for the community health workers who provide the care in the home. This approach combines aspects of the first two models and is cheaper to operate than the hospital outreach model, but more expensive than the community-based service.

Components of home care programs

The services provided by home care programs differ from one setting to another, but they commonly include:

- medical and nursing care
- counselling
- material, financial and practical support
- emotional and spiritual support
- nutritional support and food security
- palliative care
- respite care
- self-organisation of people living with HIV
- orphan support.

Nursing care

Good nursing care can improve the quality of life for people with chronic illness. Nursing can include dressing sores; helping patients to bathe and get dressed; turning them at regular intervals to avoid bed sores if they are bed-ridden; giving massage therapy; and helping them to take correct doses of medication at the right times. With appropriate training and support, family members can provide much of the nursing care needed. In many programs, community volunteers also provide nursing care during home visits.
Medical care
If they are part of a continuum of care system, home care programs refer patients who need medical care to the local clinic or primary care service. Some home care programs employ nurses to provide primary care. Nurses may be equipped with a comprehensive package of drugs such as antibiotics, anti-fungal preparations, anti-malarials and painkillers, as well as medical supplies such as bandages, gauze and latex gloves. Nurses are generally able to treat the usual HIV-related conditions such as diarrhoea, coughs, skin conditions, oral thrush, ulcers and herpes zoster, TB and common STIs. Patients requiring more specialised medical services are referred to a hospital service by the nurse.

Counselling
Individual and family counselling is an essential part of home care. Counselling can:
• provide basic information and advice to the partner and children of the person with HIV infection;
• advise patients on taking better care of their health, for example, by improving their diet, giving up drinking, smoking or injecting drugs, and taking up exercise;
• teach the family how to care for the sick person;
• teach the person with HIV how to prevent spreading the virus.

Counselling can also take place with the community. The counselling is an ongoing series of facilitated community discussions through which community members work together to name problems and explore solutions. Through community counselling, the community as a whole can acknowledge the behaviours, attitudes and norms that increase the risk of HIV infection and hinder the care of infected people. Communities can then make decisions about community-level attitudes and behaviours that support people living with HIV and their families. The facilitators of the process are sometimes called community counsellors.

Emotional and spiritual support
Even if they have not been actively involved with a church or religious group, many people find great comfort in discussing spiritual issues during chronic illness. Priests, other spiritual leaders, and family and community members who share similar spiritual beliefs can play an important role in providing emotional and spiritual support.

In many sub-Saharan African countries home care services are often provided by religious organisations. Carers are usually volunteers (mostly women) from the church. It is not unusual for volunteers to pray or read the Bible with clients and their families. However, it is important that people living with HIV who are receiving home care are not pressured into talking about spiritual issues. The home-based care project of Hua Rin, a Buddhist Temple in Chiang Mai, Thailand, provides care and support to women living with HIV as well as education to the villagers to reduce stigmatisation.

Material, financial and practical help
HIV can have a very severe impact on households, often pushing families that are already poor deeper into poverty. If the infected person is the main wage earner, the family loses income when he or she becomes sick. Other members of the family may not be able to work because they are taking care of the sick person. In addition, they have to find money to pay for mounting medical costs and medicines. Therefore, very often, the most immediate needs of a person living with HIV and their family are material and financial support. This might include food, clothing, bedding and soap, as well as money for rent or paying for children’s school fees.

Providing material and financial support is an important part of many home care programs. The Ndola (Zambia) Catholic Diocese found that the largest single item in
their home care budget is welfare support, not just for the sick person, but for other family members as well. The main form of this support is food – mealie meal, high-energy protein supplement, beans, cooking oil and salt.\(^7\)

If family members are not available or unable to do some tasks, home care can also involve providing practical help such as cleaning the sick person’s house, washing clothes and sheets, fetching water, cooking meals and accompanying the person to the hospital when required. Volunteers perform many of these tasks in home care programs.

**Nutritional support**

Nutrition is an integral part of any strategy to ensure adequate treatment and care. Poorly nourished people get sick from HIV-related infections and other health problems sooner than they would if they had enough of the right food to eat. They also find it harder to fight infections and recover from health problems, thus further shortening their lives. In addition, AIDS almost always causes severe weight loss, which is a sign of malnutrition. Nutritional problems affecting people with HIV include:\(^11\)

- loss of appetite, nausea and digestive problems, which prevent people eating and absorbing nourishment from their food;
- diarrhoea, causing dehydration and poor absorption of food;
- increased energy requirements due to fever from illnesses such as malaria or TB;
- anaemia due to inadequate iron intake or diseases such as malaria or hookworm, causing lack of energy, reduced appetite and the ability to cook, work and buy food;
- infections in the mouth or lips, making it difficult to chew and swallow food;
- poverty and insufficient supplies of food, further compounded when a person with HIV is sick and not able to earn enough (or at all) to purchase necessary supplies of food;
- environmental circumstances limiting food supplies, such as forced displacement or crop failure.

People with HIV, family members, carers and assistance programs need advice and training about food supplies and the nutrients most needed by a person with HIV, including macronutrients and micronutrients.\(^12\)

**Macronutrients**

- **energy-providing carbohydrates and fats:** an adult with HIV needs 10–15% more energy than an uninfected adult;
- **proteins:** an adult with HIV needs 50–100% more protein than an uninfected adult.

**Micronutrients (vitamins and minerals)**

- vitamins A, B6, B12, C, iron, selenium and zinc are required to fight infections;
- vitamin B6 supplements are necessary for people treated for TB with isoniazid to counteract side effects.

Planning for the supply of food for people with HIV should therefore favour foods with these nutrients. In poorer communities sufficient calorie intake is easier to achieve than increased protein, particularly where the available protein is from bulky foods such as beans and lentils. It is also important to understand how to ensure that sick people can eat when they are weak or disabled. Some general hints for people who are having trouble eating or maintaining their weight and strength are shown in Box 8.4.
Palliative care

The care of patients with an incurable illness is known as palliative care. Palliative care does not hasten or postpone death. By providing relief from pain and other distressing symptoms, as well as offering psychological and spiritual support, such care aims to help patients live as actively as possible and allow them to die with dignity. Palliative care also supports families as they prepare for the death of a loved one.

Pain control is central to palliative care. Pain and other symptoms are important causes of distress in HIV infection, causing anxiety and depression. The World Health Organization (WHO) provides a simple hierarchy for pain control, the three-step ‘analgesic ladder’:

**Step 1**: Simple analgesics such as aspirin and paracetamol. If these do not relieve the pain, move to Step 2.

**Step 2**: Codeine with or without aspirin or an anti-inflammatory such as ibuprofen. If these do not relieve the pain, move to Step 3.

**Step 3**: Strong opioid painkillers such as morphine or pethidine. Access to opioids is restricted by law and they must be prescribed by a qualified medical practitioner.

People who are nearing death are often worried about what will happen to their dependants after they die. Palliative care can help patients to make plans for the care of their children after their death, and to prepare their children for their death. Although discussing these issues can be distressing, making plans can reduce anxiety. Making a will can prevent family conflict and ensure that spouses and children are not left destitute. This is particularly important where ‘property grabbing’ is common.

Caring for people in the terminal stages of AIDS puts great strain on all involved. Care for those dying at home is most often provided by family and community members who may themselves be struggling with illness and poverty. Sometimes family members who are unable to cope may abandon the sick person. Carers need technical help with nursing and infection control, as well as emotional support to avoid burnout.

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**Box 8.4: General Nutritional Hints for People Who Are Having Trouble Eating or Maintaining Their Weight and Strength**

- Eat small amounts often.
- To supplement a regular diet of nutritious foods, vegetable oil or ground nut paste can be added to food.
- Raw vegetables are not digestible and can be easily contaminated, so they are not advisable.
- Fermented foods or drinks, either dairy-based (such as yoghurt) or cereal-based (such as mahewu) can be easily digested and increase the absorption of micronutrients.
- Foods in liquid or semi-liquid form may help reduce nausea or vomiting.
- If persistent diarrhoea is present, use soft or mashed foods and avoid irritating foods such as pepper and raw vegetables.
- Drink plenty of fluids and watch for dehydration.
- Taking vitamin tablets may be helpful.

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**Box 8.5: The Principles of Palliative and Terminal Care**

- Enhance patient and family control and the quality of life.
- Provide practical support and advice for the infected person and their loved ones.
- Provide adequate pain relief and symptom control.
- Maintain the comfort and dignity of the individual.
- Provide spiritual and emotional support for the infected person and their loved ones.
- Prepare the person living with HIV, their families and caregivers for death. Preparation includes advising people how to avoid traditional death rites that could spread infection.
- Ensure that appropriate provision is made for the children involved and that their rights are respected.
- Provide community support to a funeral.
- Provide bereavement support to the family and loved ones following death.

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1 ‘Property grabbing’ occurs in some countries in sub-Saharan Africa. It is the practice of relatives of the deceased to seize his/her property at death. This practice often results in women and orphans being left destitute.
Respite care
Carers may become exhausted if they have been looking after a sick person for a long time, or if they have had many other friends or family members die recently. Temporary or respite care by others can give the usual carer a rest. When respite care is available family and friends are more willing to care for the person with HIV and are able to have a better relationship with him or her. The morale of both the patient and the carer will be improved. Respite care might be provided through a day-care centre, a residential centre, a drop-in centre, or in the home. Provision of regular and reliable respite care should be a priority for home-based care programs.

Self-organisation of people living with HIV
Many home care programs promote the self-organisation of people living with HIV. Getting together as a group provides opportunities for people living with HIV to share common experiences, hopes and fears, and to rebuild dignity, a sense of self-worth, hope and friendships. The central role of people living with HIV in all aspects of the response, including home care, is discussed in Chapter 9.

Establishing a home-based care program
The kind of home-based care program that your organisation establishes will depend on your community. It is important that the community participates in identifying the treatment, care and support needs and in developing the program. Your needs assessment should determine the approximate number of people who will require the home care services. It is also important to find out whether there is already any organised support for home-based care, for example, by church groups. Refer to Chapters 3, 4 and 5 for information about conducting a situation analysis and planning for your home-based care program.

Key steps involved in establishing a home-based care program include:
• Identify the households in need of support and assess their care needs.
• Recruit, train and provide ongoing support for volunteers.
• Develop guidelines for nursing care, infection control and waste management for home-based care volunteers or carers.
• Establish criteria for providing other material and financial assistance for the person living with HIV and his or her family.
• Distribute home-based care kits (see ‘Material resources’ for kit contents).
• Distribute supplies for home-based care.
• Provide supportive visits, including spiritual support.
• Establish access to legal advice in relation to writing wills.
• Establish referral system with nearest health care and respite care facilities.
• Provide care for children and elderly relatives.

Resources needed for a home care program
Human resources
Identifying and recruiting carers
The most important resource of a home-based care program are the carers. The frontline providers of home care are family members, especially women and girls. Increasingly, care-giving responsibilities are falling on grandparents, particularly grandmothers. This can be an unexpected and heavy burden on older people, especially if they have no previous knowledge of HIV or basic home care skills.5

Most home care programs also rely heavily on volunteers. In many communities, volunteers are recruited from churches and other faith-based institutions. Well-motivated people can also be found in groups for people living with HIV, women’s organisations, youth movements and neighbourhood associations of various kinds.7
Training carers
Both family and volunteer carers need training in order to provide high-quality care in the home. The type of training carers receive will depend on the nature of their responsibilities. For this reason it is important for carers to understand clearly their duties and the limits of their responsibility for any client. For example, the responsibilities of the volunteers in the Ndola Catholic Diocese home care program include nursing care, counselling, and washing and cleaning the homes of their clients (Box 8.6). All carers will need information and reassurance about the risk of being exposed to HIV and how to prevent infection in the course of providing care.

Supervision and ongoing training
It is important that volunteer and family carers are not left to fend for themselves after their initial training. Regular (weekly or fortnightly) meetings between volunteers and community nurses to discuss their work and problems and to reinforce or improve their knowledge and skills is necessary. Volunteers appreciate and benefit from this kind of supportive supervision.

Motivating carers
In general, volunteers in home care programs do not receive regular remuneration for their work. However, volunteers need to earn an income. The more time they spend providing care, the less opportunity they have to earn an income. Many home care programs have recognised this problem. Some programs have found innovative ways of rewarding volunteers within often limited budgets. The Copperbelt home care program in Zambia provides volunteers with food at heavily subsidised prices, together with loans and grants for income-generating projects.

Care and support for carers
There are enormous strains on those caring for people living with HIV. Much of the stress experienced by carers is in the nature of the work itself – the fact that they are dealing with an incurable condition that largely kills young people and that causes terrible suffering. Carers are likely to be working too hard to have time to grieve with the family. The inability to cure their patients, and the sadness that they witness and share, are stressful and upsetting (see Box 8.7).

Caregivers, whether they are health care professionals, home-based care volunteers or relatives, may experience stigma and discrimination because they care for someone with HIV. The caregivers themselves may be infected, or at risk of infection, and may have to cope with their own fears of becoming ill, dependent and dying. They too are members of that community and may be grieving the loss of friends and family members.

The quality of care they provide and their ability to do so over a sustained period depends on the protection of their well-being and morale. It is important that managers of home-based care programs provide opportunities for health care staff and volunteers to meet and discuss their fears and concerns, and to receive confidential counselling if needed. Care needs to be taken to minimise stress in the workplace and to try to avoid excessive workload being placed on too few staff.

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**BOX 8.6: VOLUNTEERS IN THE NDOLA CHURCH DIOCESE HOME-BASED CARE PROGRAM**

The basic responsibilities of volunteers include:
- identifying people in their neighbourhoods who are chronically ill, and arranging for them to be seen by community nurses from the program;
- visiting patients at least once a week to check on their condition and ensure that they are taking their medication in the prescribed doses and at the correct times;
- identifying new TB patients, getting them enrolled in the directly observed therapy, short course (DOTS) program and visiting them every day to ensure they take their medicines;
- showing family members how to give basic nursing care, or, if necessary, providing such care directly;
- arranging for patients and families to receive welfare support from the program, for example, free or subsidised food, blankets, clothing, transport to hospital and assistance with funerals;
- providing emotional and spiritual support to patients and their families;
- carrying out practical jobs such as cooking food, sweeping the house and yard, washing clothes and bed sheets, or fetching water and firewood.
Material resources

Table 8.1 shows the list of medications, medical supplies and material support commonly available in home care programs. National AIDS programs in many countries provide NGOs with some of the material resources, in particular TB medicines and condoms. In PNG, the National HIV/AIDS Support Project funded by the Australian Government has supported the ‘Living with Dignity’ research project implemented by the local NGO, ‘Appropriate Technology’. The project has developed simple tools to help people with HIV care for themselves and/or be cared for in their homes. Simple bucket toilets and bucket showers have provided invaluable support for people with AIDS and their families. This initiative has led to a grant being given to Appropriate Technology Projects to distribute and test these basic kits in each province in the country.

In addition, volunteers may be given home care kits. Such kits might contain:
- analgesics, antibiotics, and anti-fungal medicines
- antiseptics
- emollient cream
- vitamin and mineral supplements
- disposable nappies, bandages, aprons and gloves.

<table>
<thead>
<tr>
<th>Medications</th>
<th>Medical supplies</th>
<th>Material support</th>
</tr>
</thead>
<tbody>
<tr>
<td>antibiotics (broad-spectrum)</td>
<td>medicine cups</td>
<td>porridge (high energy)</td>
</tr>
<tr>
<td>anti-fungals</td>
<td>disposable syringes</td>
<td>powdered milk</td>
</tr>
<tr>
<td>anti-diarrhoeals</td>
<td>disposable needles</td>
<td>eggs</td>
</tr>
<tr>
<td>oral rehydration solution</td>
<td>disinfectant for injuries</td>
<td>soap (for bathing and washing)</td>
</tr>
<tr>
<td>analgesics</td>
<td>specimen bottles and cotton</td>
<td>cocoa mix</td>
</tr>
<tr>
<td>anti-tuberculosis drugs</td>
<td>antiseptic solution</td>
<td>glucose drink</td>
</tr>
<tr>
<td>anti-malarials</td>
<td>soap</td>
<td>rice</td>
</tr>
<tr>
<td>multi-vitamins</td>
<td>water bucket</td>
<td>sugar</td>
</tr>
<tr>
<td>iron</td>
<td>towels</td>
<td>other donated foods</td>
</tr>
<tr>
<td>cough syrup</td>
<td>bedding (sheets)</td>
<td>blankets</td>
</tr>
<tr>
<td>anti-emetics</td>
<td>disposable sheets</td>
<td>clothing</td>
</tr>
<tr>
<td>gentian violet paint</td>
<td>bedpans</td>
<td>school fees</td>
</tr>
<tr>
<td>topical skin ointment</td>
<td>dressings</td>
<td>petty cash (to help with transport costs)</td>
</tr>
<tr>
<td>contraceptives</td>
<td>bandages</td>
<td>money for starting income-generating projects</td>
</tr>
<tr>
<td>sedatives</td>
<td>gloves</td>
<td></td>
</tr>
<tr>
<td>herbal medicines</td>
<td>aprons</td>
<td></td>
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<tr>
<td></td>
<td>condoms</td>
<td></td>
</tr>
</tbody>
</table>

Box 8.7: Causes of Stress and Burnout among Carers

Some of the most commonly reported causes of stress and burnout among staff and volunteers include:
- financial hardship
- stigma associated with HIV and AIDS
- secrecy and fear of disclosure among people with AIDS
- excessive workloads
- fear of infection
- the fact that AIDS is incurable
- inadequate support and supervision
- inadequate training, skills and preparation for the work
- lack of clarity about what the carer is required to do
- lack of medication and health care materials
- lack of referral mechanisms
- lack of recognition for their work.
Financial resources

Most of the people who need home-based care cannot afford to pay for the services or medication. Home care is therefore usually provided free of charge to clients. Organisations providing home-based care need funding. Members of some communities make a contribution in cash or kind to home-based care programs. Local businesses are also a source of support. They can, for example, sell basic foods at heavily subsidised prices to home care programs, provide groups of volunteers with supplies such as rubber gloves, or provide transport in the form of motorbikes or bicycles. Many home-based programs rely heavily on funding from international donor agencies and NGOs.

Primary health care

Community health centres, primary health care clinics, health posts and traditional healers provide the next level of care and their services are often made available by NGOs. Health care workers – doctors, nurses, pharmacists and counsellors – provide essential training and support to those involved in home-based care. These health care professionals should also be the contact point for referral to hospital care and other relevant services.

The care and treatment provided at the primary health care level include:

- Diagnosis and treatment of some infections commonly suffered by people living with HIV; eg TB, pneumonia, diarrhoea, thrush of the mouth and throat, STIs, and fungal skin infections. These infections can often be diagnosed at the primary level and generally respond to affordable antibiotics.

- Prevention of some common HIV-related opportunistic infections by providing medicines (prophylaxis). Many bacterial and parasitic opportunistic infections in adults and children living with HIV such as toxoplasmosis, salmonellosis, pneumococcal pneumonia, and bacteremia can be prevented with regular doses of the antibiotic co-trimoxazole. This prophylaxis should continue indefinitely unless there are side effects. If severe skin rashes occur, co-trimoxazole should be stopped. Patients will need to be followed up every month initially and then every three months. WHO and UNAIDS recommend that people living with HIV who are at risk of TB either because they live in areas where the disease is endemic and/or they have a positive TB skin test should take isoniazid to prevent the infection. Babies breastfeeding from mothers who have active pulmonary TB should also be given isoniazid.

Detection and management of tuberculosis

In many developing countries tuberculosis (TB) is the most common opportunistic infection in people living with HIV, and the most common cause of death. An HIV-infected person is ten times more likely to develop TB than an uninfected person. Tuberculosis may occur at any point in the course of infection with HIV.

Many home-based care programs include detection and management of TB. Community health workers and volunteers can play an important role in identifying people who might have TB and referring them to a clinic. Volunteers can be trained to collect sputum from patients for laboratory testing and to observe them taking their medicine. The strategy recommended by WHO for curing infections is directly observed therapy, short course or DOTS. The correct combination of TB drugs is taken by the patient for six to eight months. A community health worker or volunteer observes the patient taking their medicines daily, or in some cases three times a week. This observation, together with advice and encouragement for the patient and family members, helps to ensure that the patient stays with the treatment, and therefore reduces the chances of multiple drug-resistant TB strains developing.
The Ndola Catholic Diocese program was able to achieve a 69% cure/completion rate among TB patients through the home-based care DOTS course. Comparatively, the treatment success rates achieved by TB control programs in low-income African countries which do not use the DOTS strategy have reached only 15–20%. It is very important that the local health centre has adequate supplies of anti-tuberculosis drugs available for all patients.

**Working with traditional healers**

In many of the countries severely affected by HIV, people often attend traditional healers. There are many examples of traditional or spiritual healers and modern health practitioners working together in HIV prevention and care. Traditional healers have been trained to recognise and counsel HIV-infected patients. When the traditional healer gives the same prevention advice as the hospital or clinic staff, the message is likely to be very effective. Traditional healers may also be able to provide important relief for HIV-related symptoms.

**Referral system**

It is important that staff at the primary health care level know when and how to refer patients for further investigation or treatment. Standard treatment protocols for common problems in people living with HIV need to include indications for referral. It is helpful for primary health care staff to receive feedback from the hospital about the appropriateness of their referral and its outcome. Yet even where referral systems are in place, they are often not used. It is necessary to monitor whether systems are followed at the hospital level. Problems with communications and transport are often obstacles to effective referral.

**Hospital care**

District and referral hospitals, HIV clinics and specialists provide the next level of treatment and care for people living with HIV. Very few NGOs (except for faith-based organisations) provide clinical services at this level, although some provide counselling services and many others establish referral links with hospital care providers. The main difference between hospital care and primary health care is the availability of laboratory and other diagnostic facilities in major hospitals. Hospitals provide treatment for the opportunistic infections. Increasingly, hospitals in resource-poor countries are also providing antiretroviral treatment.

**Access to medicines for opportunistic infections and pain**

Access to appropriate medicines is an essential part of the care process for people living with HIV. Since the year 2000, the price of antiretroviral (ARV) drugs has dramatically decreased. However, for NGOs and governments in low- and middle-income countries, getting people living with HIV the drugs they need is still a difficult challenge. Although much attention has focused in recent times on ARV drugs,

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**BOX 8.8: TRADITIONAL AND MODERN HEALTH PRACTITIONERS – TOGETHER AGAINST AIDS**

In Uganda, two NGOs, the Ministry of Health, and the National AIDS Commission have been working together in an initiative called Traditional and Modern Health Practitioners Together against AIDS (THETA). Traditional healers are trained with a curriculum that covers STIs and AIDS, but also cultural beliefs and practices, counselling, leadership, sexuality, gender and legal issues. A recent evaluation found that 60% of trained traditional healers reported distributing condoms (compared with 9% of untrained traditional healers). In addition, trained traditional healers have begun to keep records, start patient support groups and improve collaboration with biomedical health practitioners.

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the vast majority of the more than 40 million people living with HIV in low- and middle-income countries at the end of 2003 remained severely deprived of even basic medications for treating HIV-related illnesses and for relieving pain.

Many of the basic drugs to treat early HIV-related diseases (eg anti-TB drugs, penicillin, broad-spectrum antibiotics, standard painkillers) are already on essential drugs lists and should be widely available in all countries. However, many opportunistic infections (which were previously rare in the community) and HIV infection itself can only be treated by drugs which have not in the past been on essential drugs lists.

UNAIDS and the WHO Action Program on Essential Drugs and Vaccines established a list of essential drugs for HIV in low-income countries. Together with Médecins sans Frontières (MSF) and UNICEF, UNAIDS and WHO have also published sources and prices of selected drugs and diagnostics for people living with HIV. The aim of the report is to help procurement agencies make informed decisions on the source of drugs and to serve as a basis for negotiating affordable prices.

The single most important reason that prevents people from obtaining the medicines they need is cost. In countries where the annual average spending on health ranges from US$10 to around US$200 per person, treatments for some opportunistic infections are beyond the financial means of many public health care systems and most individual patients.

At the national level, making drugs affordable and available requires a coordinated effort between governments, international organisations, NGOs, pharmaceutical companies and groups of people living with HIV. Improved access would:

- ensure rational selection and use of HIV related drugs;
- allocate adequate resources and develop sustainable financial mechanisms;
- strengthen reliable health care services.

NGOs providing HIV treatment, care and support services need to plan from the beginning how they will ensure access to essential medicines for their patients. Establishing links with government health services is one way of obtaining essential drugs. Because supply of drugs from the public health system is not always reliable, some NGO programs have developed other initiatives to ensure supply. However, drugs must be procured in line with national policies and national standard drug lists. One such initiative is the establishment of a revolving drug fund in which, after an initial capital investment, drug supplies are replenished with monies collected from the sale of drugs.

**Antiretroviral treatment**

Less than a decade ago there was little hope for a person living with HIV. Infection with the virus led to a complete destruction of the immune system and eventually death. New classes of ARVs became available from 1996 which were much more potent when used in combination than treatments with single drugs (monotherapy) (see Box 8.9). These new regimens, known as ‘highly active antiretroviral therapy’ (HAART), reduce the level of HIV in the blood, often to undetectable levels, and markedly improve the functioning of the immune system in HIV-infected persons.

The widespread use of HAART was a turning point for people living with HIV in high-income countries. Although HAART does not cure people, it has transformed HIV infection from an inevitably fatal disease into a chronic condition that frequently

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**BOX 8.9: CLASSES OF ANTIRETROVIRALS**

There are three classes of drugs:

- nucleoside reverse transcriptase inhibitors (NRTIs);
- non-nucleoside reverse transcriptase inhibitors (NNRTIs);
- protease inhibitors (PIs).
remains without symptoms for many years. Once people begin HAART, they must
take the drugs for life without missing doses and they often suffer side effects. However,
in the last seven years, people living with HIV in high-income countries are living
longer, with dramatically improved quality of life.

**Access to HAART**

Unfortunately, the situation is very different for most of the 38 million people living
with HIV in low-income countries. The overwhelming majority of these people
cannot afford these life-saving drugs. WHO has estimated that in 2003 some 6 million
people in low-income countries were in need of HAART, 4.1 million of whom live
in sub-Saharan Africa. Instead, a mere 400,000 people living with HIV/AIDS in the
developing world were receiving antiretroviral treatment. One-third of these live in one
country – Brazil, the only developing country that has so far implemented universal
access to ARVs.

In the last few years drug prices have plummeted because of persistent advocacy efforts
by UNAIDS, groups of people living with HIV, and a number of NGOs, including
OXFAM and Médecins sans Frontières. There has been extensive dialogue between
national governments and large pharmaceutical manufacturers to urge the lowering
of prices as well as competition from generic drug manufacturers. At the beginning
of 2000, the price of combination ARVs to treat a patient for one year was typically
between US$10,000 and US$12,000 almost everywhere. By early 2002, certain
combinations of generic ARVs were on offer for as low as US$350 per person per year.3
By late 2003, MSF and the Clinton Foundation had managed to negotiate a price
of US$140 for one year’s supply of a fixed dose combination of d4T/3TC/NVP (see
Table 8.2).

**TABLE 8.2: ANTIRETROVIRAL DRUGS – INTERNATIONAL NON-PROPRIETARY NAMES
(BRAND NAMES AND ABBREVIATIONS IN BRACKETS)**

| Nucleoside reverse transcriptase inhibitors (NRTIs) | Zidovudine [AZT] |
| Non-nucleoside reverse transcriptase inhibitors (NNRTIs) | Nevirapine (Viramune) [NVP] |
| Protease inhibitors (PIs) | Indinavir (Crixivan) |
| Commonly used regimens for initiating treatment | D4T + 3TC + NVP in a fixed dose combination (FDC) twice daily |

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3 By late 2003, MSF and the Clinton Foundation had managed to negotiate a price of US$140 for one year’s supply of a fixed dose combination of d4T/3TC/NVP (see Table 8.2).
Fixed-dose combinations are considered important tools for scaling up in resource-poor, high-prevalence settings. They are preferable because of their ease of use, distribution advantages (procurement and stock management), and effect on adherence and resistance (it is impossible to take a partial dose). Once-a-day dosing is an ultimate goal, but is not essential as field experience clearly shows that twice-daily regimens are easy for patients to adhere to.

A few middle-income countries, notably Brazil and Thailand, and more recently Costa Rica, have introduced HAART successfully within nationally funded programs. A number of NGOs have demonstrated that it is possible to provide HAART in resource-poor settings and to achieve adequate treatment compliance and good clinical outcomes. By the end of 2003, MSF had treated more than 9,000 people, including 500 children, in 19 countries. MSF looked at clinical data for ten of its larger projects which began during the period 2001–03 and found that 87.6% of a total of 6,134 patients who initiated treatment were still on ARVs, while 9.9% died and 2.0% were lost to follow-up or stopped treatment. In these ten projects, MSF has observed that 70% of patients began treatment with an advanced HIV status (WHO stage 3 or 4).iii

**Benefits of providing HAART**

- HAART can extend the duration and quality of life of people with HIV. This is an important objective in itself – but also has emotional and financial benefits for the children and elderly dependants of adults with HIV, and for productivity and the economy of local communities.
- The availability of treatment reduces the stigma associated with HIV, as happened with leprosy in many countries when dapsone became widely available. This means that even those people with HIV who are not on treatment may have a better quality of life.
- If treatment is available, people with HIV may be more willing to come forward and play an active role in prevention efforts.
- More people are likely to be willing to come forward for counselling and HIV testing, which will in turn have a positive impact on prevention efforts.
- HAART reduces the viral load of people with HIV and therefore makes them less infectious to others.

**What are the costs?**

The cost of first-line ARVs has reduced a great deal. However, these are not the only costs associated with implementing a system for comprehensive management of HIV-related disease. It is important to calculate the costs of:

- extending voluntary counselling and testing services
- HIV antibody test kits
- baseline laboratory tests
- community communication campaign
- patient information
- increased levels of clinical and counselling staff
- training
- opportunity costs of taking staff from other areas
- strengthening health information systems
- strengthening referral and discharge systems
- second-line antiretroviral drugs in case of resistance or side effects
- monitoring of the immune status of the patient and their response to HAART
- home-based care support
- drugs for prevention and treatment of opportunistic infections
- palliative care drugs.

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Challenges to implementing HAART

The cost of ARVs is not the only obstacle preventing effective treatment for people living with HIV. Other major problems are described below.

Resistance: Because the virus mutates rapidly within each host, HIV rapidly develops resistance to antiretroviral drugs. For this reason patients take a combination of drugs, and need to take their medication regularly 95% of the time, meaning they can only miss one dose per month. Any ARV treatment system needs to pay great attention to strategies to enhance adherence. When resistant virus develops it can pass from one person to another through sex or blood. There is a great danger that unregulated use of ARVs will mean that the cheaper ARV drugs soon become ineffective.

Dependency: It is important that governments should fund HAART rather than donors. Donors should provide technical support and advice, advocate for the careful introduction of treatment programs, and help to increase the capacity of the health care system to respond to the epidemic.

Reinforcement of inequities: HAART generally becomes available first in major centres. This often emphasises rural/urban inequities in access to health care services. A new HAART program draws trained staff from the health care system and may divert resources from tuberculosis, STIs or other important health programs. There is a need to select patients with HIV for treatment on the basis of the likelihood that they will adhere well to their medication regimen. This selection may result in further disadvantage for marginalised or disadvantaged people such as those who inject drugs, young homeless people, and people who live in remote places.

Co-infection: Many people with HIV have been drug users and have a high rate of other blood-borne viruses, especially hepatitis B and C, which may complicate their responses to treatment.

Despite these challenges, HAART has been delivered successfully in resource-poor settings. In addition to the MSF programs, pilot programs in Senegal, Cote d’Ivoire and Haiti have shown that people with HIV are able to take their medications as prescribed and that treatment can be successfully delivered. The innovation of DOTS for HAART used in Haiti (described in Box 8.10) will be useful in other communities.

HAART in NGO treatment, care and support programs

With the cheaper price of ARVs, and the development of simpler regimens with three drugs combined in a single tablet, there will be increasing pressure to provide HAART to people living with HIV in low-income countries. It is important that NGOs involved in treatment, care and support programs prepare themselves to participate in this much needed expansion of treatment options for people living with HIV in low-income countries. To begin with they can identify the barriers to implementing HAART in their communities and develop strategies to overcome these.

BOX 8.10: COMMUNITY-BASED HAART – THE HAITI EXAMPLE

The Harvard-affiliated Clinique Bon Sauveur in Haiti was established by Partners in Health in the middle of a squatter settlement of people displaced by a hydroelectric dam. iv From 1998, HAART was made available to a small number of patients with late-stage AIDS, whose disease no longer responded to treatment of opportunistic infections. In this program, HAART was prescribed to patients based on easily observed clinical signs and symptoms, rather than advanced laboratory tests, such as CD4 cell counts and viral load, which are not currently available in this poor and rural setting.

To ensure that patients take their ARVs regularly, the program uses the principles of directly observed therapy, which have been shown to work in treating tuberculosis. Each patient is assigned an accompagnateur, (a companion – most often a community health worker) who observes ingestion of the HAART medications daily and offers support to the patient and family. Directly observed therapy of HAART (DOT–HAART) promotes the best clinical outcome for the patient and minimises the opportunities for drug resistance to develop.

The Clinique Bon Sauveur program has treated 60 patients with advanced HIV disease, and all have had a positive clinical response, characterised by weight gain and the abatement of AIDS-related symptoms. Side effects have been rare and readily managed.

iv Partners in Health. Available at: www.pih.org/.
It is advisable that NGOs work in collaboration with hospitals to provide HAART to people living with HIV. NGO programs could play an important role in counselling and supporting people to adhere to the treatment, for example, through directly observed therapy.

If NGOs become involved in providing HAART in their community program, they must **not:**

- start HAART in someone whose HIV diagnosis has not been confirmed;
- begin treatment when long-term provision of drugs cannot be reasonably guaranteed;
- use drugs that are not from WHO-certified companies (counterfeit drugs are common);
- start in a patient not motivated to follow such treatment, or in a person who is unaware of their sero-positivity;
- prescribe ARV monotherapy, except for the prevention of perinatal HIV transmission and post-exposure prophylaxis (the latter is usually two drugs – zidovudine and lamivudine);
- start without providing adequate information about how and when to take the drugs, potential side effects, interactions with other drugs, when to stop drugs and so on.

### Vulnerability of orphans

**An estimated 14 million children have lost one or both parents to AIDS.** Approximately 12 million of these children live in sub-Saharan Africa and an estimated 1.8 million live in South and South-East Asia. As the number of adults dying of AIDS rises over the next decade, increasing numbers of orphans will grow up without parental care and love, and be deprived of their basic rights to shelter, food, health and education.

Children orphaned by AIDS begin to feel the negative effects of the disease well before their parents die. The children suffer emotionally as they watch one or both parents die slowly from an often painful illness. When the breadwinner becomes ill, the family’s income reduces or disappears entirely at a time when they need it most, to pay for health care and medicines.

Children from families affected by AIDS, particularly girls, often drop out of school because they may be the only ones who care for parents who are ill, or because they look after younger siblings. Other children leave school because they suffer discrimination, are psychologically distraught or cannot pay the school fees. UNICEF recently reviewed the effects orphaning has on schooling and child labour in 20 sub-Saharan African countries. In all countries, children aged 5 to 15 years who had lost one or both parents were less likely to be in school and more likely to be working more than

### Care and support for orphans

**Box 8.11: Benefits of linking prevention and care activities**

It is widely agreed that prevention of new HIV infections is the most effective way of reducing the long-term threat posed by the epidemic, but this is not sustainable without addressing the care and treatment needs of those already infected. Some benefits of linking HIV prevention and care activities include the following:

- Prevention activities raise awareness of HIV, increasing demand for testing and treatment.
- Counselling and testing are thought to reinforce behaviour that prevents HIV transmission.
- Increased availability of treatment encourages people with HIV to accept their condition in a more positive light and, eventually, be more visible.
- Increased visibility of HIV sustains behaviour changes that help prevent transmission.
- Increased visibility reduces stigma.

**Box 8.12: Children shoulder the burden**

When Eunice Nakyewje became a single mother at the age of 14, little did she realise that ten months later, she would be looking after her seven younger brothers and sisters – in addition to her baby.

Nakyewje left school when she became pregnant, and returned home to Masaka. Her father was already ill with AIDS and died within weeks. Her mother followed ten months later, leaving the girl to head the household. Nakyewje is now taking tailoring lessons, hoping to earn a small income to feed her family.

‘We have nothing left’, she says. ‘By the time mama and papa died, papa had sold off all our land and cattle. He wanted money for treatment.’
40 hours a week. A study in Kenya in the late 1990s found that 52% of the children orphaned by AIDS were not in school, compared with 2% of non-orphans. The future employment opportunities of these children who have little or no education will be greatly reduced.

In the countries hardest hit by HIV, care for orphans and children affected by HIV lies primarily with their families and communities. But HIV is placing huge burdens on the extended family system – the backbone of African societies – while also ravaging entire communities. This can leave many orphans with little support. A recent study in Zimbabwe, for example, found that half the street children are orphans, the majority due to AIDS. Another effect of large numbers of adults with dependents dying from AIDS is the emergence of unfamiliar types of families: families composed of the very old and the very young; households composed entirely of children; and adolescent-headed families. A World Vision survey in Rakai, Uganda, found that more than 4% of households were headed by children between the ages of 12 and 16 years. These types of families are vulnerable because, with the best will in the world, the ability of an aged grandparent or an adolescent sibling to support the family is limited.

The needs of children affected by the epidemic

It may be tempting to make a special case for children who lose their parents to AIDS. The needs of these children are similar to the needs of children who have lost their parents to other causes. The fact is that the existence of orphans in different societies is not new. What is new is the increasing scale of the problem. The needs of children who lose their parents have been described by Mukoyogo and Williams:

- love, to help them cope with their loss;
- physical needs, including the need for nutritious food, shelter, bedding, footwear, clothing and soap;
- educational and vocational needs, including formal education and information about health care and AIDS;
- health care, to cope with malnutrition and infections;
- freedom from stigmatisation;
- freedom from exploitation, eg by unscrupulous relatives taking family possessions or using an orphaned child as an unpaid domestic worker;
- appropriate socialisation.

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Responding to the needs of children orphaned by AIDS

Guiding principles

NGOs and others responding to the needs of children orphaned by AIDS should be guided by the following principles which evolved from consultations between governments, NGOs, the private sector and youth representatives at the XII International AIDS Conference in South Africa in July 2000, and subsequent regional meetings.

1 Strengthen the protection and care of orphans and other vulnerable children within their extended families and communities

In each community, the capacity of families and communities to provide protection and care must be reinforced, and effective systems developed and strengthened to monitor the status of the most vulnerable children and to prevent exploitation and abuse.

2 Strengthen the economic capacities of families and communities

It is important to establish sustainable interventions to respond to household economic needs. These will vary depending on local circumstances, and could include reduction or elimination of school-related or health care expenses, micro-enterprise or micro-finance programs, agricultural assistance, special investment funds to address local collective needs, provision of welfare assistance, or building basic infrastructure to support the productive base of the community.

3 Enhance the capacity of families and communities to respond to the psycho-social needs of orphans, vulnerable children and their caregivers

Psycho-social support efforts should be incorporated into existing community and school-based efforts to promote well-being and social integration of children. Community volunteers and outreach workers should be trained to give support to children and their caregivers.

4 Link HIV prevention activities, care and support for people living with HIV with efforts to support orphans and other vulnerable children

Programs that focus on care for vulnerable children within the context of the greater population of people living with HIV can be especially effective in HIV prevention. Making medicine and food available through home-based care and support programs can benefit both parents and children.

5 Focus on the most vulnerable children and communities, not only those orphaned by AIDS

Targeting specific categories of children can lead to increased stigmatisation and discrimination. Communities are in the best position to determine who is at greatest risk and what factors should be used to assess vulnerability, in order to establish priorities for action.

6 Give particular attention to the roles of boys and girls, and men and women, and address gender discrimination

Programs must address the increased vulnerability of women and girls to sexual abuse and exploitation. They must also address the greater burden of care that falls on them, which often results in girls dropping out of school, as well as addressing the denial of women’s and girls’ rights to own and inherit property.

7 Ensure the full involvement of young people as part of the solution

Young people should be fully involved in decisions and actions that affect their lives. Involving youth in addressing community-wide problems can lead to an increase in self-esteem and a sense of control over their lives, while contributing to responsible behaviour. Young people can help provide psycho-social support to peers, and younger children can help those who are ill, with household tasks. Young people whose caregivers are ill should be involved in decision-making about their future care.
8 **Strengthen schools and ensure access to education**
Schools can involve children in building and reinforcing community capacities to prevent HIV infection and to provide care and support for affected families through solidarity clubs or credit for community service.

9 **Reduce stigma and discrimination**
Specific efforts to address stigma and discrimination must be an integral part of all care, support and prevention activities, and should include national anti-discrimination policies and legislation. The visible participation of people living with HIV is critical, and partnerships with religious leaders and organisations have proven effective in many countries.

10 **Ensure that external support strengthens and does not undermine community initiative and motivation**
Donors, governments and NGOs should recognise that families, communities and children themselves are the frontline of response to HIV. Community ownership of interventions is of paramount importance. Outside assistance should accordingly focus on engaging in long-term partnerships to support, strengthen, and sustain ongoing grassroots initiatives through training and technical assistance, organisational development, and sustained financial and material support.

**Strategies**
The needs of children affected by the AIDS epidemic do not begin with the death of the parents, but with the knowledge that someone in their family is infected with HIV. The needs continue through to their social and sexual maturity.21

The principles expressed in the World Declaration on Child Survival, Protection and Development provide an excellent guide for planning strategies to support children affected by AIDS. Article 19 of the Declaration states:

> Every effort should be made to prevent the separation of children from their families. Whenever children are separated from their families owing to force majeur or in their own best interest, arrangements should be made for appropriate alternative family care or institutional placement, due regard being paid to the desirability of continuity in a child’s upbringing in his or her own cultural milieu. Extended families, relatives and community institutions should be given support to help to meet the special needs of orphaned, displaced and abandoned children. Efforts should be made to ensure that no child is treated as an outcast.

**Preparing children for the future**

- The earlier a parent’s infection status is known, the more time they will have to plan for the children’s future. Access to voluntary, confidential and affordable counselling and testing for adults will help with this planning.
- Continued employment for people with HIV infection while they remain fit to work is important for securing the future of their children.
- Simple treatment of opportunistic infections such as thrush, diarrhoea and fever is important because it allows parents to continue to work, support their children and to die with dignity.
- Protection of children’s inheritance and other legal rights is also important. The children’s continuing access to the family house, land and goods is essential to their survival and well-being. For example, Uganda has set up a Child Law Review Committee to look into the protection of orphans’ rights and inheritance.
Strengthen and support the capacity of families to protect and care for their children

The overwhelming majority of orphans and other children affected by HIV are living with immediate or extended family members. The safety and well-being of these children depend largely on the ability of these relatives to protect and care for them. For most of them there is no viable alternative. Even in countries where institutional care is relatively extensive, orphanages provide only for a very small portion of all vulnerable children.

Support for families can take many forms. Attention must be given to both immediate survival needs and the longer-term issues of improving the ability of households and families to cope, including economic strengthening and psycho-social support. Specific strategies include:

- Offer counselling to give emotional and psychological support. The trauma of their parents’ protracted illness followed by death leaves children with a profound sense of loss, abandonment and guilt. Therefore, they have an even greater need for love and security. Without special emotional and psychological support, they are likely to become depressed, to suffer learning difficulties at school, and to engage in anti-social or delinquent behaviour.²⁰

BOX 8.13: MEMORY BOOKS

In many countries memory books have become an important way for parents, in particular HIV-infected mothers, to tell their children of their infection. Terminally ill parents and their children work together to compile the memory book, which is often an album containing photos, written funny stories about the family, and other memorabilia.

In Uganda, The AIDS Support Organisation (TASO) began to use memory books in the early 1990s. Since 1998, the National Association of Women Living with AIDS has promoted this approach on a wider scale. HIV-infected mothers often have great difficulty in telling their children about their illness. Memory books are a great way for mothers to introduce the idea of HIV into their children’s lives and discuss its effects. The book reminds the children about their roots so that they do not lose their sense of belonging. The book also promotes HIV prevention, because the children witness and understand the suffering of their parents and do not want to go through the same thing.
• Provide basic material support for such needs as food, shelter and clothing to affected families. It is important that the survivors (children, grandparents, etc) are supported to stay together as integral members of their community. With material support, they may be able to stay in their own homes. If that is not possible, they may be supported in foster homes, preferably in their communities. In Uganda, for example, TASO assists clients to identify relatives or friends who might take over these responsibilities when the need arises. Counsellors prepare potential foster families by explaining how HIV is spread and helping to overcome fears and prejudice. TASO then supports the families by providing food, clothing and school fees.
• Improve access to basic services such as health care and education.
• Increase agricultural productivity.
• Improve access to employment and markets.
• Provide additional means for income generation.

It is essential that such strategies try to meet the needs of all vulnerable families by promoting community development and social welfare. The advantage of this approach is that it avoids the very real danger of sowing division and jealousy in poor communities by singling out HIV-affected families for privilege. It goes without saying that the community should be involved in planning their coping strategies.

Mobilise and strengthen community-based responses

The community is the second safety net for vulnerable children and households. Community groups can help vulnerable children directly or assist HIV-affected families to provide for children’s needs. Communities that have organised themselves to protect and care for vulnerable children are able to determine which children and households are most vulnerable, and to channel local or outside resources to those most in need.

Strengthen the capacity of children and young people to meet their own needs

HIV catches children in a double bind. They must support themselves and their families, often under the pressure of severe poverty, yet many are forced out of school just when they most need to prepare for their own futures. Girls are often the first to drop out, which not only undermines their own health and well-being, but also that of the next generation. Keeping vulnerable children in school is the first line of defence. Specific strategies include:
• paying for school expenses;
• providing care for relatives, thus enabling children to attend school;
• compensating for lost income.

Raise awareness in the community about the need to support children affected by HIV

Increasing awareness among policy makers, community leaders, organisations and the public about the impact of HIV on children and families helps generate a broadly shared sense of responsibility for action. Stigma and discrimination remain major challenges. Effective public information and social mobilisation can accelerate change so HIV evolves from their problem to our problem.

A comprehensive situation analysis (see Chapter 3), particularly with broad participation from stakeholders, can provide much of the information needed to drive such social mobilisation. Active involvement of the media, faith-based groups and key opinion leaders, is particularly important. For example, journalists can discuss the national scope of the problem and various solutions, while religious networks urge a compassionate response to people affected by HIV.
References


Additional resources


Chapter 9
Positive response: the central role of HIV+ people

by Susan Paxton

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**Introduction**

HIV-positive people are often seen as either vectors or victims of a deadly virus – part of the problem. They are usually unable to discuss their status openly and are forced to hide it because of the moral blame and stigma associated with AIDS. However, as infection rates continue to rise globally, more people living with HIV are looking at life beyond diagnosis. We need to focus on what is needed to enable people living with HIV to lead positive and productive lives.

People living with HIV also have much to contribute to the design, implementation, monitoring and evaluation of HIV programs and need skills and encouragement to become involved in local responses.

In this chapter, we suggest that HIV-positive people be placed at the centre of analysis and action. We present descriptions by positive people of the social and psychological effects of HIV infection. We examine why it is important to involve HIV-positive people in the response to HIV and AIDS. There is a strong link between the protection and promotion of the rights of people living with HIV and prevention of spread of HIV. We look at ways to enable positive people to be involved in program design and delivery and describe the benefits to individuals, organisations and communities of placing people living with HIV central in our response.

HIV-positive people were once HIV-negative people. They have much to share about their knowledge, attitudes and context of risk behaviour while they were HIV-negative or untested.

The various experiences of people living with HIV during and after diagnosis have a powerful impact on their lives and families and can critically enlighten our response. People living with HIV may have much to tell about local treatment, care and support services including ideas on how they can be improved. Encouraging people living with HIV to speak to HIV-negative and untested people about their own experiences is a sound behaviour-change strategy.

**People living with HIV**

Most people who are infected with HIV do not know it. Some who have never had an HIV test may suspect or believe they have become infected with the virus, for example the wife of a man who dies of an HIV-related illness and who becomes sick with similar symptoms. Others may be quite unaware of the possibility of infection. Among people who test positive, some choose not to tell anyone because they fear discriminatory treatment; some tell their partner or closest friend; others tell most of their family and friends; others are willing to become publicly positive and talk to people about living with HIV; yet others may be willing to talk to people that they do not know but not to their family or work colleagues, for a variety of reasons. It is important not to make assumptions and to respect the right of people to choose who they want to tell. Some people do not choose to publicise their HIV status, but it becomes public knowledge because of a lapse of confidentiality, either deliberate or accidental.

Any of the above groups of people living with HIV may contribute to the field of prevention and care and support, not only those who are willing or able to be publicly positive.
Cloak of secrecy and stigma

AIDS is cloaked in secrecy, which fans the rapid spread of HIV. AIDS is a life-threatening disease. People are afraid to talk about AIDS because that means discussing culturally taboo subjects such as sex and death. So people push it away and convince themselves that HIV only affects particular groups in society: gay men, injecting drug users, sex workers, ‘other people’. Early messages almost always imply that HIV spreads through immoral behaviour. People newly diagnosed with HIV, a life-threatening condition, take on an added burden of shame. The stigma results in most people choosing to hide their status and live with a carefully guarded secret. Because the face of HIV remains invisible, the community remains unaware of who can and cannot become infected. The virus continues to spread at an alarming rate and people transfer their fears onto those already living with the virus.

Discrimination and human rights abuse

Around the world people who have HIV have been refused medical treatment, forced out of their homes, lost custody of their children, been forcibly sterilised, lost their jobs, been subject to physical violence, and in some instances killed.

People living with HIV have the same rights to privacy and family life, free from violence; the same rights to housing, employment, care, support and treatment as those who are not infected. Yet positive people are often deprived of these human rights because of the universal stigma surrounding AIDS. People are unlikely to seek testing when moral blame is placed on HIV-positive people and they face subsequent discrimination and inhumane treatment. Fear and silence make it easy for HIV to spread.

By documenting and describing the discrimination that faces people living with HIV and AIDS and examining its impact on quality of life, we can develop appropriate strategies to change attitudes, policy and legislation to counter human rights violations.

EXPERIENCES OF SOCIAL EXCLUSION BECAUSE OF HIV STATUS

I became the centre of gossip in the town. My mother was hysterical. My family panicked. They felt shame for me... I lost my self-esteem. Once you have very low esteem, you lose everything. You lose your hope. You lose your dreams. It’s so futile, frustrating. At school I graduated with the highest honours and when I was diagnosed I thought, What am I going to do with the knowledge I have gained over the years? I worked hard and now I have HIV I feel useless. I’ll just wait to stop breathing. I didn’t feel any purpose at all... AIDS comes with a message of fear and I want to give a message of compassion for people living with HIV.

Philippines female, 29 years

Some people say ‘This girl is infected with HIV. I’m scared. I will sit in another place’. My friends come and we walk together. Then they say, ‘Oh, this one will get HIV walking with her’. Then my friends feel shy to walk with me, and then sometimes I’m very lonely, very sad.... I had an abscess, then I went into hospital. They didn’t want to touch me and the doctor was afraid of me. Then I’m very sad again.

Indian female, 21 years

We never talked about our status, me and my husband, so that’s where the problem started. When my husband was about to die my in-laws came home where I was staying. They took all the property. They took everything from me because they thought I was the killer. I was a witch in our country... They were doing it because they were ignorant. They took my husband away from me... A week after they took him, and the property and everything, after a week, my husband died. And when my husband died do you know what happened? They never bothered to tell me. When he died they buried him. I was not there. My kids were not there. It was very depressing.

Zimbabwean female, 32 years
Central role for people living with HIV

We need to break the silence. We need to get people to talk openly and learn to listen to what people most affected by HIV have to say about their experience. By creating an environment in which people living with HIV have a face and a voice, people begin to identify with those living with the virus. The issue becomes more familiar and tangible and the community is more likely to take action to reduce stigma and to prevent transmission. As discrimination decreases, people begin to examine their own vulnerability to infection in a responsible way.

On 1 December 1994, 42 countries signed the Paris AIDS Summit Declaration. It states, in part, that the success of our programs to confront HIV/AIDS requires the full participation of people living with HIV/AIDS. The Declaration commits governments to consult with affected groups, eliminate discrimination against people living with HIV/AIDS, and decrease women’s vulnerability to HIV. In order to carry out this commitment to greater involvement of people living with HIV/AIDS there is an acknowledgment of the need to strengthen the skills of HIV-positive people.
Strategies to facilitate the involvement of HIV-positive people

HIV robs people of control over their life. A positive diagnosis is accompanied by issues of loss, disempowerment and social ostracism. Rather than become victims many people living with HIV choose to respond in a positive way to their situation. Often they are passionately motivated to contribute to HIV prevention and care.

If a strategy is in place to ensure adequate training and support, positive people can be involved at every level of the community response to AIDS, including:

• counselling, care and support;
• disseminating information to others infected with HIV;
• prevention programs, including raising awareness and educating the community;
• designing models of health care and service delivery;
• developing policy on HIV-related matters.

At times professionals may be reluctant to involve positive people. Often workers are so preoccupied with responding to the immediate demands placed on them and it is difficult to step back and plan a strategy that recognises, accepts and supports the participation of people living with HIV. It is often easier to ignore the need for input by people living with HIV. In the long term, however, it is necessary to work sensitively with people living with HIV and encourage those willing to become involved. It is important to be flexible, to provide support such as training, and to collaborate with positive people as equal partners.
Counselling

When a person is diagnosed with HIV they often lose their self-esteem. They may feel alienated. Grief, loss and anger may be aroused. It is important to deal with these feelings before the person can begin to live positively with the virus. Counselling plays an important role in this.

In resource-limited settings, one-to-one counselling is often not available. A sustainable alternative is to provide positive people with peer- or co-counselling. As well as enabling people to come to terms with their changed identity, peer-counselling can also be invaluable in helping positive people to disclose their status to their family, which can be very stressful but also most beneficial.

Some people living with HIV may be interested in counselling others. Counselling requires training. Counsellors need to learn how to listen to others and encourage them to speak out about their feelings. They need to know when to give advice and referral and when to be silent. HIV-positive counsellors have an immediate understanding of many of the issues their clients face and can be highly sought after.

With increasing access to antiretroviral medication, people living with HIV can also be trained as treatments counsellors, providing valuable guidance on taking medicines as advised by health workers, ways to overcome drug side effects and other related issues.

Some people who become involved in HIV education, advocacy or care and support become overworked and overwhelmed by the many demands. If a positive person takes on a very active role in HIV work, the provision of some psychological support through counselling is necessary to avoid burnout.

Peer support and self-organisation

Because positive people are marginalised and isolated it is important to create a supportive environment in which they can contribute effectively.

The first step is to facilitate peer support. This means enabling HIV-positive people to meet each other in a safe, comfortable and confidential environment.

Peer support may be as simple as two people having an opportunity to meet with each other. Once a group is established, other people will join. It is a good idea for the group members to decide some rules early on such as listen to each other; respect what each other says; everything discussed in the group stays in the group and is not discussed with others. One strategy to ensure that everybody has an opportunity to speak is to allocate time, say ten minutes, for each person present to talk about what is happening in their life, without interruption. When they share common experiences, positive people learn that they are not alone and that they have a valuable role within the HIV field.
Although it may be necessary for an HIV-negative or untested worker to be present at the beginning of the first couple of meetings, it is important for the positive people to meet together without others present. This independence is helpful to the process of empowerment.

GNP+, the Global Network of People Living with HIV have produced a book ‘Positive Development’ to help people establish their own support groups. It can be downloaded from the GNP+ website: www.gnpplus.net.

Exchange of information is always valuable. Find ways to support the establishment of PLWHA newsletters and meetings.

With the increasing availability of access to the Internet, email discussion groups established by and for positive people can be a useful source of up-to-date information. If your organisation has email access set aside time to train key positive people in electronic communication.

**Care and support**

People living with HIV may become involved in home care programs. If so, it is necessary to provide them with similar training to other home care support workers. Many women living with HIV already care for partners and children who also have the virus. Those who carry this double load need additional care and support themselves.

Clients are likely to trust positive people who provide care because they understand the issues they face.

In many countries, people living with HIV have established their own day care centres that offer basic clinical treatment, care, emotional support and avenues for income generation.

Involvement in care and support can be satisfying to people living with HIV but may also be emotionally overwhelming as it raises fears about their own future. The death of a client can be a particularly difficult time for positive carers, and counselling can really help at such times.

Maintaining the confidentiality of HIV-positive clients and volunteers is vital. Staff must be trained in confidentiality. Encourage all staff to explore the implications of breaches of confidentiality; role-plays can be effective in this training. An HIV-positive person may choose to work in an AIDS organisation but may not be ready to be publicly open about their HIV status. They may not have told close members of their own family. If you are uncertain about how open an HIV-positive person is, ask them. If confidentiality cannot be guaranteed, positive people will be reluctant to become involved.

**Advocacy**

Many people living with HIV are motivated to advocate for changes to public health policy or to fight against the discrimination faced by positive people.

Improved service delivery and access to antiretroviral treatments has been hastened in many countries because of lobbying by people living with HIV.

Parents living with HIV around the globe have successfully challenged schools about their HIV policies.
Positive people in all continents have fought to retain their jobs and challenged workplace HIV policies. Sometimes such action has led to legal reform.

AIDS organisations can facilitate such advocacy work through positive people’s working groups and networks that represent a broad spectrum of the community, including people who are marginalised. Local hospital boards or government advisory committees on AIDS can benefit greatly by designating positions for representatives of people living with HIV.

However it is not enough simply to select one or two positive people to sit on relevant committees. They may not be very representative of other positive people and may not consult with others.

Many positive people involved in the community response to HIV spend years as volunteers without receiving training. People living with HIV representatives who sit on committees or boards with professional health workers, policy makers or funders are often hampered by a lack of training and support. As a result they often feel overwhelmed rather than inspired. Lack of support in their work can intimidate or undermine activists, and even risk their lives.

The first requirements of positive people involved in your organisation may be basic health care, including adequate shelter, a good diet and access to treatments for opportunistic infections and ARVs, if at all available.

Talk to positive people who want to offer their time. Find out something about their life experiences. Acknowledge the skills and talents that positive people possess before diagnosis. Those who have become actively involved in HIV work include writers, farmers, performers, doctors, teachers, and lawyers. Ask people what they want to learn in order to become more confident in the work they do. The range of skills needed may vary enormously.

Because resources are usually limited and often focussed on prevention, the opportunity to train and give control to the people who are infected is often overlooked. It is easier to supply services to people living with HIV than to support them to become active partners and participate in program design and delivery.

Governments and AIDS support organisations have a responsibility to provide resources to enable the involvement of people living with HIV in their activities. Begin with a discussion about the advantages of involving people living with HIV in the work of the organisation or department.

Community AIDS workers also require training to learn how to listen to positive people without prejudice and become sensitive to the needs of people living with HIV.
Community education

Research has shown that HIV education targeted at young people before they become sexually active is most successful in minimising future risk behaviour.\(^3\)

The school setting is the most obvious in which to reach young people, but class teachers may not be the most appropriate people to deliver HIV education in a sensitive way. Some students prefer to discuss sexual behaviour with an anonymous person and some teachers may feel uncomfortable, uncertain or embarrassed talking with students about sexual practices.

Since early in the epidemic, HIV-positive people have spoken out about living with the virus. In 1987, positive people in Uganda established the Philly Lutaaya Initiative in order to break the silence and give a face to AIDS.\(^4\) Since then positive speakers’ groups have emerged all over the world. Positive people speak out in schools, workplaces, social groups, and churches.

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**BOX 9.3: PINOY PLUS**

Pinoy Plus was founded in 1994 in the Philippines to respond to the care and support needs of Filipinos living with HIV, defend and uphold their human rights and contribute to the prevention and control of the pandemic.

Pinoy Plus has members from diverse backgrounds including sex workers, gay men, housewives, overseas workers, sailors and professionals. At first many members found themselves at odds with one another, disagreeing over the organisation’s mission and their roles and responsibilities. Pinoy Plus had a review and developed a structure that continues to respond to members’ needs. Pinoy Plus has created a tremendous impact both for its members and in the AIDS community. Grants from the Department of Health facilitated the organisation’s growth and maturation.

**Organisational development**

Members received training in the following skills in order to become more proactive:

- Basic HIV Awareness Trainers Training
- Human Rights and Advocacy
- Care Giving
- Peer Support Group Formation
- Peer Counselling
- Facilitator Training
- Gender and Sexuality
- Team Building
- Communication Skills
- Public Speaking
- Income Generation
- Proposal Writing
- Program Management
- Strategic Planning

**Monitoring of peers**

Pinoy Plus responds to the physical and psychosocial needs of members with home visits. A care and support program provides feeding, linen changes, massage, spiritual support, and daily hot meals for those who require these. Peer counselling is provided to the newly diagnosed. Family counselling is also available to help families understand the disease and the importance of moral support as well as attention and care.

**Sex workers’ and students’ HIV education and prevention**

Pinoy Plus members share their experiences of living with HIV and disseminate correct information among sex workers and students. 10,000 people have been reached.

**Legal reform**

As a consequence of their training in advocacy and their increased confidence, Pinoy Plus members lobbied policy makers and legislators for the passage of the ‘AIDS Bill’. This Act, the first law to ban discrimination based on HIV status to be passed in an Asian country, was signed by the President of the Philippines on 13 February 1998. The Act prescribes policies to prevent and control HIV and to institute a nationwide HIV information and education program.
The primary aim of positive speakers is to share the reality of living with HIV and to challenge perceptions about who can and cannot get infected. Such programs have been hailed as highly successful by reducing the distance between those with and without the virus.

Many people believe that it is possible to tell that a person has HIV by their appearance. People living with HIV who look healthy challenge this false belief as well as the stereotypes about who becomes infected.

Meeting people living with the virus encourages more open discussion about HIV and the social and sexual issues that increase its spread. Research indicates that it has a significant impact on people’s attitudes to HIV, including perceptions of vulnerability and tolerance and understanding towards people living with HIV.5,6,7

Those who have witnessed the impact of face-to-face meeting with positive speakers agree that they are effective educators.

Most positive speakers’ groups start off informally. Somebody is asked to disclose their status to a small, ‘safe’ group, such as health professionals. Requests for further talks follow. Other people living with HIV, seeing the benefits from speaking out, also begin to offer their expertise. Over time the group may offer training and establish criteria to accredit speakers. Some groups adopt a ‘buddy’ system whereby a potential speaker observes one or more talks by an established speaker before venturing out alone.

Some positive speakers may have previous experience in addressing audiences, but most will not. Training in communication and presentation skills is very useful. APN+ has developed a manual and a training module for HIV-positive speakers, *Lifting the burden of secrecy*. It can be downloaded from www.hivasiapacific.apdip.net.

Most speakers will also benefit from training in basic facts about HIV, as it equips them to answer the range of questions that may come after their talk. If you are organising a talk by a positive person, make sure you allow time for questions so that the audience can build rapport with the speaker.
The administration of positive speakers’ groups can be simple. After advertising the group through appropriate channels, a central coordinator matches requests to speakers, taking into consideration age, sex, and background. It may be necessary to get approval from the Department of Education before advertising in schools. The coordinator takes responsibility for explaining the conditions of the booking to the client, including arrangements for payment of any fees. They find out background information about the audience and venue, in order to adequately prepare the speaker. Questions to ask when taking a booking for a talk by a positive person are:

- Who is the contact person?
- How many people will be in the audience?
- What is the age range?
- What previous knowledge or experience of HIV do they have?
- Will there be any cameras or reporters present?
- In what type of space will the presentation be made?
- How long is the talk to be?

It takes special courage for positive persons to devote themselves openly to education efforts. It can be frightening and confronting to tell others that one has HIV. Going public is a huge step to take because of the stigma and shame still attached to the disease in many communities and the fear of discrimination.

Most people who are open about their status do not experience AIDS-related discrimination as a consequence of doing so. It is however essential to provide adequate emotional support (counselling or peer support) for people living with HIV who choose to disclose publicly. It is also helpful to have somebody to ‘debrief’ with after a talk. It may also be necessary to provide information about the availability of other social supports, including legal services.

If people are considering public disclosure in the media, the death of South African Gugu Dlamini, at the hands of her neighbours after her media disclosure on World AIDS Day, 1998, is a chilling reminder of the need for assured security of housing and livelihood.

People living with HIV should never be pressured to disclose their HIV-positive status as a service to the community. It is important to emphasise that encouraging the involvement of infected and affected people in HIV prevention efforts should only happen in an environment where disclosure of their status will not endanger their lives or lead to discrimination.

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**BOX 9.4: EXTRACT FROM A DISCUSSION WITH 15–16 YEAR OLD AUSTRALIAN STUDENTS AFTER A TALK BY A YOUNG WOMAN ABOUT LIVING WITH HIV**

**How did the talk by the positive person make you feel?**

‘Vulnerable.’

‘Surprised that anyone can get it.’

‘It was very relevant to us because she went to a private school just like us and she got AIDS.’

**Do you think it changed how you think about HIV-positive people?**

‘Yes, definitely.’

‘I used to be a bit worried about being around them but now it feels better.’

‘It was weird how she had AIDS. They don’t look different from anyone else. I couldn’t tell.’

**Do you discuss safer sex in school?**

The teachers always drum into us, don’t do this, don’t do that. They never really tell us why. They just say you’ll get AIDS. That’s it.’

‘It’s hard to talk to teachers. You have to know them for many years, but with the positive speaker you can ask anything. You’re not worried about what they’ll think or judge. You don’t have to see them again.’

‘She wasn’t preaching about it. She just sat down and talked to us.’

‘If you ask teachers questions, they’re going to be wondering why. And they know your parents, and they have parent–teacher interviews.’

‘The speaker wasn’t going to leave the school thinking why did she ask that question?’

‘She’s not going to leave and then go and write your history report. That’s a major difference.’

‘We would have found out more in that talk than we have in the last three years.’

**Do you think you learned more factually?**

‘Not factually, but it pushes you to use it more. The reality is that if you don’t, that’s what you’re going to end up having.’

‘We have to accept it now because it’s around. We have to accept it.’
The benefits for positive people

Taking an active part in HIV programs is enriching and can enable people living with the virus to take back control over their lives. Doing something worthwhile helps to rebuild self-esteem and improve quality of life. This benefits the individual, both psychologically and physically, and consequently, the society within which that person lives.

Many positive speakers talk of the rewards from speaking out publicly. Disclosure has a positive impact on the speaker’s well-being by lifting the burden of secrecy. Responses to talks are also very encouraging and re-establish personal dignity and self-respect.

The visibility of people living with HIV is inspiring for other positive people. It helps to develop a more optimistic outlook; that it is possible to live a healthy, useful and fulfilling life with HIV; that there is life after diagnosis. These messages can be a lifeline for those newly diagnosed.

Central to the Ottawa Charter for Health Promotion is the concept of creating an enabling environment whereby people can take control over and subsequently improve their health. It is rare for clients to have such control over their health service or education programs but adopting this approach can be mutually beneficial to clients, health care workers and the general community.

BOX 9.5: GOING PUBLIC IN AFRICA: WINGSTONE ZULU

In early February 1991 I appeared on Zambian television as the first person in the country to publicly declare his HIV status. Six days later both national daily papers carried my story... Friends melted away and my family asked me to leave their house to save them from the shame of living with a person infected with HIV. What beat me then, and still beats me today, is the fact that everyone was disappointed with me not because I contracted HIV, but because I had declared it.

When I received my HIV test results in September 1990, my two elder brothers were in hospital suffering from AIDS. Week after week I saw them being eaten alive by the disease. In December both died within a week of each other. Seeing the grief that beset my family and knowing that I was the next ‘attraction’ in this series of real life tragic dramas was incentive enough for me to do something about it. I wanted to hit back at the disease...Going public was one such way and the knowledge that I was fighting AIDS transcended all considerations.

People with HIV are crucial in this fight. Only when more of us come out and share our experiences will the battle against AIDS truly begin.

I feel I’m valuable. I can contribute. I’m not always in the position of begging. I feel I’m important. I have a part. I haven’t lost my worth.

Indonesian female, 25 years

My self-esteem and pride have increased, especially when I see in my own community that everybody knows so much more and is so active. I know that’s a result of my work. It makes me very proud of myself.

Thai female, 28 years

The main benefit of people disclosing is in improving the acceptance of people living with AIDS in northern Thailand. Several years ago the situation was very, very bad regarding acceptance and misunderstanding. Since that time efforts by people like me have made a big difference.

Thai female, 32 years
Conclusion

The protection and promotion of the rights and dignity of people infected with HIV provides more effective public health outcomes for everybody. It is the cornerstone of AIDS prevention strategies. As discrimination based on HIV status lessens and people living with HIV are treated with respect, people in the community change their perceptions and take on greater responsibility to protect themselves from infection.

Limited resources require the initiation of innovative, effective, affordable, accessible projects that maximise our capacity to respond to the HIV pandemic.

People living with HIV are well placed to become experts on the social and cultural impact of HIV/AIDS and are a necessary part of the response. Policies that encourage increased collaboration with and involvement of positive people in organisations, acknowledging their central role in the epidemic and providing adequate training and support to enable them to become active players in community AIDS programs result in a more appropriate and effective response to AIDS.

In an environment that nurtures and supports positive people and allows positive people to live with respect and dignity, free from violence, abuse, discrimination and prejudice, it is possible to create a society in which people discuss AIDS openly and hence prevent new infections.

BOX 9.6: OTTAWA CHARTER FOR HEALTH PROMOTION

‘Health promotion is the process of enabling people to increase control over, and to improve, their health. To reach a state of complete physical, mental and social well-being, an individual or group must be able to identify and to realise aspirations, to satisfy needs, and to change or cope with the environment.

Health promotion focuses on achieving equity in health. Health promotion action aims at reducing differences in current health status and ensuring equal opportunities and resources to enable all people to achieve their fullest potential. This includes a secure foundation in a supportive environment, access to information, life skills and opportunities for making healthy choices. People cannot achieve their fullest health potential unless they are able to take control of those things which determine their health. This must apply equally to women and men.

Health promotion works through concrete and effective community action in setting priorities, making decisions, planning strategies and implementing them to achieve better health. At the heart of this process is the empowerment of communities, their ownership and control of their own endeavours and destinies.

Community development draws on existing human and material resources in the community to enhance self-help and social support, and to develop flexible systems for strengthening public participation and direction of health matters. This requires full and continuous access to information, learning opportunities for health, as well as funding support...’

BOX 9.7: MAKING OUR VOICES LOUD: BEATRICE WERE

The general feeling is that HIV is for the wretched people in society. For me as a university graduate, it was terrible for people to hear this. The elite still feel that HIV is not something for them. They live in the greatest denial... I have made people appreciate that people living with HIV are not stupid people. They are able to see you looking like them, clean, reasoning sensibly, and that makes me happy that I have demystified the fears and the misconceptions...

The advantage is that we are not involved in tokenism as it was before in Uganda... you were brought out to sing, give your testimony, and then everybody felt very sorry. Now we are also involved in the planning, in making things move...

You cannot fight stigma in hiding. By hiding you create stigma for yourself. But when you come out and speak, you fight stigma very effectively. There is a saying in Africa ‘a baby that does not cry dies of starvation’. If we do not make our voices loud, we will not achieve what we want.
References

1 Special report: the legacy of the Paris Summit. ICASO, 1996.

Additional resources

Print


Useful websites

www.aidsalliance.org
www.aidseti.org
www.archives.healthdev.net/pwha-net
www.gnpplus.net
www.hivasiapacific.net
www.hivaidswebcentral.com.au
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Chapter 10
Women and AIDS: dilemmas, cares and hopes

by Wendy Holmes and Tamara Kwarteng

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Introduction

Increasing numbers of women are becoming infected with HIV. At the end of 2003, close to 19 million women were estimated to be living with HIV around the world. Women make up 47% of adults infected with HIV. In many cities AIDS is now the biggest single cause of death of women aged 20 to 40 years. The vast majority of HIV-positive women are in sub-Saharan Africa, Latin America, the Caribbean and Asia. In many sub-Saharan African countries, where heterosexual transmission is most common, more women than men are already infected by HIV. In sub-Saharan Africa AIDS accounts for over 70% of deaths of women between the ages of 20 and 44. About two-thirds of new HIV infections occur in people under 25 years, and young women are particularly at risk.

The epidemic threatens a woman in three ways:

• She may become infected herself.
• Because women are the main carers for the sick, she will carry the burden of looking after a child, husband or other close relative who develops AIDS.
• If she is HIV-positive, she may pass the infection to her baby in the womb or after birth.1

In this chapter we describe why women are vulnerable to HIV infection. We look at why the most common prevention strategies often do not help women. We identify prevention strategies, based on the views of women, that aim to change the factors that make women vulnerable to HIV infection.

We look at the impact of the epidemic on many aspects of women’s lives. Responses need to be broad and involve government agencies, non-government and community level groups. All sectors, not just health, need to think about how they can respond to the new needs and burdens that result from this epidemic.

We also look at the needs and concerns of women and their families in relation to pregnancy, childbirth and caring for babies in the context of the HIV epidemic. We present a framework to assist discussion of strategies to prevent parent-to-child transmission of HIV. Responses will need to vary from one setting to another taking into account the current and predicted prevalence of HIV infection among girls and women.
Why are women vulnerable to HIV infection?

There are cultural, socio-economic and biological factors that underlie the vulnerability of women to HIV.

Social and economic factors

In most societies women are disadvantaged economically and socially. They often have less access to education, information and skills training than boys. They have limited opportunities for employment and may not be allowed to inherit property in their own names or to access finance for business ventures. They often have limited access to health care services. The HIV epidemic shows up and reinforces the inferior status of women and emphasises the large gaps in social service systems. The disadvantaged position of women has a direct effect on their ability to control sexual relations within and outside marriage. Contrary to popular beliefs in most societies it is married women who are most vulnerable to HIV. Married women or those with regular partners often have the most difficulty in negotiating safer sex. Suggesting use of a condom implies a lack of trust or infidelity. Many women feel unable to challenge their partners about extra-marital sex for fear of conflict.

The tolerance and silence about men’s infidelity is proving to be deadly for millions of women and men. A study from Pune in India illustrates a situation common in many societies.

Poverty increases the vulnerability of both men and women to HIV. Global economic forces often pressure men to migrate far from home for employment, increasing the likelihood of risky sex. For women with limited education, training and employment opportunities, selling sex is often their only means to survive or to feed their children. Strategies for responding to the risk associated with sex work are discussed in Chapter 11.

Millions of girls and women are sexually exploited. They are expected to pay for life’s opportunities with sex, such as gaining admission to a crowded classroom, securing employment or a market trading license, or crossing a border. In such situations the woman has little chance to ask for safer sex.

Sexual violence is a disturbing occurrence for millions of women, with additional fears and sometimes deadly consequences in the HIV era. The physical trauma of violent sex makes transmission of HIV more likely.

Biological factors

There is some evidence that women are more likely to become infected if exposed to HIV during unprotected vaginal intercourse than a man. This may be because there is a larger surface area within the vagina that is exposed to male secretions and after intercourse male secretions remain in the vagina for longer than the penis is exposed to female secretions.

Young women may be more vulnerable to infection because the lining of the genital tract is immature. Older women may also be at more risk because of the thinner lining of the vagina after menopause. Women are also likely to be more susceptible to infection with HIV during pregnancy and post-partum. At this time alterations of the healthy vaginal bacteria such as candidiasis and bacterial vaginosis are more likely – these increase the risk of transmission. Also the lining of the cervix is more exposed.
and there are immunological changes likely to facilitate transmission of the virus across the mucosa.

The sexually transmitted infections (STIs) that cause ulcers, especially syphilis, chancroid and herpes simplex, significantly increase the risk of HIV transmission. Women may have these infections without knowing because the ulcer is hidden. Non-ulcerative STIs such as gonorrhoea and chlamydia, may cause inflammation and increase risk of transmission of HIV, but without symptoms. So the woman is unaware that she is infected and does not seek treatment. Other reasons why women are less likely to access treatment for STIs include:

- shame associated with STIs;
- difficulty in getting to clinics;
- lack of money to pay for treatment;
- other responsibilities;
- negative attitudes of health workers.

Certain sexual practices may increase the risk of HIV infection for women. In some societies there is a belief that sex is more pleasurable when there is increased friction, so women use herbs, cloths or a variety of other substances to dry and heat the vagina. This practice may cause irritation of the vagina and increase vulnerability to HIV.

HIV can spread more easily through anal sex than through vaginal sex. Heterosexual anal sex is much more common than most people recognise in most societies. Couples may have anal sex to preserve virginity, to avoid pregnancy, for sexual pleasure and in a search for sexual variety.

### What impact does HIV have on women?

The HIV epidemic affects many aspects of women’s lives, especially when the rates of infection are high in the community. Young girls may fear having boyfriends, or worry about an arranged marriage. Women and girls have an additional reason to fear rape. Women with boyfriends or husbands worry about how to persuade their partners to be faithful, or to use condoms. Many women, as well as men, do not like condoms and feel that their long-term use interferes with a loving relationship.

If women have received a test result that shows infection with HIV they may worry that others will find out. The burden of secrecy can be great. Women may be rejected by their families or employers if they disclose their status. Even where HIV infection is very common it is still seen as linked to promiscuity. This means that women with HIV often face more discrimination than positive men.

Women are more likely to be tested for HIV than men – especially if there is routine testing in antenatal clinics as part of programs to prevent transmission of HIV to babies. Pregnant women often decide not to tell their husbands or family that they have been diagnosed with HIV for fear of stigma and rejection.

Whether women are subsistence farmers or in the workforce their workload is likely to increase as fellow workers become ill or die. Nurses, midwives, health care professionals and volunteers have to cope with uncertainty, rapidly changing knowledge, their own fears, and not being able to cure the disease. Dealing with the fears of women and their families, and with sick and dying children, is very stressful. The need to keep their knowledge of patients confidential can also be a burden. It is easy for them to feel overwhelmed.

In most cultures caring for the sick is the duty of women. Women may find themselves caring for a sick husband, and sick children, and they may be ill themselves. Elderly women may find themselves caring for sick adult children.
Similarly, women are expected to take on the care of orphaned children. This is becoming a very great problem in many countries where women of reproductive age are becoming ill with AIDS and dying, leaving young children. This means that there is an increasing number of small babies whose mothers are too ill to care for them or have died. Traditionally an aunt or grandmother would care for the baby, and often breastfeed the baby. But the multiple burdens of the epidemic may strain these traditional coping mechanisms. The need to care for orphaned babies may mean that older girls cannot attend school, or that elderly people cannot tend their fields and become exhausted.

The HIV epidemic increases the needs of women to be able to generate income. When husbands become sick and die women often lose their source of financial support. Lack of property and inheritance rights add to their risk of increasing poverty. Health care and funeral costs also add to the financial burden on families.

Do current prevention strategies work for women?

Four main messages form the core of many programs for preventing the sexual transmission of HIV:
• abstain from sex;
• have one faithful partner;
• use condoms always;
• get appropriate treatment for STIs.

When we examine these strategies we see that they are not relevant for most women. Many women have only one sexual partner. Many women are forced to sell or exchange sexual intercourse for economic reasons. Messages that encourage condom use are usually aimed at men. It is men that use condoms. Studies with sex workers have shown that some women are able to persuade men to use condoms, but this remains a rare skill. Most men do not use condoms and most women do not have the ability or power to protect themselves in this way. 'Women have little choice. To ask is to risk conflict; not to ask is to risk infection and death'.

Many women do not have the choice to abstain from sex. They do not have the power to insist that their partner be faithful to them. This quote from a study in Uganda shows how helpless women feel:

My husband has not yet learnt the bitterness of AIDS, so there is a likelihood that I will [get AIDS] because he loves other women.

To protect the lives of women and children it seems that we really need a social revolution to change the power imbalances in relationships and in society. In the past decade advocacy by women's groups has led to some progress. But in the short term we need to identify ways to prevent the spread of HIV that women are able to control.
How can women protect themselves from HIV infection?

Strategies need to address both the immediate needs of women as well as the underlying social, cultural and economic factors that contribute to their vulnerability. Immediate needs include basic information about HIV and other STIs, access to condoms, and support for home-based care. Longer-term strategies that promote mutual respect between men and women and equal access to resources are also needed. In all societies women and men have different roles and responsibilities but they should have equal rights and status. It is important to advocate for changes in social attitudes and legislation that protects the human rights of women, such as the right to inherit and the right to have children.

Strategies to meet immediate needs

Extending information about HIV infection

Many programs have emphasised delivering information about HIV to women who are thought to be at high risk of HIV infection – for example to women who work in beer halls, to sex workers, or to young women. But it is not possible to predict accurately which women in a community are at risk of HIV. For example, in many communities married women are at great risk of infection with HIV through the behaviour of their husbands. So it is important to think about how to reach all women, single and married, young and older women, with the information that they need to protect themselves.

Studies show that it is most effective to introduce the subject of sexual health in school at an early age, if possible before young people become sexually active. It is important to have discussions with children about sexual relationships and responsibilities, respect, gender issues, and positive aspects of sex as well as about the risks of pregnancy, STIs and HIV. It is also appropriate for children to learn about the impact of the spread of the epidemic on individuals, families and communities to discourage stigma and encourage caring attitudes. Discussion and support groups can help women build and maintain confidence in themselves.

Women are more likely to be receptive to information and advice gained through their family and friends. Small campaigns involving discussion groups or peer-led communication that draw on existing networks of friends, family, youth, and church groups, may have more significant and lasting impact on women than mass media campaigns.

In some situations training in assertiveness may be appropriate. The training method will depend on the cultural context. Encouraging assertiveness skills in marginalised women, for example, women in prison, will require a different approach to training women in a society where the status of women is generally low. Role-plays can be useful. Training in social and craft skills can contribute to a sense of competence and strengthen self-esteem. However, it is important to discuss possible reactions to girls and women who display more assertive behaviour. Unless general community attitudes change girls and women who assert themselves may be shunned or be at increased risk of violence.

BOX 10.2: ADOLESCENT PEER EDUCATION IN INDIA

An AIDS prevention project in an Indian city trained adolescent girls to be peer educators. The program was very successful: the girls became more confident and were able to teach others about issues related to sexual health. However, there was concern among older project staff that the girls might now be at some risk because of their confident behaviour, and might find it difficult to find marriage partners. Knowledge about sex and reproduction is usually hidden from girls until they marry. Some may believe that these young girls acquired their knowledge through experience rather than through education and so may be rejected. The project staff decided to broaden the subject matter of the training, for example to include ‘child health’, to avoid the perception that this was ‘sex training’. They also planned to include discussion of gender roles, communication skills and life skills. They arranged for adolescent peer educators to be linked with the adult women peer educators.

In some situations training in assertiveness may be appropriate. The training method will depend on the cultural context. Encouraging assertiveness skills in marginalised women, for example, women in prison, will require a different approach to training women in a society where the status of women is generally low. Role-plays can be useful. Training in social and craft skills can contribute to a sense of competence and strengthen self-esteem. However, it is important to discuss possible reactions to girls and women who display more assertive behaviour. Unless general community attitudes change girls and women who assert themselves may be shunned or be at increased risk of violence.
Involving men
Societies’ norms and expectations put boys and men at risk of infection with HIV, unless they have information and access to the means to protect themselves. They then pass the infection on to women and possibly to their children, usually without knowing that they are infected. Men have a right to the information that their behaviour may cause the death of themselves, their wife and their babies. Men are often the decision-makers in relation to sex, pregnancy, childbirth and infant feeding. Effective strategies to prevent transmission of HIV, for example, use of condoms or abstinence, are largely under the control of men. For these reasons HIV prevention and care programs must make efforts to assist men to change risky behaviour. Men as well as women need to know how to use condoms. We need to understand that men can find it difficult to admit that there are things that they do not know about sex. Men also need to be engaged in discussions of how to reduce sexual violence. It is important that both men and women are presented with the same safer sex messages, although this may occur separately.

HIV prevention activities that involve only women may lead to resentment from male community leaders. This is less likely to happen if they are consulted and understand the purpose of the activities.

Access to services
There has been a welcome move towards integration of reproductive health services, including STI prevention and treatment, family planning services, and maternal and child health care services. HIV prevention activities for women work best when they can be integrated with other services. Women’s access to STI diagnosis and treatment services may be constrained by social stigma and economic factors, but they are more likely to be able to attend family planning or maternal and child health services. Ministries of Health of many countries are trying to achieve this integration, but it is not easy. Training of health staff has generally been separate. Involving men in family planning, antenatal care, and child health care is also difficult because they have often been seen as ‘women’s business’.

New technologies
In recent years researchers have given more attention to the development of affordable technologies for preventing HIV infection which can be controlled by women. These include improving the female condom, and the development of an effective microbicide.

The ‘female condom’ is made from polythene film. It is like a plastic bag with a flexible ring at each end. A woman can easily insert the condom by squeezing one ring and placing it in position over the cervix. The other ring rests against the vulva outside the vagina. A study sponsored by UNAIDS in Thailand in 1997 showed that STIs dropped by 34% and unprotected sex fell by 25% among sex workers when they had access to female condoms. Sales of the female condom have been increasing in countries of central and southern Africa, and several studies have shown that many men and women like them.

A common advantage of the female condom mentioned by women who have used it is that a woman can use it without talking about it or needing any active cooperation from her partner. It can be put in place hours before intercourse, so a woman can protect herself in unpredictable circumstances. UNAIDS has been promoting use of the female condom and has negotiated with the manufacturer for a cheaper price. However, the female condom remains more expensive than the male condom and this is the main barrier to its use. In some countries the government provides male condoms free or at subsidised prices. NGOs can provide women with information and advocate for greater subsidies and wider availability of the female condom.
A ‘microbicide’ is a substance that is suitable for use in the vagina (or the rectum), which will kill the virus, and could also reduce the risk of STI infection. If these substances cause irritation and inflammation in the vagina they may increase the risk of transmission of HIV. At present there is no microbicide available that has been proved to be safe and effective. Studies of the spermicide nonoxynol-9 suggest that it will not be a useful microbicide. There are a number of compounds ready to start large-scale efficacy trials, but researchers face many difficulties in setting up ethical clinical trials of potential microbicides.

Work on female-controlled prevention methods needs to have greater priority and funding. Female condoms and microbicides are not alternatives to male condoms, but provide women with options that are under their control. Although NGOs may not be involved themselves in the development of these technologies they can advocate for further research and increased availability. They can also contribute to discussion of difficult ethical considerations when planning trials of these methods.

**Strategies which address the social and economic factors that make women vulnerable**

It is not just men’s behaviour that puts women at risk, but characteristics of the relationships between men and women. To try to change these relationships in the long term it is important to provide opportunities for boys and girls to share experiences and to discuss their roles while they are young. If this happens within the community as well as at school – for example through presentation of a drama or puppet show followed by discussion – then adults may also think about their own relationships. The Stepping Stones manual outlines a series of participatory exercises to stimulate community discussions. This has been an effective way to enable communities to address social problems and gender communication barriers that contribute to men’s and women’s vulnerability to HIV.11

Initiatives which assist girls and young women to continue their education are also important. This may mean assisting communities to identify and support those in need of help with school fees, school uniforms or books. Some girls are unable to attend school because they are looking after younger siblings. Supporting local community child care arrangements may help these girls to attend school or further training.

Schemes which offer young women opportunities to earn an income or obtain low interest credit are needed to provide alternatives to sex work. This is particularly important in areas where migration of young women to enter sex work has become common, and in areas where men visit sex workers. We should not see these as ‘rehabilitation programs’ for female sex workers, but as broader development initiatives which increase the range of options available to low income women.

**Policy making and the law**

The decision-making bodies of national AIDS programs should include women from various backgrounds, not only senior health professionals. NGOs can play an important advocacy role. HIV policy should include consideration of legal issues and population policy such as school leaving age, minimum age of marriage, family planning and social welfare issues. In many poor countries there is no provision for social welfare. Where it does exist the process of application for assistance is often a barrier, especially for rural and illiterate women.
Laws which deny women the right to independent ownership of property or access to financial credit reinforce the economic dependency of women. The removal of such legal barriers could provide women with options other than prostitution. Measures that reduce the economic dependence of married women may assist in increasing their power to negotiate condom use and to discuss infidelity with their husbands.

**Strategies to lessen the impact**

A wide range of strategies is needed to address the broad impacts of the HIV epidemic on women, and help them to cope. It is important that a variety of organisations and sectors consider what they can do to help. There is a danger that HIV-specific projects may be viewed as being responsible for all responses to the epidemic. Women have different needs and preferences so a variety of responses is needed. For example, support for women’s groups is helpful, but some women prefer not to take part in collective activities. Religious groups are often the first to organise help for home-based care and orphan support. But women with different beliefs may not feel comfortable to seek assistance from church groups.

**Women’s groups for advocacy and support**

Women have traditionally helped each other in times of difficulty. Many new women’s groups have been established in response to the HIV epidemic, and existing women’s organisations have taken on new roles in relation to new problems. These organisations may be local, national or international. International umbrella organisations can be a great support to local groups. NGOs can play an important role in providing information about international and national women’s groups and networks. For example, the International Community of Women Living With HIV/AIDS was established in July 1992 at the International Conference on AIDS in Amsterdam, when a group of HIV-positive women from 27 countries came together. The Society for Women and AIDS in Africa (SWAA), a pan-African NGO led by women, works to empower women to address the causes and consequences of the epidemic on women in Africa. There are now several hundred members of SWAA in 30 African countries. Since 1990 it has grown from an NGO whose initial engagement was in providing education, information, and general awareness to one advocating for the development of policies to ensure that women become an important focus of national HIV programs.

Electronic communications have increased the ability of women’s groups to communicate with each other and to access up-to-date information cheaply. But many poor countries lack the telecommunications infrastructure necessary for access to email and the Internet. NGOs and funding agencies may be able to help small groups to be able to use electronic communications.

**Community mobilisation for home-based care and orphan support**

Good coordination is needed to ensure that the chronically ill and dying continue to receive follow up care and support when they leave the hospital or clinic. Home-based care is less expensive and often preferred by both patients and carers. But home-based care requires support. It is also necessary to mobilise community support to assist in the care of orphans within their own extended families or local communities. These issues are discussed in more detail in Chapter 8.

We also need to develop mechanisms that provide health care workers with support and reduce feelings of isolation and frustration. These might include the distribution of newsletters and regular meetings where health care workers can speak freely.

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**BOX 10.3: THE COST OF RECEIVING FINANCIAL SUPPORT**

In a southern African country rural women caring for an orphaned child have to come into town each month to receive a small amount of financial support from the Social Welfare Department. The cost of transport and the time involved make it uneconomic to claim the benefit.
Income-generating activities and small loans schemes

Since there is a clear relationship between poverty and vulnerability to HIV, micro-finance schemes have an important role to play. Many small income-generating projects and revolving loan or micro-credit schemes have failed due to lack of careful planning and management. It is best if NGOs with experience in responding to the HIV epidemic can make links with micro-finance organisations or community banks. It is important not to underestimate the barriers to setting up a successful small business. Local business opportunities need to be analysed carefully.

Women’s dilemma: having children in the era of the HIV epidemic

Children are highly valued in most cultures. In many societies, a woman’s role and status are closely linked to childbearing. There may be strong family expectations that a newly married couple will soon have a baby. For many reasons women who know that they are infected with HIV, or who fear that they may be, may still want to become pregnant.12

One of the dilemmas in preventing heterosexual transmission of HIV is that the practice of safer sex through consistent condom use also prevents pregnancy.

Although voluntary counselling and HIV testing services are becoming more widely available, most women in resource-poor settings do not know whether they are infected with HIV or not. Awareness of the possibility and consequences of mother-to-child transmission is increasing so women may fear becoming pregnant, and need access to good advice and contraception.

Pregnant women may fear that the baby might be infected with HIV during pregnancy or childbirth, or through breastfeeding. They need supportive counselling and information about risks. This should include honest acknowledgement of areas of uncertainty. They may want to consider termination of pregnancy where it is legal. There are actions that couples or women themselves can take that can reduce the risk of transmission to the baby and this can help a woman to regain a sense of control. If a pregnant woman knows that she has HIV she may be able to take an antiretroviral drug to reduce the risk that HIV will pass to the baby.

Stigma and the fear of discrimination are great sources of distress. Many women who know that they are infected with HIV live with secrecy because they fear discrimination.5,6 Pregnancy may be accompanied by worry that their HIV status will become known. This worry may influence women’s willingness to attend antenatal care, to be tested for HIV, and, if positive, to accept interventions to reduce risk of transmission to the baby.

Once the baby is born parents need support to cope with uncertainty until the baby is old enough for diagnosis of infection. Until then every symptom is likely to provoke anxiety.

For a mother, the illness of her baby may be the way that her HIV infection, and that of her husband, first comes to light. She may have been blamed by her husband’s relatives for the recurrent illness and failure to thrive of her child. She has to cope with the burden of recurrent illness of her child without hope of recovery. This is likely to involve many trips to clinic, hospital or traditional healer which cost her money, time and distress, and affects her other children. She may also need help with feelings of guilt, or anger with her husband.
Many mothers, fathers and siblings have to cope with the loss of their baby, which may follow the deaths of other babies or other family members.

When HIV-positive mothers become ill they worry about who will care for their children when they can no longer do so. The uninfected children of infected mothers tend to have worse health and a greater risk of dying than the children of uninfected mothers in the same settings.

**Contraception and HIV**

HIV-positive women have the right to make an informed choice about whether they want to become pregnant or not. Those who want to avoid pregnancy need advice about contraception. When HIV-positive women choose not to breastfeed they are likely to become pregnant again quickly unless they are warned about the rapid return of their fertility and have access to contraception. Promoting contraception to prevent unwanted pregnancies in the general community will reduce the numbers of babies born to infected women who do not know their HIV status.

Only the male and female condoms are known to provide good protection against HIV infection. Female barrier methods, including the diaphragm, cervical caps and the female condom, reduce the risk of other STIs, including gonorrhoea, chlamydia and trichomoniasis.
At present there is no evidence that oral contraceptives, injectable contraceptives or intra-uterine devices increase vulnerability to HIV infection. The spermicide nonoxynol-9 may cause some inflammation of the vagina and thereby increase the risk of infection with HIV. Women should be warned that douching (washing inside) the vagina, or using substances in the vagina to prevent conception, may cause inflammation and increase risk. Sex workers who wash out the vagina after sex to avoid pregnancy might increase their vulnerability to HIV by causing inflammation of the mucosal lining of the vagina.

Intra-uterine contraceptive devices (IUDs) should not be given to women who have multiple sexual partners or whose partner has multiple partners because they are at high risk of STIs. When a woman with an IUD becomes infected with an STI there is a higher risk of complications such as pelvic inflammatory disease.

At present it is reasonable to recommend oral contraceptives, injectable contraceptives or IUDs to women infected with HIV. A study in Kenya found that the rate of complications with use of IUDs was no higher in HIV-positive women than in HIV-negative women. However, it is important to encourage HIV-positive women, when it is in their power, to use condoms as well to prevent re-infection and transmission of HIV to others.

**Parent-to-child transmission of HIV: prevention and care**

There have been important advances in preventing HIV passing from infected mothers to their babies, and these are slowly becoming available to more women. NGOs have an important role to play in this difficult area. Preventing HIV from passing from an infected mother to her baby is often thought of as a hospital or clinic service that begins with identifying which women are infected with HIV in the antenatal clinic. However to reduce the number of babies with HIV infection in a community we need a broad approach that includes interventions to prevent women becoming infected with HIV when they are pregnant, during labour and during lactation, as well as interventions to reduce the risk of transmission to the baby when the mother is already infected. Table 10.1 (see page 223) provides a framework for thinking about the range of primary and secondary interventions that will help to reduce the number of children with HIV.

As in other areas of the response to HIV, NGOs can play an important role by working closely with government services.

It is helpful to think about preventing parent-to-child transmission (PTCT) of HIV within a ‘child survival’ approach. This emphasises the need for balance in counselling women about infant feeding so that they can make the safest choice for their circumstances. This approach also highlights the need to provide follow-up care and support for mothers found to be positive to enable them to live longer and happier lives and to care for their children.

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1. This framework is consistent with the WHO/UNICEF/UNAIDS ‘four-prong approach’ which recommends four integrated strategies: 1. Preventing HIV infection in young people and women of childbearing age; 2. Preventing unwanted pregnancy among women with HIV infection; 3. Preventing transmission of HIV from an infected mother to her infant; 4. Care and support. See www.unaids.org/publications/documents/mtct/mtct_TU4.ppt.

2. We use the term ‘parent-to-child transmission’ (PTCT) when talking of public health and policy aspects to acknowledge the role of the father in transmission of HIV to children. We use the term ‘mother-to-child transmission’ (MTCT) when referring to the risk of transmission from an infected woman to her baby.
Mother-to-child transmission (MTCT) of HIV has been a difficult area to study and much uncertainty remains about influences on the risk of transmission, including patterns of breastfeeding. In Chapter 1 there is a summary of knowledge of mother-to-child transmission of HIV. It is important to keep up with the findings of new studies – Internet searches can help you to do this.

Despite these uncertainties we can reduce the number of babies infected with HIV by paying attention to factors which we know increase the risk. The interventions that can help to prevent PTCT of HIV relate to areas of life that have great cultural and social significance – sexual behaviour, the desire to have babies, pregnancy, childbirth, the post-partum period, and infant feeding. They are areas of intimate concern to women, yet often governed by men. Community education needs to include men and older women as well as young women.

**Primary prevention**

Of course the most effective and important way to prevent transmission of HIV from mother to child is to prevent young men and women from becoming infected with HIV. Community education to raise awareness that babies can be infected with HIV can contribute to primary prevention by appealing to men’s sense of responsibility for their families.

It is especially important to prevent women becoming infected with HIV during pregnancy or while lactating. We can think of such strategies as primary prevention specific to prevention of HIV infection in babies. This is because the peak in viral load that occurs in the weeks after infection means that the risk of transmission to the baby then is higher than for a woman who has been infected for longer and has a low viral load. Husbands may become infected through unprotected sex outside marriage during pregnancy or the weeks after the birth. They will then be particularly infectious due to a high viral load when they begin to have sex with their wives again.

The introduction of a routine evening ‘couple’ antenatal visit would provide an opportunity to give the man information about the risk for his wife and baby if he has unprotected sex outside the marriage while his wife is pregnant or breastfeeding. Men have a right to this information. The couple visit could be promoted in relation to the need to diagnose and treat for infectious diseases generally, rather than with a focus on HIV, and to plan for emergency transport for delivery. If VCT for HIV is available then the couple could be counselled together and the issue of blame addressed with both present. The woman could be asked at the first visit whether she is willing to be counselled about testing with her husband.

Visits around the time of delivery offer an important opportunity to give the father advice about the importance of using condoms or remaining abstinent to protect the health of his wife and baby. Many men feel a new sense of responsibility with the birth of a new baby. There may be ceremonies or events around the time of birth which could be used as an opportunity to counsel and provide information and condoms.

Blood transfusion during childbirth is another potential source of infection to the woman and then to the baby. There is a need to minimise these through training midwives in active management of third stage of labor and introducing strict transfusion criteria in hospitals. Women should not receive a transfusion except to save their life.
Other activities to prevent new infections during and after pregnancy include:
• promotion of the idea of planning for pregnancy;
• improving access to VCT (outside pregnancy) for couples;
• promotion of condoms;
• strengthening detection and management of STIs;
• developing communication materials to support these activities, especially addressing men.

Sometimes a couple seek advice because they have a strong desire to have a baby but know that the man is infected with HIV and the wife is uninfected. They need advice about how they can maximise the chance of pregnancy while minimising the risk of transmission of HIV to the uninfected partner. It is possible to teach women how to recognise when they ovulate by noticing the changes in their cervical mucus (see Box 10.4). The couple can be advised to have unprotected sex at this time once each month. At all other times they should use condoms to reduce the risk of infection to the uninfected partner. This approach minimises but does not eliminate the risk that HIV will pass to the woman, so it is important that the woman is also counselled alone to be sure that she understands and is willing to take the risk. But she is less likely to become infected in this way than if the couple simply have unprotected sex throughout the month because they want a baby.

If VCT is offered in the antenatal clinic it is important that women or couples who test negative receive counselling to try to prevent the woman becoming infected later during the pregnancy, or afterwards while breastfeeding.

**Secondary prevention**

Secondary prevention means preventing transmission of HIV to the baby when the mother is infected. Many countries have begun to implement secondary prevention interventions that depend on testing women for HIV during pregnancy. These include antiretroviral prophylaxis, avoidance or modification of breastfeeding and elective caesarean section. We discuss these hospital or clinic-based interventions, as well as those that can be promoted for the population in general in order to reach infected women who do not know their status.

**Population-based secondary prevention**

Many women infected with HIV do not know that they have the virus. Many women do not yet have access to antenatal VCT, and those who do may prefer not to be tested for HIV, or may not be in a position to decide. There are secondary prevention interventions that will assist the health of women and men in general, and do not depend on knowing which pregnant women are HIV-positive. For example, improving information and access to contraception helps to prevent unwanted pregnancies, including unwanted pregnancies of women who are unaware that they are infected with HIV. Poor nutrition and frequent infections tend to increase viral load, so it is important to help pregnant women stay healthy. Exclusive breastfeeding is likely to carry a lower risk of transmission of HIV to the baby than mixed feeding, so promotion of exclusive breastfeeding for all babies will be likely to lower the number of babies with HIV.

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**BOX 10.4: CERVICAL MUCUS**

Cervical mucus – which can be felt at the entrance to the vagina – changes throughout the menstrual cycle. Immediately after the menstrual period there are several dry days with little or no discharge. As the oestrogen levels rise sticky white or cream mucus begins to appear at the entrance to the vagina. On separating the fingers this mucus breaks easily. The amounts of this mucus increase as the days go by. Two or three days before ovulation the mucus becomes much more profuse, clear, stringy and slippery. It looks like raw egg white. On separating the fingers the mucus stretches for two or more inches (five or more centimetres). After ovulation this type of mucus changes abruptly and the mucus becomes sticky. Sexual intercourse on the second or third day of the slippery fertile mucus is most likely to result in conception.
Population-based secondary prevention interventions include:

- preventing unwanted pregnancies;
- training health workers to counsel women with chronic illness to postpone pregnancy until they have been well for six months;
- promotion of quality antenatal care with treatment of STIs and other infections, and nutrition advice;
- training of midwives and traditional birth attendants to reduce unnecessary obstetric interventions;
- promotion of exclusive breastfeeding for all;
- breastfeeding training for health care workers to minimise breast problems.

These interventions can be integrated with existing women’s and children’s health programs.

**Hospital or clinic-based secondary prevention**

These interventions are possible when the woman knows her HIV status. In some settings there are pregnant women that already know that they are infected with HIV — they need advice and information about these interventions. Routine offering of HIV testing in the antenatal clinic is becoming more common, but it is still unavailable in many resource-poor settings.

**Antiretroviral prophylaxis**

A 1994 US study showed that zidovudine given during pregnancy, intravenously during labour, and for six weeks to the baby, reduces transmission by 68%. Since then there have been a number of randomised controlled trials of shorter and simpler regimens of antiretroviral drugs given in the last month of pregnancy or at the time of delivery. In Thailand, administration of a short course of zidovudine for four weeks during pregnancy, with oral doses during labour, was found to reduce the risk of transmission by half; the babies were not breastfed. In breastfed populations this regimen is less effective. A study in Uganda showed that a single dose of the non-nucleoside reverse transcriptase inhibitor, nevirapine, given at the time of delivery to the mother, and then to the newborn, reduced the risk of HIV infection by half. This is a very low cost and practical intervention, and has been approved by WHO. Studies are being conducted to determine whether transmission can be reduced by giving antiretroviral drugs to the baby during the breastfeeding period. If pregnant women with HIV meet the WHO criteria for treatment they should ideally receive full combination antiretroviral therapy. This will lower their viral load and lower the risk to the baby. There are also studies underway to determine the safety and efficacy of giving pregnant women who do not yet need HIV treatment combination antiretroviral treatment for 6 or 12 months so that they can breastfeed more safely. We do not yet know the effects on the mother and baby of stopping treatment.

**Elective caesarean section**

Caesarean section before the onset of labour allows the baby to avoid contact with the mother’s blood and cervical secretions. Studies show that elective caesarean section can reduce the risk of MTCT by 50 to 66%. However HIV-positive mothers may have a higher risk of complications than HIV-negative women. In resource-poor settings it is important to consider the safety of caesarean section, the cost, whether women can access caesarean section, and whether they will be able to do so for future pregnancies. The need to explain to others why they are avoiding labour may cause a problem to some women.

Unless the woman has access to a very safe caesarean section it is better to have a vaginal delivery. This is because while the death of a baby is always sad, the death of a mother is a tragedy for her family and the community, and puts the lives of her other children at risk.
HIV and infant feeding counselling

In guidelines published in January 2001, WHO, UNICEF and UNAIDS recommend that women known to be infected with HIV should exclusively breastfeed their babies unless replacement feeding is acceptable, feasible, affordable, sustainable and safe. The guidelines stress the importance of protecting, promoting and supporting breastfeeding as the best method of feeding for infants whose mothers are HIV-negative or who do not know their HIV status.

HIV-infected pregnant women need advice and counselling to help them to make an informed decision about whether to breastfeed or not. Weighing the risks has been difficult in resource-poor settings because we know little about the safety, affordability and practical problems associated with alternatives to breastfeeding.

If a woman chooses not to breastfeed she will need support to provide an adequate replacement safely. Where few women are infected with HIV it may be possible for women who cannot afford infant formula to receive subsidised or free formula for six to 12 months. Where HIV prevalence is high it will not be possible to supply commercial infant formula for all babies who need it. Care must be taken to ensure that breastfeeding in general is not undermined by the availability of free or subsidised infant formula.

It is possible to make homemade formulas (Box 10.6) from animal milks, such as cow, buffalo or goat milk. Unmodified animal milk has too great a proportion of protein and can damage the baby’s kidneys and irritate the gut. It is necessary to dilute the milk with water, and add sugar, for energy.

Babies need 40 x 500gm tins of commercial infant formula for six months. Homemade formula will require 92 litres of animal milk in the first six months. A lactating woman needs an extra 500 calories a day – so breastfeeding is not without cost – but it is much cheaper than providing a replacement.

HIV is killed easily by heat – the virus dies above 56°C. A woman could express her breast milk, boil it and feed by cup to her baby. Although some of the anti-infective properties are reduced, many important components are unaffected, and heated breast milk provides all the nutrients the baby needs. However it would be difficult for a woman to express her milk for weeks without the stimulation of the baby sucking at the breast. Experience suggests that this is not an acceptable option for most women. However, some women may want to try this inexpensive and nutritionally appropriate option. They will need support and advice about other alternatives in case they are unable to maintain their supply of breast milk. They will also need practical advice about boiling milk in a small pan with a lid to avoid small amounts rapidly boiling away.

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**BOX 10.5: CURRENT RECOMMENDATIONS OF THE INTER-AGENCY TASK TEAM ON INFANT FEEDING AND HIV-INFECTED MOTHERS**

- When replacement feeding is acceptable, feasible, affordable, sustainable and safe, avoidance of all breastfeeding by HIV-infected mothers is recommended.
- Otherwise, exclusive breastfeeding is recommended during the first months of life.
- To minimise HIV transmission risk, breastfeeding should be discontinued as soon as feasible, taking into account local circumstances, the individual woman’s situation and the risks of replacement feeding (including infections other than HIV and malnutrition).
- When HIV-infected mothers choose not to breastfeed from birth or to stop breastfeeding later, they should be provided with specific guidance and support for at least the first two years of the child’s life to ensure adequate replacement feeding. Programs should strive to improve conditions that will make replacement feeding safer for HIV-infected mothers and families.
- HIV-infected mothers who breastfeed should be provided with specific guidance and support when they cease breastfeeding to avoid harmful nutritional and psychological consequences and to maintain breast health.


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**BOX 10.6: RECIPE FOR COW’S MILK FORMULA FOR A BABY FROM BIRTH TO SIX MONTHS**

To make 150 mL of formula:
- 100 mL of cow’s milk
- 50 mL of water
- 10 grams (2 teaspoons) of sugar.

Boil the mixture. (Such formulas lack micronutrients.)
This method can be useful during weaning for mothers who cease to breastfeed early.

Whatever replacement is used, it is important that the mother or carer is taught how to use a cup to feed the baby. A cup is simple to clean thoroughly and does not need to be sterilised. Bacteria grow easily in bottles and teats, which are difficult to clean and need to be boiled before use. Even a newborn baby can cup feed, and cup feeding ensures that the mother or caregiver holds the baby during feeding.

It is possible that a female relative could breastfeed a baby who has an infected mother. In many cultures even postmenopausal grandmothers have re-lactated in order to feed a baby. Such traditional solutions can be encouraged.

It is important to be sure that the ‘wet-nurse’ is not infected with HIV and they should be counselled about the possibility that if the baby is infected with HIV there is a small risk that it may be transmitted to the wet-nurse.

In many countries breastfeeding is seen as an important part of mothering by the whole community. Women may find it very difficult not to breastfeed. Girls grow up expecting and looking forward to breastfeeding, a source of pleasure for the mother as well as the baby. A woman who does not breastfeed may meet with social disapproval. She needs to be prepared for this and given support. She may also feel that she is not a good mother and take time to come to terms with choosing not to breastfeed, especially if the decision has been made by a health professional or by her husband or his mother. It will be helpful to emphasise that she is a good mother because she has weighed up the risks and made a difficult choice in the best interests of her child. She can be reminded that there are many things that mothers do for their children; feeding is only one of them. Women who do not breastfeed need to be counselled to expect a rapid return of menses and fertility. Women may also be stigmatised if they are assumed to have HIV because they do not breastfeed.

There is increasing evidence from many settings that women are able to breastfeed exclusively if given information and support.

It is important to develop locally appropriate guidelines for counsellors about HIV and infant feeding. Counsellors need training in how to help a pregnant women assess the risks for her baby in her own circumstances. Whether she chooses to breastfeed or replacement feed she needs to know how to feed her baby as safely as possible.

Discussing the following questions can help a woman to decide whether she will be able to replacement feed safely:

- Can you afford to buy milk and sugar for the baby for six months?
- Is it possible for you to obtain cow or buffalo milk regularly?
- Will you be able to boil water and milk?
- Will you be able to prepare feeds in a clean way in your present circumstances?
- Will you have time to make formula and feed the baby by cup?
• Is there anyone who will be able to help you to feed the baby?
• What do you think your family/your friends/your neighbours will say if you don’t breastfeed?
• How will you feel yourself if you don’t breastfeed?
• What will you do if you have to travel with your baby?
• What will you do about feeding the baby during the night?
• What will you do if your husband, or other children, are hungry and ask for the baby’s milk?

Discussing the following questions can help a woman to decide whether she will be able to breastfeed safely:
• What will be the problems if you decide to breastfeed?
• What will make it difficult to exclusively breastfeed?
• Is there a belief that colostrum is harmful?
• Are newborn babies routinely given water?
• Is there a belief that it is important to give herbs or medicines or any other fluid before the breast milk ‘comes in’?
• Who makes the decision about when to give the baby foods in addition to breast milk?
• Are there times when you have to leave the baby and someone else usually gives the baby other milk or foods? Could you express and heat your breast milk at these times?

**Ethical considerations**

Offering HIV testing during pregnancy may have unintended adverse effects so this intervention needs to be introduced carefully. When a woman attends antenatal care she is not thinking of having an HIV test, yet may accept when it is offered because she thinks it is expected. In many studies a high proportion of those who agreed to be tested did not return for their results. Women may justifiably fear the consequences
of disclosure of their status for themselves and their children, including family conflict, stigma, isolation, fear, secret-keeping, expulsion from the family or violence. Sometimes husbands prevent their wives returning for the results and the woman then misses out on antenatal and delivery care.

Several countries have introduced group counselling before HIV testing in antenatal clinics because of resource constraints and the need to improve coverage. It is important to study the impact of group counselling on informed consent.

In many societies the meaning of ‘informed consent’ may be confusing or problematic. Women, especially young married women, may have little autonomy. They may have no experience of being asked to make important decisions and may feel anxious. Issues of pregnancy, childbirth and care of babies may also concern the husband, mother-in-law, or extended family. Whether and how they should be included in counselling can best be resolved through consultation with the community.

The majority of HIV-infected pregnant married women have been infected by their husbands, so a positive HIV test result is a ‘marker’ of HIV infection in the husband. When a woman is tested she is put in a position where she has a responsibility to inform her husband if she has a positive result. But he has not had the opportunity to receive pre-test counselling and give informed consent to knowing his HIV status. It is best if couples can be counselled and tested together, if they agree.

The test-dependent interventions offer a woman some hope for her child but leave her with the knowledge that she has a fatal disease. It is important to include follow-up care and support for the woman and her family when such a program is introduced. This may include counselling, support groups, and providing prophylaxis and treatment for opportunistic infections. The reductions in prices of lifelong treatment with combination antiretroviral drugs sharpen ethical concerns about identifying women with HIV during pregnancy without providing access to treatment. Noerine Kaleeba, UNAIDS Community Mobilisation Officer, has declared that we should not forget that the most important way to support children is to keep their parents alive: ‘As long as I am still alive and healthy, I will be able to take care of my children’.

Because of the potential for adverse effects there is a need to prepare carefully for the introduction of test-dependent interventions. They require:

- well-functioning maternal and child health services;
- accessible and acceptable VCT services;
- quality and confidential testing facilities;
- sustainable supply of antiretroviral drugs in appropriate formulations;
- community acceptance of those infected and affected by HIV;
- health care workers trained in VCT and counselling for HIV and infant feeding;
- resources for follow-up care and support of infected mothers, babies and their families.

Developing responses to PTCT

Appropriate strategies to prevent parent-to-child transmission, to provide care and support for pregnant women and mothers or carers of young babies, and to protect breastfeeding, will vary from one developing country setting to another. Interventions should be integrated with existing community-based programs, rather than establishing separate structures and processes.

Situation analysis

An assessment of the local situation is necessary to provide information to be able to prepare guidelines for counselling, training for health workers and counsellors, and materials for community education. Planning for the situation analysis and subsequent
strategies should include all those who will need to be involved in implementation of the strategies. These might include:

- health care workers
- child care workers
- counsellors
- community support group volunteers
- women and men infected with HIV
- community representatives
- officials of the Ministry of Health, of Social Welfare, and of Women’s Affairs
- traditional healers
- private doctors
- family planning workers
- traditional birth attendants
- church groups
- relevant NGOs
- business leaders.

Different settings, such as subsistence farms, commercial farm compounds, urban centres and slum communities need to be included in the situation analysis. The questions to be answered in the situation analysis need to be decided after discussion by all involved but might include:

- What is the prevalence of HIV infection among women of reproductive age?
- What are the needs and concerns of pregnant women? (This could include, for example: contraception; abortion; fear of childbirth; fear of having infected child; inclusion of husband in counselling and testing; infant feeding choices; access to antenatal care; caring for older children.)
- What are the attitudes of women and their husbands towards counselling and testing for HIV?
- What are the cultural beliefs in relation to pregnancy, childbirth, the post-partum period and infant feeding?
- Who makes decisions in relation to pregnancy, attendance at antenatal care, delivery care and infant feeding? Is it the woman, her husband, her mother-in-law or other family members?
- What are the likely consequences if a pregnant woman discloses a positive HIV test result to her family?
- What are the influences on breastfeeding practices? How common is exclusive breastfeeding? (Include questions about anything the baby might receive by mouth in the first days of life, as well as early introduction of foods and drink other than breast milk.)
- Are there any practical, safe, affordable and acceptable alternatives to breastfeeding in this setting?
- How can breastfeeding be protected in this setting?
- How much would it cost to feed a baby with commercial infant formula for six months?
- What are the needs and concerns of female relatives caring for motherless babies under 12 months?
- What roles do traditional healers play in support and care for pregnant women, and mothers/carers with babies?
- What are the training needs of health workers, traditional birth attendants, midwives, nurses, and doctors in relation to support for pregnant women and mothers with babies?
- What were weaning food practices before the emergency, and what are the current infant feeding practices?
- What can be done to support home-based care of sick babies?
• What role can the private sector (farming and business) play in contributing to support for pregnant women and their babies?
• What role can volunteer carers/counsellors play in support of antenatal women and mothers with babies?
• What advice are pregnant women currently given in relation to risk of mother-to-child transmission of HIV?
• What are attitudes towards breastfeeding and artificial infant feeding?

Planning activities

Once local information has been gathered in the situation analysis, and the latest information and guidelines from the international agencies such as WHO, UNICEF and UNAIDS have been read and shared, it is possible to plan strategies with all involved.

NGOs are often in a good position to develop capacity to address the needs and concerns of people that already know they are HIV-positive, in relation to pregnancy, childbirth, breastfeeding, weaning and child care.

They are also able to contribute to strategies to prevent women becoming infected during pregnancy and the post-partum period and lower the risk of transmission of HIV from infected mothers to children through population-based strategies.

Finally they may be able to help with the careful preparation for the introduction of specific hospital-based secondary prevention programs. If these are already in place NGOs can form useful links with hospitals and clinics to provide follow-up support.

The issues are complex so it can be helpful to use a framework such as Table 10.1 to facilitate discussion and planning for the prevention of parent-to-child transmission of HIV. The appropriateness and feasibility of different strategies will vary in different settings.

### TABLE 10.1: PARENT-TO-CHILD TRANSMISSION OF HIV – PREVENTION AND CARE

<table>
<thead>
<tr>
<th>Primary prevention (prevent infection of women and men)</th>
<th>Secondary prevention (prevent HIV passing from positive women to infants)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Non-specific interventions</strong> (Prevent transmission between men and women)</td>
<td><strong>Population-based interventions</strong> (Do not depend on testing during pregnancy)</td>
</tr>
<tr>
<td>• Reduce stigma</td>
<td>• Prevent unwanted pregnancies.</td>
</tr>
<tr>
<td>• Increase community resilience and capacity for behaviour change</td>
<td>• Encourage women with any chronic illness to avoid pregnancy until well for six months.</td>
</tr>
<tr>
<td>• Provide access to quality VCT.</td>
<td>• Improve health of pregnant women.</td>
</tr>
<tr>
<td>• Peer education</td>
<td>• Reduce risk of MTCT at delivery.</td>
</tr>
<tr>
<td>• Promote and distribute condoms.</td>
<td>• Reduce risk of transmission through breastfeeding – promote exclusive breastfeeding, train health workers.</td>
</tr>
<tr>
<td>• Improve treatment of STIs.</td>
<td></td>
</tr>
<tr>
<td>• Behaviour change communication with youth.</td>
<td></td>
</tr>
<tr>
<td>• Address problem of child sexual abuse.</td>
<td></td>
</tr>
<tr>
<td><strong>Specific interventions</strong> (Prevent new infections during pregnancy, at delivery, and during lactation)</td>
<td><strong>Test-dependent interventions</strong> (Depend on knowledge of women’s HIV status)</td>
</tr>
<tr>
<td>• Introduce as routine an evening ‘couple’ visit as the second antenatal visit.</td>
<td>• Assist HIV-positive women to avoid unwanted pregnancy.</td>
</tr>
<tr>
<td>• Counsel fathers after delivery, and provide condoms.</td>
<td>• Provide VCT for pregnant women. For those HIV-positive offer:</td>
</tr>
<tr>
<td>• Train midwives/doctors to reduce need for transfusions; implement strict transfusion criteria and safe injection practice.</td>
<td>– antiretroviral prophylaxis</td>
</tr>
<tr>
<td>• Community education about PTCT, especially addressing men.</td>
<td>– counselling to assist women to make a choice between exclusive breast or replacement feeding, and follow-up support</td>
</tr>
<tr>
<td>• Counsel discordant couples.</td>
<td>– elective caesarean section (if feasible)</td>
</tr>
<tr>
<td>• Counsel women/couples when a woman tests negative for HIV during pregnancy.</td>
<td>– counselling about termination of pregnancy (if legal)</td>
</tr>
</tbody>
</table>

PLUS: Care and follow-up support for infected mothers, sick babies and carers of orphaned babies
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Chapter 11
Focus on sex work

by Tamara Kwarteng

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Introduction

The HIV epidemic has shone a searchlight on the world of sex work. Often described as the ‘oldest profession in the world’, sex work has always existed. However, sex workers have often been subject to persecution, stigma and violence. When HIV was first identified, sex workers were immediately named as likely carriers. In some places this led to further stigmatisation and to repressive measures. Advocacy to protect their rights may need to be the first step in minimising the impact of the epidemic on sex workers. Sex workers have sometimes been the focus of effective HIV prevention, care and support programs. Research among sex workers has contributed a great deal to our knowledge about HIV transmission and effective strategies for preventing its spread. Sex workers themselves have often played a role in educating their clients about safer sex and condom use.

There has been much less attention paid to the behaviour of the clients of sex workers. One reason for this is that they are generally more difficult to reach. Studies show that clients come from a cross-section of the population.¹

Over the years, a number of different approaches to providing health promotion and support services to sex workers have been tried in many countries. They have provided us with important lessons about which strategies work. One of the most important lessons is that prevention programs for sex workers are most effective when they begin with a concern for the protection of the health and rights of sex workers.

In this chapter we describe the essential elements of preventing HIV infection among sex workers and their clients, and provide some examples.

Strategies are needed that reach sex workers, their clients, and those who manage or control them, with information and motivation to make changes that will protect the health of sex workers and the community. But strategies that aim to make it easier for people to protect their health by increasing their control over their lives are also essential. These include providing access to health care, supplying condoms, and making agreements with police which enable sex workers to carry condoms and supporting sex workers’ rights organisations. Where these enabling strategies work well, they help sex workers to put knowledge about HIV prevention into practice.
Understanding sex work

Sex work occurs in one form or another all over the world. It is practised in cities, towns and rural areas in both developed and developing countries. Studies have shown that the factors which help promote and sustain the development of sex work in a community or locality include:

- a large proportion of sexually active population;
- a high ratio of males to females; and, most importantly,
- unequal socioeconomic conditions that make sex work an economic opportunity for the worker and affordable by the client.

In addition to urban centres, these circumstances may be found in mining and industrial areas, ports, communities along main transit and transport routes, military barracks, and frontier market towns. Increasingly sex work is also associated with travel and tourism, especially sex tourism.

How is sex work organised?

Sex work is organised in many different ways. In some places sex transactions or activities take place in establishments such as brothels, night clubs, drinking bars, restaurants and massage parlours. For this formal setup, there is usually a manager, madam, and/or pimp who acts as an intermediary between the sex worker and client and takes a proportion (in some cases all) of the money earned from each transaction.

Sex work also takes place informally in a variety of ways. For example, streetwalkers or self-employed callgirls and boys do not work out of establishments and usually find their clients independently. Sometimes men or women may sell or trade sex occasionally when they need money for specific (usually urgent) purposes such as paying school fees or medical expenses. The boundaries of informal sex work are often blurred; so that a woman who has three or four regular sex partners who support her by paying her rent or children’s school fees may not regard herself as a sex worker. Similarly, exchanging sex for money or material goods — clothing, gifts — may be part of many relationships which neither partner regards as sex work.

In most countries sex work takes place in a mix of formal and informal settings. Each setting requires a different approach for preventing HIV and STI infection among sex workers and their clients.2

Who is involved in sex work?

When developing HIV responses, it is important to identify the individuals and groups involved both directly and indirectly in sex work in your community and to understand the relationships between them. These include the clients, spouses or boyfriends of sex workers, business owners, managers, madams and pimps, as well as the sex workers themselves.

Sex workers

The primary reason that people sell sex is poverty. Sex work usually pays more than other occupations available to many women and men, particularly those with little education. Sex work can be flexible, allowing other activities such as attending school or college, or caring for children.

Many female sex workers, particularly those working in brothels or bars, become involved as children or adolescents. They often migrate from rural areas or small towns to an urban setting, either because they were procured by brothels or pimps or as job seekers. For large numbers of girls and women in Asia and Eastern Europe, migration into sex work is not voluntary. They are sold into sexual slavery, often by family
members. In recent years there has been a great increase in trafficking of adults and children for sexual exploitation, especially in the countries of the former Soviet Union, and in South-East Asia. Many sex workers have been through a brutal induction period during which they are often confined, raped, beaten and humiliated.

Men also sell sexual services to men in almost all countries, even those in which homosexuality is not acknowledged. Men sell sex in recognised clubs, bars, saunas, brothels and beaches, as well as informally through chance meetings and social situations. Male sex work is usually very discreet because in most places it is illegal and there is a strong stigma associated with homosexuality. In some places, male sex workers see themselves as heterosexual and have wives and girlfriends. For example, a study of 131 bar-based sex workers in Chiang Mai, Thailand, found that 53% identified as heterosexual and a further 11% as bisexual. More than 50% had had a steady girlfriend at some time in their lives.

Women sometimes pay men for sexual services. In some countries there are escort agencies for female clients. The most visible form of male to female sex work is in tourist resorts.

The degree of control that sex workers have over their own lives varies greatly. For example, educated high-class callgirls living in their own apartment who sell sex to clients on their own terms are in a stronger position to refuse practices that they know may endanger their health. On the other hand a poorly educated sex worker living and working in a brothel, with every aspect of her daily life controlled by the owner of the brothel, has little choice about practising safer sex. Many of the world’s poorest women live and work under such conditions. The very high prevalence of HIV infection among low-income female sex workers around the world reveals the close association between HIV infection and poverty.

Groups that are marginalised and discriminated against, and therefore find it hard to get jobs, may resort to sex work to obtain an income. These may include homosexuals, and transsexual and transgender people. In some societies they have traditionally formed recognisable communities that provide a sense of identity and protection, such as the hijra of India, the waria of Indonesia, and the kathoey of Thailand. Their clients are often heterosexual men.

Clients

Clients of sex workers come from a cross-section of the population. They include all ages, classes and ethnic backgrounds. There may be stages of life when men are more likely to visit sex workers — for example, friends or relatives may take them to a brothel before their wedding, or a husband may be tempted to visit a sex worker when his wife is pregnant or during the post-partum period. In rural areas there may be seasons in the agricultural calendar when men are more likely to visit a sex worker. Research and prevention programs have shown that clients of sex workers include occupational groups such as long distance truck drivers, politicians, tourists, bureaucrats and business travellers, soldiers, miners and seafarers. The common factor linking these groups of men is that they all move around for their work and may be separated from their families for long periods of time. Some HIV prevention workers use the term ‘mobile men with money’.

Partners of sex workers

Sex workers may have sexual partners that are not clients. Studies have shown that even when sex workers use condoms with their clients, they are much less likely to use them with husbands, wives or lovers. One reason that sex workers give for not practising safe sex with their partner is that they do not want to be reminded of work. Condoms may provide a welcome sense of a barrier with clients — but they want to feel intimate with their own partner.
Owners and managers of sex work businesses

Sex work businesses refer to establishments such as brothels, massage parlours, night clubs, drinking bars, restaurants, hotels, guesthouses, or escort services, where sex work takes place or is negotiated.

The ability of sex workers to stay safe at work depends to a large extent on the attitudes and knowledge of the owners and managers of sex work businesses. These vary greatly. Some owners and managers are protective towards sex workers, and provide a safe working environment for them. This includes establishing a ‘100% condom use’ policy in their premises, making sure that condoms and lubricants are always available and excluding clients who are not willing to use condoms from their premises. But there are exploitative managers who put the demands of the clients before the health of the sex worker. Under such conditions, even when they know about the risk of unprotected intercourse, sex workers cannot insist on safe sex with clients who are not willing to use condoms.

When developing strategies to prevent HIV infection among sex workers and clients, it is important to understand the relationships with sex business owners and managers from all perspectives.

Why are sex workers vulnerable to HIV and STIs?

The rates of HIV infection among sex workers in many developing countries have been found to be much higher than most other groups in the community. The prevalence of HIV infection varies between different countries, between different locations within a country, and between different kinds of sex workers. For example, in Thailand during the mid-1990s, HIV prevalence among brothel-based female sex workers averaged more than 30% whereas ‘indirect’ sex workers had an average prevalence of just over 10%. Brothel-based sex workers had an average of 20–35 clients per week compared with 5–7 clients per week for indirect sex workers. In 1994, at the height of the HIV epidemic in Thailand, the HIV prevalence among brothel-based sex workers in the northern region of the country was almost 40% compared with 22% in the northeast region and 24% in Bangkok. In the same year, HIV prevalence among pregnant women ranged between 1.3% in the northeast and 3% in the north. HIV prevalence among female sex workers has been as high as 60% in Bombay and 52% in Abidjan, Cote D’Ivoire.

Male sex workers may be even more vulnerable to HIV infection than female sex workers because unprotected receptive anal sex poses a higher risk of transmission than vaginal sex. Male sex workers were not the target of Thailand’s 100% condom campaign and HIV prevalence remained high in this group in 1999 (between 9.3% and 12.4%).

Sex workers are at high risk of occupational exposure to infection with HIV and other STIs because they have unprotected sex with large numbers of partners. Biological factors that increase susceptibility include damage to the thin lining of the vagina (the mucosa) from the friction of frequent sex, and frequent application of agents to dry the vagina, to prevent pregnancy, or to clean the vagina between clients. These may also alter the protective mechanisms of the vagina, such as the secretions and natural lactobacilli which keep the vagina at a mildly acidic pH.

A number of social, economic and political factors increase the vulnerability of sex workers to HIV infection. They include:

- **Discrimination against sex workers.** This limits their access to legal, health care and social services. Government responses to the threat of HIV have sometimes included punitive measures against sex workers – for example
compulsory HIV testing and imprisonment of those found positive.

- **Lack of laws and policies that protect the human rights of sex workers.**
  In many countries sex work is illegal. Although the extent to which such laws are enforced varies from one place to another, in general laws against sex work increase the vulnerability of sex workers to infection with HIV. Sex workers conduct their activities secretly to avoid arrest and are less likely to seek health services. Anecdotal reports suggest that in some countries mere possession of a condom by a woman may lead to her being accused by police as a sex worker.

- **Acceptance of violence, including sexual violence, against sex workers by clients, pimps and police.** Many sex workers report that trying to insist on condom use may result in violence. Gang rapes of sex workers by police have sometimes been reported.

- **Increasing mobility** has played a key role in spreading HIV around the world. Both sex workers and clients may travel for, or in search of, work. This mobility makes effective and sustainable prevention work difficult. For example, in China’s Tibet Autonomous Region, there is a major influx of female sex workers in Spring every year from neighbouring Sichuan province coinciding with the annual influx of single male workers.

- **Concurrent injecting drug use and sex work.** People who inject drugs are often engaged in selling sex for money or drugs. For example, 3.5% of a sample of female sex workers in Sao Paolo, Brazil and 84% of street sex workers in Melbourne, Australia, had a history of injecting drugs. A study in Eastern Canada found that 34% of 552 male injecting drug users indicated that they had had sex with male clients in the previous three months for either money, goods or drugs.

It is important to ask sex workers about the factors that may increase their vulnerability when planning strategies to prevent HIV and STI infection.

**Assessing the sex work situation**

The first step in planning a response to the threat of HIV infection among sex workers is to conduct a situation assessment. In Chapter 3 we describe questions for collecting information to understand HIV in your community, including some questions about the nature of sex work. We provide a more detailed set of questions for assessing the sex work situation in your community in this section, adapted from the Healthlink publication *Making sex work safe.*

We emphasise in Chapter 4 that community participation is essential for an effective situation assessment. It is important to involve sex workers in planning, collecting and analysing information about the situation. Generally, the earlier sex workers are involved, the more useful the result will be. Training in research skills such as developing question guides, interviewing, facilitating focus group discussions and analysis will help sex workers to participate effectively. Time and place of meetings need to be convenient for sex workers and the style of meetings must not be alienating.

**BOX 11.1: EFFECTS OF LAWS AGAINST SEX WORK**

- Sex workers move frequently or live secretly to avoid arrest.
- Sex workers are brought into contact with other criminal activities.
- Frequent arrests or abuse by police increases sex workers’ sense of powerlessness and lowers self-esteem.
- Sex work establishments pretend they don’t offer sex. Condoms are sometimes discouraged because they can be used as evidence that sex work is taking place. Street sex workers do not carry condoms for similar reasons.
- Laws against clients can mean that sex workers and clients must meet secretly, which reduces the time available to the sex worker to negotiate safe sex.
- Sex workers may not have the right to expect reports of violence against them to be treated seriously by police and courts.

Source: Adapted from Network of sex work projects (1997)
The key questions to be answered when assessing the sex work situation in your community are:

- Who is involved in sex work directly or indirectly?
- How is sex work organised?
- What is the legal context?
- What sexual services are practised?
- What sexual health services are available to sex workers and clients?
- What do sex workers want? What problems do they experience?

### Who is involved in sex work?

#### Sex workers

- Where do most sex workers come from? What are their stories?
- To what extent do men and women move in and out of sex work?
- Are there any networks or associations of sex workers or relevant sexual minorities such as gay men or transsexuals? If so what do those organisations do?
- What ethnic, religious, language or caste groups do sex workers belong to?
- Do male sex workers identify as gay, bisexual or heterosexual? Do they have links to any gay community?
- Do sex workers take drugs? If so, which ones?

#### Clients

- How can clients be grouped? For example, local single men, local married men, migrant labourers, truck drivers, tourists, military men, men who identify as gay? Do groups vary in each sex work location?
- How can these groups be reached?
- When are men most likely to visit a sex worker?
- What languages do clients speak?
- Have clients been targeted by general health education campaigns? What is their understanding of sexual health?
- What are the knowledge, attitudes and practices of clients in relation to condom use, and health care seeking for STIs?

### Influences

A range of people have an important influence on how sex work operates:

- families of sex workers;
- lovers and spouses;
- people with whom sex workers share accommodation, friends and neighbours, drug dealers, sex worker organisations;
- landlords, bar and café managers, and others who allow their premises to be used for sex work;
- managers of brothels, bars, escort agencies and other formal sex businesses where sex workers operate;
- taxi or trishaw drivers, nightclub staff, advertisers and others who are paid to facilitate meetings between clients and sex workers;
- police and other law enforcement agencies;
- doctors, health and social workers, counsellors, outreach workers;
- politicians and policy makers;
- religious or community leaders;
- local community groups.

Other people who support the sex industry:

- What tasks are performed by people who do not directly provide sexual services, eg finding or getting clients, providing premises, cleaning, serving drinks or food, protecting sex workers from violence?
• What are the priorities and interests of these people?
• What are the similarities and differences between their priorities and those of the sex workers?
• How do these people relate to sex workers, clients and to each other? Is there rivalry or violence? Are there associations of sex business owners or other ways to address them collectively?
• What languages are spoken?

How is sex work organised?

Arrangement
• What are the contact sites for sex work?
• What are the transaction sites? (eg bars, sex workers' homes, car parks)?
• To what extent are sex workers free to move about?
• Are there existing sex worker organisations and what services do they provide (eg child care, legal assistance, support, education, credit union)?

Location
• Where does sex work occur?
• Where are those who influence the sex industry located?
• Where do most clients come from?
• Where are law enforcement agencies located (eg police)?
• Where are condom distribution points and health and welfare services?

Working conditions
• What is the balance of power between sex workers and clients, and between sex workers and business owners and managers?
• Does the balance of power vary according to contact/transaction site, age of sex workers, economic level of the establishment and/or the client?
• To what extent can sex workers choose or turn down clients who are abusive, drunk or refuse to use condoms?
• Is there access to running water and adequate supplies of condoms and water-soluble lubricants?
• Can sex workers communicate freely with each other?
• What other health and safety issues affect sex workers, eg compulsory consumption of alcohol, incidence of hepatitis, violence?

What is the legal and policy context?

Legal context
• What laws affect the sex industry, either directly or indirectly?
• Do the same laws and regulations apply to women, men and transgender people? If not, what are the differences?
• Are sex work businesses and activities legal or illegal? If they are illegal, do they operate through tolerance, corruption, weak laws, or inadequate resources to enforce the law?
• What penalties exist (eg fines, jail, deportation) and against whom are they used?
• Do sex workers avoid STI services because they are associated with police or other authorities?
• Are laws against rape and physical assault enforced when sex workers are the victims?
• How do police and other law enforcement agencies respond when sex workers report crimes in which they are the victims?
Policy context

- Are sex workers required to undergo regular examinations for HIV or other STIs? If so, how often and in what circumstances?
- Are sex workers given regular antibiotic injections to prevent STIs? (such injections are inappropriate and dangerous)
- What are the consequences for them of having or not having HIV and STI tests?
- What are the consequences of testing positive to HIV or another STI?
- How do sex workers and health care workers feel about the local STI policy?
- Do STI services include health education?

What sexual services are practised?

- What kinds of sex are practised by sex workers and their clients?
- Do sex practices vary according to type of contact or transaction site (eg between bar, brothel and street-based sex work) and/or geographical region (different parts of the city)?
- Do sex practices (and safe sex) vary with different types of clients and partners?
- Are people familiar with condoms?
- What are people’s attitudes to condom use?
- Where are condoms available and at what cost (and how does the cost of condoms compare with the cost of sex)?
- Are lubricants available and are they used? Are they oil or water-based?
- In which situations are condoms more or less likely to be used and why?
- Are other contraceptives used?
- What, if any, myths or misinformation exist?

What sexual health services are used by sex workers?

- What STI services are available?
- What is the quality of these services?
- Are the health services welcoming to sex workers? Have the staff been well trained?
- What symptoms do sex workers recognise as suggesting an STI?
- What medications do sex workers use?
- What do sex workers do if they feel ill? Who or where do they go first for advice?
- Are health services available at a convenient time and place?
- Do people feel stigmatised by using services?
- Does the cost of services affect whether people use them?

The methods described in Chapter 4 for collecting data will help you to gather answers to these questions. In particular the participatory mapping exercise is useful for getting visual representation of how sex work is organised in the community.

An example of a sex work situation assessment report is shown in Box 11.2.
BOX 11.2: NEEDS ASSESSMENT REPORT

Location
Coastal city at one end of a major truck route that goes through three other major cities (and many towns) within the country to the capital of a neighbouring country.

Population
500,000, of whom: men 300,000; women 80,000; children 120,000.

HIV/STI
Prevalence of HIV and STIs thought to be low among the population overall. However surveys among sex workers and men who have sex with men reveal very high levels of STIs, with a growing problem of HIV.

Major employers
Trucking company employs 1,350 long-distance drivers; military camp with 50,000 men; shipping company with 2,035 male employees; several factories with around 1,000 male employees each; two factories (textile factory and cigarette factory) together employing 1,500 women. Large informal employment sector, including street vendors and small business owners (eg kiosks, small hotels and boarding houses, unlicensed drinking establishments). Other economic activities: major daily market in the centre of the city used by farmers and other traders. Wednesday is the biggest market day attracting people for a wide area.

Housing
Most workers are migrants from other parts of the country or neighbouring countries. Transport workers include men from other countries that the truck route passes through. Few workers in the formal sector live with their families; most live in the company dormitories or small hotels that are clustered in three districts in the city.

ORGANISATION OF SEX WORK

Female sex workers
About 12,000 women work in bars, serving drinks and also, on a more or less regular basis, engaging in sex with men in exchange for money (tips). Another 3,500–4,000 live in small apartments or single rooms, sometimes two women sharing, and earn their living through the provision of sexual services. Some trade sex for money, contacting clients on the street, near small hotels that rent rooms for short periods of time, in the harbour area, or in nearby bars. A few women provide services to tourists, contacting clients in hotel bars.

Male sex workers
Approximately 1,500 young men provide sexual services to men, most of whom contact clients in the harbour area or on the beach, and a few of whom contact clients in one of the bars near a five star hotel.

Management
Women who work in the bars are generally controlled by the bar owners, many of whom are women who are former sex workers, although a few are men. The bar owners are worried that all the talk about AIDS will hurt their business. Many are wary of having any health education materials or condoms on the premises for fear of discouraging customers. In addition, they are afraid that if they had stocks of condoms, the police might use that fact as an excuse to raid the bar.

Contact/transaction site
Most bars have small rooms in the back where the bar workers can take clients for ‘quickie’ sex. Women also take clients out to their own rooms, often in the same area, for ‘all-night’ transactions.

Turnover
There is an estimated 50% turnover in the sex worker population per year (ie 50% of the women leave the area and/or stop doing sex work, to be replaced by a similar number of newcomers or returning migrants). There is also a significant amount of movement within the city, from one establishment to another, and also from one category or level of sex work to another.
CHAPTER 11: FOCUS ON SEX WORK

BOX 11.2: NEEDS ASSESSMENT REPORT (cont)

Professional career
A few sex workers manage to save up enough money to buy a bar, becoming bar owners who then hire other women to work in their bars.

Legal status
Prostitution is illegal, but the police rarely arrest anyone. Very occasionally, usually before or during a big tourist convention, or just before a big military ship is expected, police round up a lot of women and put them in camps on the edge of the town.

STI services
The family planning clinic is willing to provide STI services, but tends to be disapproving of prostitution, so few sex workers go there. The primary health care clinic has hours specifically set aside for STI services, usually in the morning before the factories open. However, few women go there, partly because of the hours (when they are generally asleep), but also because they don’t feel welcome. Running water and electricity are often cut off, making it difficult for health care workers to sterilise syringes, speculums and other medical instruments. Diagnoses are often made on the basis of symptoms. Many women treat themselves with antibiotics, bought from traditional healers and street vendors.

Condom availability
Some condoms are available from pharmacies, but are expensive. Family planning clinics distribute condoms, but are usually unwilling to give them to single women. They will only give married women 10 to 12 condoms per month, which is not enough for sex workers. In addition, the breakage rate for condoms distributed by the family planning clinic is fairly high, leading to a high distrust of condoms. No water-based lubricants are available, which may be one reason for high breakage rate.
Preventing HIV infection among sex workers and clients

To prevent HIV infection among sex workers, their clients and partners, we need to use three approaches:

- Prevent people from entering sex work.
- Reduce vulnerability and risk of those involved in sex work.
- Help those who wish to leave sex work to do so.

Preventing entry into sex work

A significant proportion of sex workers is forced by circumstances beyond their control to enter the profession. Factors which play a key role in pushing people into sex work include:

- **Poverty and limited opportunities, particularly for women and young people.** The vast majority of sex workers have few other options for making a living, often because they have little or no education and marketable skills. Women and men in low-income jobs, such as in textile factories, may need to supplement their income with part-time or short-term sex work.

- **Sexual exploitation, including trafficking.** Poverty causes families to push young daughters into sex work. Commercial trafficking of women and children by large organised crime networks occurs on a large scale within countries and at the regional and global levels. Young girls are especially vulnerable to being trafficked because their youth and virginity are associated with freedom from HIV infection.

**Strategies**

In addition to general development initiatives, where large numbers of young women are pushed into sex work, it is necessary to develop specific programs to address the underlying socio-economic issues. The best-documented efforts to prevent entry into sex work by young girls are from Thailand. Since 1992, when a national effort was launched to eradicate child prostitution and assist those at risk of entering the sex industry, a number of projects have been implemented (see Box 11.3). The main strategies used in the Thai projects were:

- **Expand education and employment opportunities for young women** by:
  - providing vocational training for young women when they complete school;
  - engaging with the private sector to provide jobs for girls after they complete their training;
  - providing scholarships to those at risk of dropping out of school to further their education in local schools;
  - providing scholarships to boarding schools for young women who cannot stay at home for a variety of reasons.

- **Strengthen the family and community structure** to create a strong culture of protecting young people from sexual exploitation by:
  - providing information about the effects of child prostitution and child abuse;
  - mobilising community leaders to help change attitudes about child sexual exploitation;
  - providing income-generating opportunities to impoverished families who are at risk of selling their children into the sex trade.

These strategies can be incorporated into existing community development projects. For example, an NGO which is implementing a women’s literacy project can identify and include young girls who may have dropped out of school early or who were never given the opportunity to attend school and provide them with basic literacy skills so that they can rejoin the education system or attend vocational training.
BOX 11.3: THE THAI WOMEN OF TOMORROW PROJECT

The main objectives of the project, which was initiated in 1992, were to change the attitudes of girls and parents in the northern part of Thailand regarding prostitution and to provide a means for the girls to avoid becoming sex workers through improved education and career opportunities.

The project encourages girls who finish Grade 6 to continue school for three more years. This is because available data shows that girls who leave school at Grade 6 are more likely to enter the sex industry than Grade 9 graduates. The main strategies of the project are:

- providing information to families about the danger of sex work and HIV;
- providing girls from poor families with scholarships to enable them to complete Grade 9;
- providing job training and placement. Four job training programs are offered: assistant health worker career program; modern fashion and design; secretarial and computer training; and assistant jewelry cutter training program. A special training skills program is also provided for girls who are too young to enter the four vocational training programs.

The project has had an impact in several ways:

- The education campaigns conducted to show families what happens to girls who are sold into sex work is helping to change attitudes in the community leaving school and going into sex work. Large numbers of girls and their parents have now opted to either continue the girls’ education or join vocational training programs.
- Of the 425 girls who have participated in the four vocational training programs:
  - 146 attended the Assistant Health Worker training program and are now employed in local government and private hospitals;
  - 75 trained at the Computer Centre and are placed in secretarial positions at several established companies;
  - 150 trained in the modern fashion and design for three months and are placed in several garment and leather-making companies;
  - 60 girls trained in jewelry business and are employed by companies in Bangkok.

Source: Adapted from UNAIDS (1999)
Reducing vulnerability and risk among sex workers, their clients and partners

Behaviour change strategies are used to inform sex workers and others about sexual health and aim to motivate people to make changes which promote health. Enabling strategies are those which help to create an environment in which sex workers can put knowledge about how to work safely into practice. Both types of strategies are necessary.

We have discussed the role of behaviour change in HIV prevention in Chapter 7. It is important to direct behaviour change efforts not just to sex workers, but also to clients and others involved in the sex industry.

Sex workers are often knowledgeable about HIV, how it is transmitted, and how infection can be prevented. Therefore behaviour change messages need to go beyond raising awareness about the virus and include education on the safety of different kinds of safe sex practices, how to negotiate the use of condoms with clients, how to obtain and use male or female condoms, how to obtain and use affordable water-based lubricants, the symptoms of STIs, contraception and maternal health issues, and clarifying misunderstandings about unsafe traditional practices and beliefs.

If clients are fully informed about sexual health they are more likely to want to have safe sex. However, clients tend to be more difficult to access than sex workers, and are not an easily identified group. To reach them we need strategies for reaching the general sexually-active male population.

Owners and managers of sex businesses, police, partners and associates of sex workers should also have accurate information about prevention of HIV and other STIs and be encouraged to promote safer sex. For example, the police can agree not to confiscate condoms or use them as evidence in prosecution. For this to occur we need to encourage well-informed political leadership and support. Education directed at people who influence the sex industry can encourage a communal culture of safe sex.

How to begin

How you begin will depend on the nature of your organisation and whether you already have contacts with sex workers. It is essential that approaches to people in sex work are made in a respectful way, with full consultation, and that sufficient time is allowed to build trust. Some organisations have begun their HIV prevention and care work with sex workers through advocacy efforts. For example, they may persuade lawyers to go to court to defend the rights of imprisoned sex workers with HIV.

Advocacy for sex workers as a group takes several forms. Since almost every country has laws about sex work which increase the vulnerability of sex workers to HIV and STIs and the effectiveness of health promotion activities, projects often urge changes in the legislation or in the ways that laws are enforced.

There might be another NGO already working with sex workers that you could collaborate with to supply behaviour change communication materials and activities. Your organisation might be able to channel funds to help the establishment of small community based organisations (CBOs) of sex workers. If such CBOs already exist you might provide funding for training in management, communication and proposal-writing skills.

Key informants can help in contacting sex workers. For example, a project in Senegal, implemented by Family Health International, used registered sex workers to approach sex workers who work in secret. You might reach long distance truck drivers through the trucking companies. Miners in South Africa were reached through the health authorities of the mining companies. In Laos, young female sex workers are reached through contact with members of the mass organisation, the Lao Youth Union.
Strategies for behaviour change communication

These include peer education, outreach, and counselling.

Experience has shown that health promotion for sex workers is most effective when it is carried out by women or men who work or have worked in the sex industry (peer educators). Clients and partners are also usually more receptive to prevention messages given by their peers (see Box 11.4).

Effective peer health promotion depends on:
• identifying peer educators that are acceptable to their peers;
• providing adequate training for the educators so that they are credible to their peers;
• providing peer educators with appropriate communication materials, condoms and water-based lubricants;
• supporting, motivating and coordinating peer educators.

For behaviour change messages, outreach is often through face-to-face discussions or group education sessions in the workplace or home, informal meeting places or local community venues. In Mozambique, a team of sex workers goes six nights a week to night clubs and drinking bars where they discuss HIV prevention with both female sex workers and male clients and distribute condoms. In the daytime, other members of the group visit market places and conduct community education, using song, dance, and role-play to get behaviour change messages across.15

Education materials are important for whatever method is chosen to convey behaviour change messages. Good education materials have a clear purpose (for example, to increase knowledge about symptoms of STIs), audience (for example, female sex workers), and message (for example, the importance of obtaining treatment for symptoms of common STIs). We describe the process of developing education materials in Chapter 7.

Counselling can help sex workers acquire valuable information and skills which are specific to their circumstances, experience or culture. It is valuable because it addresses individual experience and circumstances. It is best if counselling takes place in private. The confidentiality of those who seek counselling should be respected. Counsellors should be adequately trained and be trusted by the sex workers.

Enabling strategies

Enabling strategies help to create conditions that allow sex workers to put behaviour change strategies into practice. The best enabling strategies are decriminalisation of sex work and ensuring that sex workers have full civil rights. These are dealt with at a policy level and often take a long time to achieve, but helping sex workers to have a voice and have access to legal services is helpful.
Other enabling strategies include:
• distribution of condoms and lubricants;
• provision of sexual health and family planning services;
• training in negotiating safe sex with clients;
• alternate income generating programs;
• community development strategies;
• advocacy and civil rights.

Distribution of condoms and lubricants
Ready access to affordable condoms is central to the promotion of sexual health. In Thailand, condoms were initially distributed through public STI clinics; however, after a few years, social marketing campaigns led to decreased reliance on public sector distribution systems. Sex workers with many clients each day may complain of vaginal irritation and pain when using condoms. Lubricants reduce these problems and decrease condom breakage. Sex workers often use oil-based lubricants such as Vaseline and lotions — but these affect the latex in condoms, increasing the risk that they will break. Distribution of affordable water-based lubricants is very important for all sex workers. Male sex workers who practice receptive anal sex are at particularly high risk unless they use lubricants.

Female sex workers, like many women, often have difficulty in persuading a reluctant male client to use a condom. The female condom gives women an effective protective method which they can control. In Thailand, a group of sex workers were given the option of using the female condom if clients refused or were unable to use male condoms. Another group was instructed to use male condoms consistently. The proportion of unprotected sexual acts was reduced by 17% in the group that had the female condom option. The incidence of STIs in the group also reduced by 24%.16 The study showed that offering female sex workers an additional choice may result in better protection. Where female condoms are acceptable and affordable, they should be included in condom distribution programs.
Some methods for distributing condoms and lubricants have been described in Chapter 7. Although free distribution of condoms to sex workers is ideal, social marketing, or selling condoms and lubricants at subsidised prices, is usually more sustainable. Free distribution of condoms and lubricants can help outreach workers gain access to sex businesses or provide an incentive to sex workers to attend an STI clinic or educational session. However, in most developing countries, where the need is greatest, NGOs and community organisations do not have a steady supply of free condoms. Ideally, the owners of premises where sex is exchanged for money, such as brothels, bars, and hotels, should be persuaded to provide condoms free of charge to clients.

Organisations should develop an appropriate strategy for their own situation based on an assessment of the practicalities of supplying condoms. In general, it is preferable to employ a range of methods – free, targeted distribution, community-based distribution, health facilities and commercial outlets such as pharmacies and village stores.

To prevent HIV transmission through sex work, it is important that condoms are always used and used correctly. The ‘100% Condom Use Program for Sex Work’ (see Box 11.6) was first started in Thailand in 1989 and has subsequently been applied in Cambodia. This program has demonstrated that it is possible to get clients to use condoms. This approach is possible in formal sex work situations such as brothels and massage parlours.

The Network of Sex Work Projects has pointed out that because sex work tends to be seen as a behaviour not an occupation – who you are, not what you do – sex workers are often not recognised as legitimate partners in discussions of their conditions of employment. When a 100% Condom Use Program is implemented it is vital to involve sex workers in planning and to be aware that new possibilities for corruption and exploitation may be created inadvertently. There are alternative approaches to promoting health in sex workers, such as the Sonagachi project in Kolkata, India.

When men visit sex workers and learn about how and why to use condoms they may use this knowledge in their other sexual contacts.

BOX 11.6: 100% CONDOM USE PROGRAM FOR SEX WORKERS

The first pilot program for 100% condom use in brothels and other commercial sex establishments was launched in 1989. Findings over a two-year period showed the program was significantly effective in:

- reducing the incidence of STIs;
- reducing the prevalence of HIV in specific target populations;
- changing attitudes and practices regarding condom use;
- improving the rate of condom use in sex establishments.

The main strategy of the program is to gain the agreement of the owners and managers of all commercial sex establishments to enforce condom use as a condition of commercial sex. Sex workers should be instructed to refuse sex to any customer who refuses to use a condom. If all sex establishments enforce this policy, clients have no choice – they either use condoms or they don’t have sex. The program provides benefits to many people and organisations:

Benefits to governments and political leaders

It reduces the rates of STI and lowers the risk of HIV transmission. This in turn lowers the burden placed on the health care system. Political leaders are seen as forward-looking, responsible leaders who are taking effective action to protect people’s health.

Benefits to sex workers

The sex worker, knowing she has the support of her employer, can insist on condom use. She also knows she must refuse him if he refuses to use a condom. She and her colleagues know they are at risk of HIV infection, so they benefit by being protected from the dangers of HIV and other STIs.

Benefits to male clients

The program shows them that condom use is acceptable, expected and required. They are protected from STI, including HIV. Furthermore, by minimising their own exposure to HIV, male clients minimise the risk to their wives and other sexual partners, as well as future children.

 Benefits to sex establishments

In many communities where HIV is widespread, sex establishments are blamed and there is pressure to close them down. The 100% condom use program creates a more positive perception and tolerance for them to continue operating. Because all establishments are implementing the program, owners will not lose money. Male clients cannot take their business elsewhere. Because the health of sex workers is improved through the program, they don’t have to stop working for treatment so owners’ expenses are reduced. Owners’ improved relationship with the police and other authorities means that they become part of the solution rather than the cause of the problem. Local leaders, police and health workers need to work together to develop the program, and to ensure the agreement and cooperation of the owners of sex establishments. When they do not cooperate, they face sanctions, including warnings and the temporary or permanent closure of their businesses.

Source: Extracted from WHO Regional Office (2000)
Provision of health care and contraceptive services

Sex workers often have limited access to good quality sexual and reproductive health care services. Even when they are available, sex workers may not use health care services for reasons such as stigma, inconvenient opening hours, cost, language and other cultural barriers. Thailand's 100% condom campaign included compulsory regular attendance by brothel-based sex workers at government-run STI clinics, where general reproductive health advice was provided. However, many so-called 'indirect' sex workers slipped through the net and did not access these services.

Some projects have tried to make health care services more accessible to sex workers by promoting clinics for them. In Abidjan (Cote d'Ivoire), the Project RETRO-CI set up a confidential clinic for female sex workers called the ‘Clinique de Confiance’. To ensure confidentiality, the clinic is located in a discreet place in a popular area in town, and does not advertise itself as a clinic. It offers free STI treatment, HIV counselling and testing, and promotes the use of condoms to sex workers and their regular partners.21

Other projects have tried to improve the quality and access of existing health facilities (see Box 11.7). In Rio de Janeiro (Brazil), sex workers receive a card with a list of public health care facilities that provide good quality STI care. Clinics were put on the list if they had STI drugs available and their physicians had received training in STI care.22

It remains unclear whether it is better to set up special services for sex workers and their clients or to integrate STI services into primary health care. However, experience from a number of different countries suggests that sex workers prefer specialised services to attending primary health care clinics open to the general public. Specialised services also provide better opportunities for education and regular screening activities. As well as providing treatment, STI services can play a significant role in health promotion. Their role is particularly important where there are no other sources of health information.

Treatment with antiretroviral drugs is becoming more widely available for people with HIV. It is important to consider how to overcome unjustified barriers to treatment that HIV-positive sex workers may experience. However when people lead highly mobile or unstable lives, for example, if they inject addictive drugs, they may find it impossible to take antiretroviral drugs regularly. This results in rapid development of resistance and failure of treatment – a problem for both the individual and for the wider population. It is important to ensure that treatment programs include provision for support to help people stop using illicit drugs or alcohol so that they can access effective treatment.

Conditions which attract sex workers to clinics are:

- **A suitable location**
  Clinics should be located near places where sex work occurs. They could be in mobile units which visit sex workers. For example, services for long distance truck drivers and sex workers could be located in the truck stops where commercial sex takes place.

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**BOX 11.7: HIV AND STI CLINIC IN RUILI, CHINA**

A charitable clinic was set up to provide HIV/STI education and care to commercial sex workers in Ruili. Despite regular promotion of the clinic, few people had utilised the service. Therefore, a qualitative study was carried out among 89 sex workers between March and April 2001 to look at the background of our target group, their medical-seeking behaviours and the range of services expected. The turnover rates of sex workers were high. They had good awareness but poor knowledge of STIs/HIV. Many self-medicated or sought advice from peers. They had serious concerns about private practitioners and the quality of drugs from pharmacies. They found our clinic inconvenient and it did not meet their needs. Subsequently, we refurbished the clinic, implemented changes and retrained our staff. The number of patients treated three weeks after re-opening of the clinic has increased by three fold, with many of them still sex workers, and the clinic’s income increased by 58%. This experience has important implications for policy makers and other NGOs working with sex workers.
• **Convenient opening hours**
   Some clinics have asked local sex workers what times would be suitable for them and have altered their opening hours as a result.

• **A welcoming environment**
   A non-threatening and friendly environment is important. Some clinics provide interpreters so that people can speak a language they comfortable with. Appropriate staff training is vital.

• **Child care**
   Volunteer groups of women can often be organised and supported to promote child care when women attend clinics.

• **Short waiting times**
   Long waiting times are often a problem in busy clinics. It may help to let sex workers know the clinic’s least busy times, or arrange separate sessions. In some cases outreach workers have distributed vouchers which entitle sex workers to an immediate appointment – but be cautious of causing resentment and stigma from other patients.

• **Respect for privacy**
   Health workers should not expect people to reveal whether they are paid for sex when they begin visiting a clinic. People tend to disclose information about their circumstances only when they feel comfortable to do so. Staff can often gain information about multiple partners by skilful history-taking, without having to ask whether a person has been paid for sex.

• **Confidentiality**
   It is important that people using health care services, especially STI services, should feel confident that details about their treatment are not passed on to anyone else. Health records must be kept securely, and all staff should be trained in the importance of confidentiality. It is also important to tell and show patients the arrangements for confidentiality so that they do not feel anxious about this.

**Training in negotiating safe sex with clients**

Sex workers often have to deal with clients who want to have unprotected sex. Negotiating with a client to have safe sex, from a position of relative powerlessness, is a vital skill for sex workers.

Sex workers have several choices about how to react to demands for unprotected sex:

• **Refuse the client** – this eliminates risk of HIV, but leaves the worker unpaid. It may also lead to an unpleasant scene with the client and possible difficulties with managers.

• **Discuss the matter with the client and try to persuade them about the benefits of safe sex for everyone**. Sex workers may get together to role-play how they might discuss this with different types of clients. Ask them to prepare some likely scenarios from their experience for practice.

• **Offer a non-penetrative sexual service** – such as sex between the thighs. Some sex workers become so skilled that the client may not realise that they have had sex without penetration.

• **Try to put a condom on him without him realising** – some sex workers become skilled at doing this using their mouth.

• **Solidarity** – if all the sex workers in a brothel or a given area refuse unprotected sex, then the client cannot obtain unsafe sexual services from others and may be more likely to agree to use a condom.
Alternative income generating programs

Schemes which assist sex workers to earn income from other sources can have an important role in health promotion. Research in Kenya and Nigeria has shown that sex workers with additional sources of income are less likely to be HIV positive. Additional sources of income are very important where sex work is seasonal or very poorly paid.

Strategies for helping sex workers to earn income from other sources include:

- providing loans to sex workers to start a small business (including selling condoms and lubricants), buy land or farm, or for credit cooperatives;
- providing training for other jobs;
- developing new skills such as literacy or learning another language.

Some women and men use income generation schemes to leave the sex industry. Others use their newly developed skills and economic power to be more efficient sex workers, for example by learning a language spoken by tourists or buying condoms in bulk.

Many alternative income generating activities lack clear goals and do not have realistic expectations of what sex workers might achieve. Often people engaged in these schemes do not have the necessary skills (and do not get training to develop skills) to make a success of the chosen small business. If your organisation does not have the necessary skills, it is good idea to form a partnership with the experienced NGOs or micro-finance organisations to make a success of the income generation project.

Community development

Community development refers to strategies that aim to support sex workers as a community, rather than as individuals. It is more effective for sex workers to advocate for their legal and civil rights, for example, as a group. Some suggestions for community development include:

- **Self-organisation of sex workers** can help overcome problems of isolation and lack of self-esteem caused by stigma and discrimination. It can also help to promote and sustain safe sex and safer working conditions by increasing sex workers’ control of their working environment.

- **Drop-in centres**, situated near streets or bars where sex workers operate can provide tea, snacks, condoms, lubricants, health promotion materials and activities, counselling and referral to appropriate health and welfare services. As well as addressing welfare needs this kind of environment can lead to sex workers making group discussions about work practices.

- **Anti-violence activities**. Minimising violence is one of the most important aspects of making the sex industry safe. Many projects offer self-defence classes and training for personal security.
• **Liaison between the police and sex work projects** can have a number of benefits. For example, it can prevent peer educators and project staff from being arrested or harassed, and it can help ensure that police actions do not make it risky for sex workers and sex businesses to possess safe sex information and condoms. Police liaison is particularly important in countries where it is the police, rather than the law, who determines how sex workers are treated.

**Helping those who wish to leave sex work**

It is important to be aware that this is a very sensitive issue. Attempts to encourage women or men to leave sex work may be viewed with suspicion and distrust. Such attempts may be interpreted as judgemental and further reinforce feelings of marginalisation from the rest of society. Sex workers who have undergone many months or years of restriction of movements, violence and sexual assault as their induction to sex work may eventually gain some measure of seniority and relative independence. Leaving sex work may no longer be a desirable aim for them. There may be no opportunities to earn a similar income for themselves and their dependents. Sex workers may not be able to imagine being able to ‘return’ to society – they may feel that they will always be stigmatised and rejected by their families and communities. They may be far from their original homes and have no way of returning, and no family support or connections in the place where they have been selling sex. Sometimes efforts to find and free young girls and boys that have been trafficked and sexually exploited have resulted in further exploitation and abuse. This is a specialised area – NGOs need to work closely with government support services and there needs to be clear accountability and provision for careful monitoring of activities.

Through some of the strategies described above people in sex work may gain new skills and confidence, as well as new contacts. These may then give them opportunities to leave sex work.

**BOX 11.10: YOUNG MALE SEX WORKERS IN RIO DE JANEIRO**

There are some 2000 or more male sex workers aged 11 to 23 years working in the streets of Rio de Janeiro. An outreach program was started in 1989 to provide the sex workers with counselling, information and education about AIDS and to distribute free condoms.

The sex workers did not think that AIDS was a bigger threat to their lives than hunger or violence from police and clients, for example. Nevertheless, they welcomed the project from the start, because it provided an opportunity for face-to-face conversations with people who showed concern about them.

Initial discussions with the sex workers revealed that although they have sex with men, most of them identify as heterosexual and have no contact with the gay community. They are therefore not reached by information produced for gay men. Secondly, because they were mostly illiterate, information produced for the general population did not reach them either. Therefore, although the direct face-to-face counselling and education program developed by the project was labour intensive, it was the most effective way of reaching them.

At the beginning of the program, only 15% of the young sex workers reported using condoms consistently. Six months into the project, the figure had increased to 65%, and one year later to 80%. There was an associated decrease in the STI levels from 75% to 32% in the first six months of the intervention.

**BOX 11.11: KEY ELEMENTS OF HIV/STI PREVENTION FOR SEX WORKERS**

- An understanding of the sub-culture of sex work
- An understanding of the reasons for sex workers entering and remaining in the sex industry
- The active participation of sex workers in decisions about the project priorities and the design and implementation of the project
- Involving sex workers in designing education materials and as peer educators
- Providing STI services which are both accessible (extended opening hours, friendly hours, etc) and affordable.
- Promoting the self-organisation of sex workers
- Involving clients and owners/managers of sex work venues in health promotion programs and activities
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Chapter 12
Focus on injecting drug use

by Tamara Kwarteng

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Introduction

Injecting drug use is widespread around the world. An estimated 10 million people in 136 countries inject drugs.\(^1\) Sharing or use of contaminated needles, syringes and other injecting equipment is a very efficient way of spreading HIV. Since people who inject drugs commonly share injecting equipment, HIV can spread very rapidly among them. Currently, 114 countries have reported HIV infection among people who inject drugs. As many as 3.3 million of these estimated 10 million people are infected with HIV.\(^2\) Asia has the largest number. Injecting drug use is the most common cause of HIV transmission in many Asian countries, including Malaysia, Vietnam, Yunnan province in China and the north-east states of India. It is also the major factor in HIV epidemics in Eastern Europe, several of the Newly Independent States, a number of Latin American countries, North America and some countries in Southern Europe, North Africa and the Middle East.

Worldwide, the drugs most commonly injected are heroin, amphetamines and cocaine, although many other drugs are injected, including tranquillisers and other pharmaceuticals. Factors influencing the choice of drug include price and availability.\(^3\) Drugs are usually readily available and cheaper in the areas where they are produced or through which they are trafficked. For example, the explosive increase in the injection of heroin in South-East Asia – particularly in Myanmar, north-east India, China, Thailand and Vietnam – has been linked to the production and ready availability of pure grade heroin in the so-called Golden Triangle region of Thailand, Myanmar, and Laos.

HIV infection among people who inject drugs can spread rapidly. In the past 20 years, explosive HIV epidemics have occurred in diverse cities and towns in both high-income and low-income countries, including New York, Edinburgh, Bangkok, Ho Chi Minh City, Manipur State in north-east India, Yunnan Province in China, and Moscow. In some cities, HIV prevalence has risen from less than 5% to more than 40% in a 12-month period. Manipur State in north-east India provides one of the best lessons about how quickly HIV epidemics can spread among people who inject drugs. In 1988, the HIV prevalence among people who inject drugs in Manipur was zero. Four years later more than 70% were estimated to be HIV-positive.

HIV epidemics among injecting drug users invariably spread to other groups in the community. Most people who inject drugs are young, male and sexually active and can become infected with HIV and pass on the infection through sexual intercourse with regular and casual partners. The overlap between injecting drug use and sex work is well documented, with people who inject drugs often buying sex or selling sex to pay for their drugs. Twenty percent of street-based sex workers in Hanoi, Vietnam, reported recent drug injection, while 23% of male drug users bought sex.\(^1\)

The speed with which HIV can spread through injecting drug use, the illegal nature of drug use in most countries, and the social stigma and marginalisation suffered by people who inject drugs make effective responses very difficult. Nevertheless, there is evidence from high- and low-income countries that it is possible to stop, and even reverse, HIV epidemics spread through injecting drug use. Three main approaches have been used to control drug use and to prevent the harmful effects of injecting drug use – reducing the supply of illicit drugs, reducing the demand for illicit drugs, and harm reduction.

In this chapter, we focus on strategies to reduce the demand for illicit drugs and to reduce the harm associated with drug use. We describe the vulnerability of people who inject drugs to HIV and the harmful effects of injecting drug use on themselves, their families, and the community. We summarise methods of assessing HIV epidemics and describe effective prevention, care and support strategies and how they may be applied in low-income settings.\(^1\)

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\(^1\) Much of this chapter has been adapted from Ball A, Crofts N, Manual for reducing drug-related harm in Asia and the chapter ‘HIV risk reduction in injecting drug users’.\(^2\)
Injecting drug use and HIV vulnerability

Users of heroin and other injectable drugs do not always inject. In some situations, the drugs are smoked or inhaled. However, when the drug becomes scarce or expensive (usually as a result of drug control efforts), it becomes uneconomical for the drug user to inhale the drug because much of it is lost in smoke. Under these conditions, many drug users turn to injecting since this gives the maximum desired effect.\(^3\)

Injecting drug users are at risk of becoming infected with HIV when they share equipment used to prepare and inject drugs (spoons, needles, syringes). There are many reasons why drug users share injecting equipment. For example, if needles and syringes are expensive and/or hard to get, they may be forced to share.

Experience from different parts of the world has shown clearly that the most important factor influencing the sharing of injecting equipment is the social and legal situation in which they live. Drug use, particularly injecting drug use, is illegal in most countries and people who inject drugs are stigmatised. The way that the police deal with people who inject drugs, however, varies a great deal from one place to another. In some places the police can use the mere possession of a needle and syringe as evidence of a crime. Many people who inject drugs are therefore afraid of carrying injecting equipment for fear of being searched and arrested by the police. Rather than buy or obtain a new needle and syringe, they prefer to use the injecting equipment where they purchase the drugs and leave without any evidence of injecting on them. This situation give rise to ‘shooting galleries’, where the needles and syringes are provided by the drug dealer, and are used by many people without proper cleaning or disinfection between use.\(^3\)

Prisons are another context where the risk of HIV transmission through injecting drug use is high. Drug users who are sent to prison do not necessarily stop using drugs. Many can obtain drugs while in prison and they share injecting equipment because they cannot get clean needles and syringes. The regular searches that take place in prison cells make it risky for prisoners to keep injecting equipment.

Some use the services of ‘professional injectors’ if they are not able to inject themselves. For a fee, the ‘professional injector’ supplies the needle and syringe while the users provide the drug with which they are injected. The needles and syringes may not be properly cleaned and disinfected between injections; hence, there is a great danger of spreading HIV and other blood-borne viruses.

Vulnerability to HIV infection is also influenced by the stigma, discrimination and isolation that injecting drug users suffer. In practice, this can mean that they cannot access necessary health and social services. In essence, the social and legal situations around drug use drive users underground, and make it difficult to reach them with information and services. Strategies to address the social and legal context need to be included in any effective HIV prevention program for people who inject drugs.

HIV risk among drug users does not arise only from injecting. Many types of psychoactive substances, whether injected or not – including alcohol – are risky because they affect the individual’s ability to make decisions about safe sexual behaviour. Studies in the United States have associated crack-cocaine use with increased levels of high-risk sexual behaviours and found that an increasing proportion of people with AIDS are crack-cocaine users. Studies have also found that drug users, particularly people who inject drugs, are more likely to be involved in the sex industry. The high risk of HIV infection among sex workers is well documented (Chapter 11).
When combined with the need to get money to buy drugs, injecting drug users who work in the sex industry may be less likely to insist on safe sex with a client who is reluctant to use a condom.

It is important that efforts to reduce the risk and vulnerability to HIV infection also include strategies to address sexual transmission risks (see Chapters 7 and 11 for strategies to reduce sexual transmission of HIV).

**Harmful effects of injecting drug use**

Apart from the risk of HIV infection through sharing equipment, there are other harmful effects of injecting drug use, including:

- death from overdose;
- infection with other blood-borne viruses including hepatitis B and hepatitis C;
- spread of HIV or hepatitis B to sexual partners;
- abscesses and bacterial blood infections from dirty needles;
- collapsed veins;
- blood clots from impurities in the drug;
- family conflict;
- STIs and sexual violence associated with prostitution;
- criminal behaviour and time in prison.

Some of the other harmful consequences are more immediately obvious for people who inject drugs than HIV infection, which may take years to show any effects. It is therefore important that HIV prevention programs include strategies to address other harmful effects of drug use. Lessons from a number of programs show that strategies that address the immediate health and social problems increase the effectiveness of HIV prevention strategies. The idea of harm reduction is to reduce the harmful effects of injecting drugs for the users, their families, and the community.

**Assessing the drug use situation**

The first step in planning a response to HIV is to conduct a situation assessment which will help to understand the policies and factors that influence drug use in your community. The assessment should also give you information about what resources are available in your community to respond to drug use and HIV.

Because it is illegal to inject drugs it is often difficult for governments and communities to admit openly that it occurs. Those who inject are often reluctant to admit their drug use or to seek information and treatment. This means that it is difficult to ask about the extent and nature of injecting drug use.

The need to respond quickly to injecting drug use and HIV epidemics means we have to use research methods that can give reliable information quickly, are not expensive, are culturally acceptable and feasible. The World Health Organization’s *Rapid assessment and response (RAR) guide on IDU* is an example of a methodology that has been developed specifically to gather information for designing appropriate and timely responses. Rapid situation assessments involve collecting information from a variety of sources, including government statistics and interviews with people who know about the local situation.

The first step in conducting a rapid assessment of injecting drug use in a community is to locate and examine information that already exists, including:

- official estimates of drug use and the number of drug users and injectors;
- official estimates of sex workers and the number of people arrested for sex work;
- number and type of arrests for drug-related offences;
• drugs seized, including analysis of drugs for purity and diluents;
• surveys of drug use;
• proportion of HIV infections among drug users;
• number and type of hospital admissions for drug related conditions;
• number of people on methadone and other drug substitution programs (and on waiting lists);
• newspaper articles on drug use, policy, HIV etc;
• records of parliamentary debates dealing with drug use and/or HIV;
• annual reports from government and non-government agencies dealing with drug use and HIV;
• minutes of public meetings dealing with drug use and HIV.

The information will be available from a variety of sources including:

• **Drug treatment programs:** can provide information about the numbers and characteristics of drug users who seek treatment and the drugs being used in that area. They may also provide contact with drug users for in-depth interviews.

• **Health care facilities:** including hospital emergency rooms, mental health services, STI clinics, dermatology clinics, and primary health care sites. Staff may have information on the complications arising from drug use, where drug users live etc. Families of drug users also often approach doctors at general or psychiatric hospitals about their family member's drug use.

• **STI clinics and/or HIV surveillance systems:** should be able to provide information on HIV, hepatitis and STIs.

• **National AIDS programs:** can provide information on the programs in place.

• **Pharmacists and shopkeepers:** if they sell needles and syringes they will probably have contact with drug users, have information on how many needles and syringes they are selling etc.

• **Police, prisons and other law enforcement:** can provide information on drug-related arrests, drugs seized etc.

• **Social service agencies:** may have contact with drug users and their families

• **NGOs:** may work with youth, drug users, sex workers, or through providing maternal and child health care, have come into contact with drug users.

• **Faith-based organisations:** may be providing services, including counselling for drug users and their families.

• **Journalists:** may provide information from their research and/or give access to newspaper files.

• **Social scientists and medical researchers:** in universities or research institutions, may have information from studies conducted with drug users or can provide information on particular patterns and behaviours.

In Chapter 3, we described questions for collecting information to understand HIV in your community, including some questions about the nature of injecting drug use. A more detailed set of questions for assessing the injecting drug use situation in your community can be found in *Manual for reducing drug related harm in Asia*, Chapter 2.³

We emphasised in Chapter 4 that community participation is essential for a situation assessment to be meaningful. It is important to involve people who inject drugs in collecting and analysing information about the situation and their needs. Generally, the earlier people who inject drugs become involved, the more useful the result will be. People who inject drugs may need training in order to participate effectively. For example, they may need training to conduct interviews, facilitate focus groups or undertake structured observations. Times and places of meetings need to be convenient and the style of meetings must not be alienating.
Preventing harm associated with injecting drug use

Key approaches for preventing harm associated with injecting drug use

Three main approaches have been used to control drug use and to prevent the harmful effects of injecting drug use – reducing the supply of illicit drugs, reducing the demand for illicit drugs, and harm reduction.

Reducing the supply of drugs

Reducing the supply of drugs through law enforcement is an approach which is common to all countries. All the evidence to date suggests that despite the huge amounts of human and financial resources which go into preventing illicit drugs from being produced and trafficked, the drugs do get to their intended markets. Law enforcement agencies may have periods of success when they manage to close a particular supply route. However, because of the huge profits that can be made from selling illicit drugs, new supply routes, new dealers and traffickers soon replace any that are put out of business. On its own, restricting the supply of drugs is not an effective strategy for controlling drug use.

Reducing the demand for drugs

A second approach to control drug use is to reduce the demand for drugs through education, social and economic development of the community, and rehabilitation and treatment for drug users. Strategies to reduce the demand for illicit drugs will usually aim to prevent people from starting to inject and/or provide support and treatment services to people who use drugs and want to stop. Recovery from drug use is difficult. A drug user would usually make several attempts to stop using but may relapse several times for various reasons. For most drug users, this is a long-term strategy which often fails and does not protect them from the harmful effects of drug use described previously, including HIV infection.

Harm reduction

The third approach is harm reduction. The basis for the harm reduction approach is that it is necessary and possible to prevent harmful effects of injecting drug use without necessarily stopping people from using drugs. The harm reduction approach emphasises the short-term goals of preventing people who inject drugs from becoming infected with incurable diseases (HIV, hepatitis C). Because HIV can spread very rapidly it is necessary to implement strategies that will reduce the risk of infection even as people continue to use drugs. Harm reduction strategies include education about drug use, HIV and other blood-borne diseases; safe injecting; needle and syringe exchange programs (NSEP), drug treatment and substitution programs. Harm reduction strategies are increasingly being adopted or adapted, according to the needs of different countries or communities.

Comprehensive approach

Effective control of drug use needs a combination of all three approaches. However, a greater emphasis on harm reduction is most important for preventing HIV infection and other harms among users, their families and the community. Individual risk reduction strategies are most effective when implemented in a supportive environment. Therefore, a comprehensive approach would also include strategies to create a safe and supportive environment for people who inject drugs to adopt healthier behaviours. The strategies described below are consistent with the demand reduction and harm reduction approaches for controlling drug use and preventing HIV and other harms.
Strategies to reduce individual risk behaviours

At the individual level, strategies are needed to change behaviour in order to reduce, and ultimately, eliminate risks. Given appropriate information and opportunity, people are likely to change both their drug-using and sexual behaviours to protect themselves and their partners. Specific strategies for reducing risk include:

- behaviour change communication, including information, education and communication (IEC), and risk reduction counselling;
- needle-syringe programs (NSP);
- disinfection of injecting equipment programs;
- drug treatment programs;
- voluntary counselling and HIV testing (VCT).

Behaviour change strategies

Please refer to Chapter 7 for information about the general principles of behaviour change, best practice for developing and delivering information, education and communication (IEC) messages and materials. IEC materials that seek to communicate with drug users need to be prepared by drug users because they understand what drug injectors do and why they do it. They can express messages in ways that other drug users will understand.

The aim of a behaviour change program for people who inject drugs is to provide information and support to encourage them to practise safer injecting behaviour and to have safer sex. People who inject drugs should be provided with information about how HIV is transmitted through sharing injecting equipment and through unprotected sex, and the ways to prevent infection.

Behaviour change messages should also cover the following areas where appropriate:

- risks of sharing injecting equipment;
- risks of sharing drug preparations paraphernalia (filters, cookers, water);
- risks of drug preparation techniques;
- how to clean/sterilise needles and syringes;
- where to get sterile needles and syringes;
- how to dispose of used injection equipment safely;
- alternatives to drug injection;
- what drug treatment services are available;
- how to prevent and manage drug overdose;
- how to prevent abscesses.

There are different ways of reaching people who inject drugs with information. **Mass media** campaigns can raise general awareness of HIV. However, it is not advisable to use mass media to provide the necessary and often sensitive advice about using drugs safely. Information delivered through mass media can reach everyone in the community and specific reference to people who inject drugs may increase stigmatisation and public disapproval.

It is much more effective to **target information** specifically to people who inject drugs. Explicit information on risk reduction strategies, based on a local situation assessment, and developed in collaboration with drug users can be delivered in a variety of ways. Posters, videos, newsletter, key rings, advertising on syringes and toilet doors, street theatre etc, can be used to communicate these messages. The most effective way is through **outreach and peer education**. Outreach

**BOX 12.1: OPTIONS FOR SAFE INJECTION**

The options for safe injection, in decreasing order of safety are:

- No injecting – use drugs in other ways eg smoking or inhaling if possible.
- If you inject, use a new set of injecting equipment for every injection. Do **not** share needles, cookers/spoons or filters with other people who inject drugs.
- If you need to re-use any injecting equipment, use your own every time. Clean the needle and syringe after you use it.
- If you need to use someone else’s injecting equipment, clean the needles and syringes.
- When cleaning needles and syringes, use an approved method (see Box 12.3).
workers can be ex-drug users, current users and/or non-users. There are benefits and disadvantages to employing each type of outreach worker but the disadvantages seem to be lessened by employing mixed groups and providing appropriate training and supervision. Peer educators are drug injectors who have been trained to work with their community. Peer and outreach educators may undertake a range of tasks including providing injecting equipment and bleach, collecting used injecting equipment, disseminating information about how to use bleach and issues related to health care and counselling.

Injecting drug user groups can be very effective at coordinating and supporting peer educators. The development and maintenance of such groups requires the cooperation of the police or law enforcement officers.

**Risk reduction counselling**, another behaviour change strategy, aims to help individuals to understand their behaviours and their environment, so that they will protect themselves against the risks of injecting drug use. Risk reduction counselling addresses the experience and circumstances of individuals (see Chapter 7). It often includes:

- accurate HIV and drug use information;
- personal HIV risk assessment (making the individual aware of his/her specific behaviours and the risk associated with them);
- training in safer injecting and safe sex skills such as how to sterilise injection equipment and how to use condoms;
- solving problems, for example getting help, dealing with crises, selecting appropriate prevention or treatment options, etc;
- reducing stress or coping better with stressful situations.

The setting for counselling will influence whether the services are accepted and used by people who inject drugs. Because they are afraid of being arrested or harassed by the police, they can be hard to reach with information and services. Outreach services that provide counselling – often in association with other services such as the provision of injection equipment, condoms and primary health care – in the places where people who inject drugs live and meet are more effective than traditional centre-based programs.

Counsellors should be adequately trained and be trustworthy to people who inject drugs. They should understand local drug use, know local resources and referral practices, be non-judgmental and respect the confidentiality and other rights of people who inject drugs.

**Needle-syringe programs (NSPs)**

To enable people to act on safe drug injecting messages, it is essential that they are able to obtain clean injecting equipment when they need to use them. Often people will share their injecting equipment because they have difficulty obtaining new equipment. Needle-syringe programs have been shown to be a very effective way of improving access to clean injecting equipment and so preventing the spread of HIV. A study in over 80 cities showed that the incidence of HIV decreased by 5.8% per year in the 29 cities with NSPs and increased by 5.9% per year in those without. Countries that implemented harm reduction strategies early in the epidemic, such as Australia, New Zealand, the United Kingdom, the Netherlands and Denmark, have had a much lower rate of infection among drug users than in other countries.

Needle-syringe programs save lives and money. A recent study commissioned by the Australian government found that NSPs prevented 25,000 new HIV infections and 21,000 hepatitis C infections in 10 years. NSPs have cost the state and federal governments approximately A$130 million. However, preventing HIV/AIDS and hepatitis C infections has saved about A$1.3 billion in treatment costs for HIV and hepatitis C alone.
Establishing a needle-syringe program can be difficult and requires a great deal of preparation. There are often fears in the community that allowing needle and syringe distribution will promote and increase drug use. There is a great deal of evidence that NSPs do not lead to increased drug use or the recruitment of new injecting drug users. Community education to achieve understanding and support is necessary at every stage of developing and putting a needle-syringe program in place. Community members may also be concerned that needles and syringes will be discarded in public places and be a source of danger to others, especially children who may play with them. Campaigns to clear away needles and syringes and to ensure that they are properly and carefully disposed of can do much to reduce anger against drug users and NSPs.

It is also essential to have the support of the police for a successful needle-syringe program. Because drug use is illegal in most countries, people who inject drugs and outreach workers can be harassed and arrested for possessing needles and syringes and organisations distributing needles and syringes can be closed down. Education of police and advocacy with those who make and implement laws is necessary when planning a NSP. Local police may have a good understanding of the drug-using context and have often been willing to cooperate when they understand the benefits to the community as well as to the drug users. Steps that can be taken to gain the support of the police include:

- Consult with senior police early in the planning phase to gain their permission and ongoing support.
- Educate junior police about what the program is aiming to achieve.
- Identify individual police officers who support the harm reduction approach and encourage and train them to be peer educators among the police.
- Offer HIV education sessions in police training courses.
- Visit police stations and police officers and find out their concerns.
- Invite members of the police to be on the board or advisory groups of HIV prevention programs for people who inject drugs.
- Obtain police permission, or an amnesty in writing, for needle and syringe exchange.

There are many different ways of providing needles and syringes. The situation analysis should provide information about the most appropriate places to situate NSPs. It is important, however, that needle-syringe services are located close to where the drug users live or buy and use the drugs. People tend to inject near where they buy the drugs. The less deviation from their normal lives involved in collecting or disposing of equipment, the more likely they are to use the needle-syringe service.

Needle-syringe programs may be situated in a health clinic, a welfare or youth centre, drug treatment facility or provided through outreach. Outreach workers need to be well trained, supervised and supported.

Needles and syringes may be provided on a one-for-one basis, where a single sterile needle and syringe can be provided for each used one returned. In some situations NSPs can supply as much sterile equipment as people request. Clients collect sterile equipment not only for themselves but also for distribution to others – in effect,
working as unpaid peer outreach workers. This approach has several advantages. It increases efficiency and reduces the pressure on NSP staff. Most importantly, it increases the reach to populations who would not otherwise attend the needle-syringe program. It is important to emphasise safe disposal of used equipment with this approach. Besides needles and syringes, NSPs may also distribute other injecting equipment such as clean water, swabs, spoons and cooking pots.

When planning a needle-syringe program, it is very important to determine how you will dispose of used injecting equipment. The NSP needs to pay particular attention to disposal practices by users; used syringes laying around upsets both the general community and the police and is the surest way to close down a NSP program.

One of the important lessons learned from needle-syringe programs is that in order to reduce the spread of HIV, the program needs to reach as many injecting individuals in the community as possible. The example of Lifesaving and Lifegiving Society (LALS) in Kathmandu shows that a small needle-syringe program (reaching only 1000 of the estimated 25,000 to 40,000 injecting drug users) may help slow the epidemic, but can do little to prevent an explosive epidemic once drug injection and HIV prevalence rises. The situation analysis should provide information about the approximate number of people who inject drugs in the community. Consult with injecting drug users to estimate the numbers of needles and syringes that will need to be ordered. Monitor the use closely so that sufficient supplies are in stock.

NSPs also allow an opportunity to provide information and referral to treatment and rehabilitation services for those who want to stop injecting.

**Disinfection of injecting equipment**

Disinfection of injecting equipment reduces the amount of infectious virus in used needles and syringes and lessens the chances of transmission when they are re-used. Bleach is the most common substance used by most programs to disinfect used needles and syringes. It is effective at rapidly destroying most viruses in the blood, including HIV and hepatitis viruses. Other chemicals that can also be used to disinfect used injecting equipment include iodine, hydrogen peroxide, detergents and strong alcohol.

**BOX 12.3: CLEANING WITH BLEACH**

1. Rinse the syringe several times with cold water. The aim is to get rid of any blood which may be left in the needle or syringe.
2. Fill the syringe with full-strength bleach. Shake the syringe for at least 30 seconds. Squirt the bleach into the drain or toilet. Fill the syringe again, shake for 30 seconds and squirt into the drain or toilet.
3. Rinse the syringe with clean cold water at least twice.
4. After injecting, rinse the syringe with water several times to remove any blood.

Bleach can be provided either as a solution (often in small disposable bottles) or as powder to be made into a solution before use. As is the case with needle-syringe programs, bleach can be distributed by outreach workers or health care workers in a wide range of settings. It is important to teach people how to use bleach properly to disinfect injecting equipment. If the disinfection is not carried out properly, there is risk of infection with HIV when the needle-syringe is re-used.

Disinfection programs are not as effective as needle-syringe programs. They are the less-effective alternative where it is not possible to establish needle-syringe program. In some settings, bleach provides a backup to support needle-syringe programs where injecting equipment is not available.

**Drug substitution programs**

It is possible to stop heroin use abruptly (‘cold turkey’), but it is painful and causes symptoms of diarrhoea and muscle pains as well as severe cravings for the drug. It is common for people to return to using the drug after stopping for some time. Drug substitution is a treatment for drug-dependent individuals with a drug that works in a similar way to the drug they are dependent on. This prevents withdrawal symptoms and
craving associated with ‘cold turkey’ treatment. Most substitution programs replace an injected illicit drug (such as street heroin) with an oral legal drug (such as methadone).

Drug substitution has several advantages including the following:
• It encourages a change from injection to non-injection of drugs, therefore reducing the risk of contracting or transmitting HIV.
• It enables a switch from ‘black market’ drugs of unknown quality, purity and potency to legal drugs of known purity and potency.
• The risks of overdoses and other medical complications are reduced.
• It enables the drug user to lead a more normal and productive life, avoiding crime and prostitution and keeping them out of the dangerous environment of prisons.

Methadone syrup taken by mouth is a long-acting substitute for heroin that prevents withdrawal symptoms. It is the most widely used treatment for opiate dependence. There is clear evidence that methadone maintenance is safe, improves the health of many users, prevents deaths, reduces crime and enables people to go back to work and provide for their families. A methadone service provides opportunities to provide other services to drug users. However some injectors do misuse the methadone they are prescribed - they may sell or even inject the methadone, while some continue to inject heroin.

Other drugs that can be used for drug substitution are buprenorphine, tincture of opium, levo-alpha-acetylmethadol (LAAM), morphine, codeine, and naltrexone. Buprenorphine is a synthetic painkiller. When the price of heroin increases some drug users begin using buprenorphine as an alternative. Buprenorphine is a good substitute drug for people with low to moderate opiate dependency because it has few side effects, only mild withdrawal symptoms, and does not need to be taken every day.

Drug substitutes can be delivered in a variety of settings. In recent times, community-based models of delivery have made drug substitution programs possible in resource-poor settings, including urban slums in India and rural communities in Thailand. In the case of methadone substitution, the drug is prescribed by a medical doctor and dispensed through pharmacies, community health facilities, mobile dispensing vans or other client-centred services such as a drop-in centre. An important principle of these programs is that the supply of methadone or other drug substitute needs to be consistent.

A major limiting factor has been the relatively high cost of some substitute drugs, requiring funding assistance from international development agencies or client fees. Some countries are producing generic methadone and buprenorphine at a cheaper cost, making them more affordable in resource-poor communities.

Successful treatment and rehabilitation for drug use is only possible if the drug user is motivated to make the change. Experience shows that if drug users wait for weeks to get into a treatment and rehabilitation program by the time it is their turn they may have lost their motivation. In addition, only voluntary detoxification is effective in the long term. When drug addictions are ‘treated’ in prison or prison-like rehabilitation centres, relapse rates are high, especially when family members or the authorities arrange the detention.

**Voluntary counselling and testing (VCT)**

Voluntary counselling and testing are key components of prevention and care programs. Knowing one’s HIV status allows and can promote changes in behaviours to prevent infection. Such knowledge can lead to modifications in one’s lifestyle to improve health, including seeking treatment for opportunistic infections. Please refer to Chapter 7 for more detailed description of the role of VCT in HIV prevention and care programs.
Strategies to create a safe and supportive environment for people who inject drugs

Strategies to reduce individual risk behaviours described above rely heavily on the support and involvement of different sectors of the community, ranging from government leaders to people who inject drugs. As we discussed previously, punitive laws again drug use, as well as stigma, discrimination and isolation, reduce the effectiveness of strategies to reduce individual risk behaviours. Efforts to mobilise community action, to change laws and policies that affect prevention efforts, and to mobilise people who inject drugs are important components of comprehensive approach to preventing HIV.

Mobilising community action

Illicit drug use often provokes strong community reaction. Therefore, an essential part of developing a response to drug use and HIV is to get into the community and talk with people about their needs and concerns. While there may be initial and continuing hostility to drug use and users, genuine community consultation and discussion can lead to adoption of effective policies and strategies for HIV prevention. For example, SHALOM project staff in Manipur held extensive consultations with church leaders, different ethnic groups, drug users and their families and the police. They encouraged community discussion through different forums. The result of the consultation and discussion process is captured by the following quote by the Superintendent of Police in 1995:

> We have chosen to live with the lesser evil of drug abuse in order to curb the AIDS menace, and so I have not had occasion to regret my decision to allow the syringe and needle-exchange program.

Some simple ways to consult and mobilise community action include:

- Use existing community networks, gatherings and forums (church meetings, community groups, etc) to find out people’s views on drug use and HIV risk in the community.
- With the permission of school principals, speak with students about HIV and drug use.
- Post a box at a school, or outside your program, where young people can write and leave questions about drugs and HIV.
- Convince a local radio station to run a program where people can ring in and ask an expert about their concerns.
- Organise consultations with people who inject drugs, ex-users and other affected groups.

**BOX 12.4: COMMUNITY ACTION ON INJECTING DRUG USE AND HIV IN RUILI COUNTY, CHINA**

Handeng village, located in Long Dao Xiang in a remote part of Ruili, Yunnan province, China, has a population of 304. Since the 1980s, 46 drug users have been identified as HIV positive. During the 1990s, increased drug use created other problems such as poverty, drug trafficking and violence. Handeng became notorious as a ‘problem village’.

A community-oriented project aimed at reducing the demand for heroin was piloted in the village in 1991. Groups representing different sections of the community – village leaders, parents, women, youth – were established to formulate and implement the community action. The groups met once a month to discuss their specific problems and determine strategies. They conducted public awareness campaigns and educational activities for the different groups. They provided assistance and materials (including condoms) to drug users and families of HIV-positive people.

Knowledge about HIV/AIDS and drug use increased in the community. There were also significant attitudinal changes to drug use, the risk of HIV/AIDS and contraception. Most importantly, new cases of injecting drug use-related HIV infection reduced enormously.
Strategies to change laws and policies that affect prevention efforts for people who inject drugs

Many countries have policies and laws that make it difficult to put prevention strategies such as NSPs, outreach education and drug treatment programs into place. Strong arguments and advocacy, presenting harm reduction in a broad way that includes strategies to prevent drug use, can help to change existing laws and regulations that hamper prevention efforts.

Although it is much better if the laws of the country are modified to support the harm reduction approach, this can take a long time. More often than not, NGOs negotiate with the police in their community to allow the prevention work to continue even if existing laws prohibit their work. Education and advocacy with community and religious leaders, as well as law enforcement agencies are important strategies for creating a safe and supportive environment. When community leaders and the police are able to see the benefits of harm reduction, they can be important allies. In Manipur, the success of local level harm reduction, undertaken with the support of the local police, led to changes in the state laws and policies regarding HIV and injecting drug use.

Mobilising drug users

Involving current and ex-drug users in designing, promoting and delivering services is important for prevention programs. Peer educators, outreach workers and networks can bring prevention services to the hardest-to-reach people and help establish trust between them and health and community services. Participation of drug users can happen in the following ways:

• As peer educators, drug users have proven effective in reducing both risk behaviour and infection rates, while peer-based NSPs have proven better at reaching new clients than programs conducted by non-peers.

• Drug-user organisations offer a structured group of current and ex-drug users, along with interested individuals that can represent the interests of drug users, advocate on their behalf and support and implement HIV prevention and other programs for drug users.
Case study: Hy Vong Café – Café Hope, Ho Chi Minh City, Vietnam

The HIV epidemic in Vietnam began and remains largely among people who inject drugs. In many parts of the country, 40% or more of people who inject drugs are infected with the virus. Hy Vong (‘Hope’) Café in Ho Chi Minh City (HCMC) is Vietnam’s first needle-exchange café. It began as a program implemented by Save the Children Fund (UK), but is now supported by the Vietnamese and Canadian governments.

Café Hope is a small building in an enclosed area of a park near the waterfront. It is managed by the Provincial AIDS Committee of HCMC. Due to an agreement with the police not to target the park unduly or arrest people simply for injection, the area is a ‘safe injection park’. Needle exchange consists of one container with sterile needles and syringes and another for disposal, located at the front of the café. In addition to the needle exchange, the café provides condoms, information, tea or coffee, facilities for showering or washing clothes and a small STI clinic.

The café is run by experienced ex-injecting peer workers, who also talk with the customers, settle disputes and provide education and information. It is open every day for 10 hours. About 350 clients use the café every day. While most of the clients are male, increasing numbers of female sex workers who also inject drugs visit the café.

BOX 12.5: KEY ELEMENTS OF HIV PREVENTION AMONG PEOPLE WHO INJECT DRUGS

- HIV prevention should start as early as possible. Once HIV has been introduced into a local community of injecting drug users, there is the possibility of extremely rapid spread.
- Interventions should be based on a regular assessment of the nature and magnitude of drug abuse as well as trends and patterns of HIV infection.
- Illicit drug use problems cannot be solved simply by criminal justice initiatives. A punitive approach may drive people most in need of prevention and care services underground. Where appropriate, drug abuse treatment should be offered, either as an alternative or in addition to punishment. HIV prevention and drug abuse treatment programs within criminal justice institutions are also important components in preventing the transmission of HIV.
- Developing effective responses to the problem of HIV among drug users is facilitated by consulting drug users and the communities they live in. Programs need to be realistic and meaningful to the people they are designed to reach.
- A comprehensive package of interventions for HIV prevention among drug abusers could include: AIDS education, life skills training, condom distribution, voluntary and confidential counselling and HIV testing, access to clean needles and syringes, bleach materials, and referral to a variety of treatment options. This complete package should be implemented along with drug abuse prevention, especially among young people.
- HIV prevention programs should also focus on sexual risk behaviours among people who inject drugs or use other substances.
- Outreach work and peer education outside the normal service settings, working hours and other conventional work arrangements is needed to reach those groups that are not effectively contacted by existing services or by traditional health education.
References


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Chapter 13
Implementing, monitoring and evaluating the project

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Introduction

Having discussed needs assessment, project design and planning, we now come to what is often the most difficult part of the project cycle – the implementation phase. This chapter is about setting up the structures and systems necessary for getting the project done. More importantly, we also discuss the management of human, financial and technical resources available to the project.

Many of the constraints identified during the period of situation analysis and needs assessment will be experienced first hand while trying to get the project work done. Some of the key issues during implementation include:

- consulting project participants regularly – community members, donors, staff etc;
- managing personnel;
- managing money and other resources;
- developing and maintaining a project monitoring system;
- keeping the various stakeholders, including donors, informed on project progress;
- evaluating the project;
- planning for sustainability of the project.

Don’t forget that the best-planned project may fail because communities and other stakeholders, such as the Ministry of Health, are not adequately consulted or not sufficiently committed, project staff are not performing adequately or the project funds are not managed efficiently.
Consultation

We have described the importance of consultation when developing a project. The need for consultation with a range of stakeholders, including those most affected by project activities, continues when the project is being implemented.

Formal processes

You can continue the consultation process in a number of ways. If your project involves partner NGOs or government counterparts, it is helpful to establish a Project Coordinating Committee (PCC). PCCs normally include a representative of the donor agency. Some donor funded projects are managed by Management Companies. If your project may be funded by such a donor program, then a representative of the Management or Contracting Agency may also be represented on the PCC. It is important to include local community members and local government representatives on this committee.

Where you have established a PCC, you should also establish a Project Steering Committee involving all the locally-based members of the PCC (eg without the donor and contracting agency representatives).

A Project Steering Committee usually meets monthly. The Project Manager normally attends meetings of the Project Steering Committee and Project Coordinating Committee, but is not a member. He or she attends to provide information to the committees as requested and to feed back information and recommendations for action to the project team.

It is very important to ensure that the Project Steering and Coordinating Committees include people who are familiar with how the project works ‘on the ground’. These committees should have several lines of project information coming to them. They should not solely rely on information given by the project manager. The members of these committees should not be involved in the direct implementation of the project.

The main roles of these committees are to monitor or supervise the project and to guide the project in its general direction (see Box 13.1). Detailed, day-to-day management is the responsibility of the project manager.

If the donor is not keen to be a member of a Project Coordinating Committee, it is better to have only one Project Steering Committee, the one that meets monthly.

Informal processes

You can also encourage informal consultation by providing opportunities for members of the community to express their opinions.

There may be an area of the project office that can be open to the community and provide a social space where project activities might be informally discussed. Encourage project staff to be aware of the need to capture ideas or suggestions made by community members. Project staff might keep their own notebooks to record ideas, suggestions or their own insights.

Remember the stakeholders!!

BOX 13.1: WHAT IS THE ROLE OF THE PROJECT STEERING COMMITTEE?

The Project Steering Committee:
• provides a means for ensuring ongoing communication with the community, other stakeholders and funders;
• supports and provides guidance to the project workers;
• ensures that the monitoring and evaluation plan is in place;
• helps to solve problems if the project goes off track.

The Project Steering Committee is NOT responsible for the management of the staff, nor the day-to-day running of the project or organisation. Management is always the responsibility of the implementing organisation.

A suggestion box that allows people to make anonymous comments about the project can also be revealing. A periodic newsletter which provides an update on project activities, and which invites stakeholders to contribute their own stories, is a useful communication tool. A simple format is fine. People in remote areas are often ‘starved’ of reading materials.

**Personnel management**

Projects most often fail or achieve less than they set out to achieve because of difficulties with project staff. Many NGOs operate on limited funding, and may not be able to employ highly skilled staff because they cannot match the kinds of salaries or conditions offered in the private (business) sector for example. The risk of burnout is also high because the issues that have to be addressed in an AIDS prevention, care and support project can be distressing and emotionally draining. Therefore recruiting, supporting and guiding suitable staff are essential to effective implementation of a project.

There is a wide variety of management styles, which depend on local culture and on the personalities and talents of the project team and the project manager. There are many books on management. *On being in charge*, available from WHO, is a particularly useful book, as is *Developing plans and proposals for new initiatives*. Another excellent resource is *Tool box for building strong and healthy community organisations working in HIV/AIDS and sexual health*.

**Recruitment**

The cost of recruitment for new staff should be included in the budget. The first step in recruiting staff is to have a clear description of the job and how it fits into the overall structure of the organisation. It is also important to have a transparent process for selecting candidates. The requirements of the job should be matched with the skills and experience of the candidate selected. This means that a clear position description should be at the centre of the selection process and the job should not be changed to fit a candidate without the skills and experience that you need.

Before you start interviewing it is worth spending a little time thinking about appropriate questions and discussing them with the interview panel. Always check references and try to talk to those the applicant has worked with in the past as well (they may not be offered as referees).

**Motivation of team members**

When you think about how to motivate members of the team it is helpful to think back over your own experiences of being managed or supervised. The same causes of dissatisfaction are very common, and factors that increase motivation are also easy to recognise and common to most people.

Factors that increase motivation include:
- sense of achievement
- recognition
- work satisfaction
- a sense of responsibility
- the possibility of advancement
- self-improvement
- adequate remuneration.
Common causes of dissatisfaction are:
- inefficient administration
- poor working conditions
- poor personal relations
- low pay
- incompetent supervision
- dissatisfaction with management.

The manager can play an important role in maintaining morale through celebrating achievements and providing opportunities for informal discussion among staff members.

Don’t be afraid of being a supervisor, but be cautious about the way in which this is done. No one appreciates a policing style of supervision; this only encourages people to appear to be doing the right thing.

The best style of supervision is respectful, friendly, regular, predictable, supportive, educational and based on mutually-agreed work roles and tasks. Failure to spend adequate time on supervision is a common management problem.

Expatriates involved in a project, whether long-term or short-term, often have different work styles to those of local staff. They may be particularly enthusiastic about the idea of progress and would like to achieve rapid change. They may find the work exciting and enjoy working long hours. However, local staff are more likely to view their job as just one part of their life, and are likely to have family and community commitments. This difference in approach can cause resentment and conflict.

Staff development

Project staff gain new skills through their work. However, other opportunities to develop their professional skills through short courses, study tours, and attending conferences are valuable and increase motivation.

Although staff members may require professional development in different areas, all staff should be encouraged to develop good communication and presentation skills. This is a useful skill not only for presenting at conferences but also to convincingly describe the goals, activities and successes of the project to those outside your project.

Donors are usually open to staff development (often called ‘capacity-building’) being included as part of the project plan and project objectives.

Delegation

Delegation often saves time and staff become more knowledgeable and skilful. However, the work may not be done or it may be done less well if key tasks are delegated to staff that do not yet have the required skills. Therefore, it is important to delegate appropriately taking the worker’s level of skill and experience into account.

If you delegate too many tasks or tasks that a worker does not have the skills to carry out, you will undermine the worker’s confidence and lower morale.
Communication

Good communication avoids many problems. All staff cannot be involved in all decisions, but they like to feel that they know what is going on. It helps to take minutes of management meetings and make them available to all staff promptly. Issues that are genuinely sensitive or that involve a particular member of staff should be omitted from those meeting minutes. Staff should feel that they are able to communicate with management, and they should know the procedure for raising questions or suggestions. Access to email makes communications cheaper and easier.

Conflict resolution

A good manager will try to notice small problems between staff before they blow up into large problems. A manager who is approachable is more likely to hear about problems while they are still minor and manageable.

Make sure that all staff members are aware of the procedure for making complaints and try to respond to complaints promptly.

Have a procedure for dealing with sexual harassment. It helps to develop this with staff so that they are aware of gender issues in their work. One person of each sex should be nominated as a person with whom staff may talk in confidence if they are concerned about sexual harassment.

Have clear disciplinary procedures. It is important to document problems with staff and to keep the records in a confidential way.

In some instances, it may be desirable to ask a staff member to leave the team. To avoid prolonged disputes related to staff dismissal, it is critical to have written guidelines on procedures relating to staff recruitment and dismissal. There should be a clear procedure of warnings, ample opportunities for discussion with the particular staff member involved, opportunities for remedial action, the notice required to dismiss a staff member, and the amount of compensation due to that person. Do make sure that your procedures are consistent with the country’s labour laws.

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**BOX 13.2: HOW DO YOU DISCIPLINE STAFF?**

This is perhaps one of the most difficult areas of management. Ideally, it is better to address problems early, rather than get to the point where staff need to be dismissed. Regular staff supervision and performance appraisal will greatly assist in preventing the need to dismiss staff.

The process for disciplining staff includes four steps. Importantly, please note that staff are entitled to have a union representative (where relevant, and if they choose) present with them at each stage.

**Step 1: Verbal notice**

A verbal notice that a problem has occurred is given, followed by a discussion regarding what can be done to address the issue and in what time frame changes should be made. The supervisor should make a note (in the staff member’s personnel file) that a verbal notice was given.

**Step 2: Issue first written notice**

If the problems occur again then a written notice should be given. Again, a note should be made in the personnel file and a copy of the written notice should be given to the staff member.

**Step 3: Issue final written notice**

If the problems keep occurring, then the organisation can issue a final written notice. A final written notice should state that unless the behaviour ceases or there is significant improvement, a disciplinary hearing will be called and the staff member could be dismissed. Again, a note is made in the personnel file and a copy is given to the staff member.

**Step 4: Conduct a disciplinary hearing**

At this meeting the situation is discussed and the staff member may be dismissed, suspended from duties or demoted. Organisations can decide on a time limit after which the file notes of warnings may be removed from the personnel file and destroyed. This may be a six month or 12 month period.

Responsibility to staff

It is very important for the organisation to discuss what responsibilities they have to their staff, and develop written guidelines to follow (see Box 13.3). For example, if a staff member becomes sick what support will the organisation be able to provide? In areas with a high prevalence of HIV it is likely that some staff members might have frequent absences for illness and eventually need medical care and support. Others may request time off to visit sick relatives or to attend funerals. Costs for the organisation may be great, so guidelines will be helpful.

Working with volunteers

Volunteers are an important part of most community-based HIV programs. Volunteers are found in all positions – managers and administrators, counsellors, peer educators, fund raisers etc – and significantly increase the capacity of NGOs and CBOs. Encouraging and supporting volunteers is an important way for organisations to remain connected to their communities.

There are many reasons why people volunteer their skills and/or labour. Many people volunteer out of a strong desire to help. Others may wish to learn particular skills or hope to be ultimately employed at some stage. For others volunteering may be a way to meet new friends.

There are special challenges to managing volunteers. In the first instance, because they are not paid, it is essential for projects to understand what motivates them and how their interest can be retained. Volunteers need the same protection as paid staff. They need to be protected against discrimination and be provided with a safe and healthy workplace.

To make sure that the contributions of volunteers to your organisation are mutually beneficial and satisfactory, it is important to develop and put in place policies to guide your relationship. There should be a clear process for recruitment and orientation, coordination, training, support and supervision. It is particularly important that policies about paying incentives or honoraria are clearly spelt out. Volunteers also need to know the kinds of expenses for which they will be reimbursed.

If your program relies heavily on volunteer staff, a paid staff member should be given the responsibility of coordinating and supporting volunteers.

Finally, it is important to plan for the possibility that volunteers will eventually want to leave the project. Your organisation should clearly show its appreciation for their participation.
Managing money and other resources

Financial management system

Managing money in a large program is complex and responsible work and may need to be done by an accountant. In a smaller project, the manager may have to take responsibility for this task. Either way, it is useful for your organisation to establish a transparent system for managing finances that will help you to be accountable to funders, community members and clients. Depending on the complexity of your program, your financial management system could include the following:

- sources of income and budgets for your project(s);
- asset management, including fixed assets such as computers and vehicles, and investments;
- financial control arrangements such as account signatories, expenditure authorisations, petty cash and audits;
- administering a bank account;
- record keeping;
- purchasing;
- financial reporting.

For more information on financial management systems for community organisations, we refer you to the manual *Tool box for building strong and healthy community organisations working in HIV/AIDS and sexual health*, Parts 1 and 2 by Felicity Young.

Keeping track of your money

There are two types of money: invisible money that is in the form of a budgetary allocation, and visible money, or cash.

A budget allocation may never be visible as cash because it involves drawing down of resources, such as a store for drugs used in the treatment of STIs, to an agreed limit (eg $500 a month). To keep track of this type of money, keep a ledger that records the date that the resources were drawn (eg 500 capsules of ampicillin), a withdrawal reference number which is duplicated in the records of the storekeeper, the value of the requisition (debit), and the remaining budget allocation for that time period (credit).

Visible money is accounted for using an imprest system. An imprest is an advance of cash for a particular purpose and replenished when needed up to the amount allocated in the project budget for the particular period (eg three months). The imprest is always replenished up to the original amount. For example, the training officer may be given $300 for training materials. When he or she has purchased materials and has almost used up the $300, he or she brings a petty cash voucher to the manager which details how the money was spent and is accompanied by the relevant receipts from the vendor. This voucher should show the original amount, the amount spent (itemised), and the balance of funds remaining. Let’s say our training officer has spent $276.75 with $23.25 remaining in cash. After examining and discussing the petty cash voucher, the manager may now provide another $276.75 to bring the training officer’s imprest up to the original $300.

It is sensible to have at least two people who keep track of the project budget. In the organisation of the accounts system and petty cash be careful not to expose people to temptation. When project staff are living in times of financial difficulty they can be under great pressure from friends and family to take advantage of their position.
Resource centre

The project will inevitably gather many reports and articles about aspects of HIV infection. Establish a resource centre with box files. Subscribe to the various free newsletters that are available and to the relevant mailing lists if you have access to email (see Appendix 2). Publicise the resource centre to those who might find it useful – such as other NGOs, training centres and the local hospital.

Management of vehicles

Vehicles are the most common cause of arguments. Shared vehicles tend to be poorly cared for because no one takes responsibility. Develop a protocol with all staff so that everyone agrees to it. The protocol should address the issues of maintenance, procedure for booking the vehicle, and accidents. It is essential to keep a logbook in the vehicle to record all journeys.

Monitoring and evaluating your project

As we discussed in Chapter 5, it is important to draw up a monitoring and evaluation plan when you develop the overall plan for your project. In this section we describe how a system for monitoring progress of the project could be established. We also describe a process for conducting an evaluation.

Monitoring

Management information system (MIS)

As we defined in Chapter 5, ‘monitoring’ is the regular, methodical process of gathering information throughout the project life for tracking the project’s performance against the plan. An important way of monitoring implementation over time is to establish a management information system (MIS). A MIS provides routine information on:

• project inputs (eg number of volunteers, number of condoms purchased, funds);
• project activities (eg number of community education sessions conducted, number of workshops conducted, number of leaflets distributed);
• project outputs (eg number of condoms distributed, number of peer educator contacts).

Your project should also consider having, and regularly updating, the following information:

• map of project area;
• list of project participants (eg members of Steering Committee, project implementers and clients);
• description of the organisational structure of the project (eg who reports to whom, who does what);
• description of what the project does and how it does it;
• description of the monitoring and evaluation system itself (see Chapter 5, Table 5.3 and Table 5.4).
Collecting information

It is important to remember that information that goes into the MIS is routine information. This means that the information is collected as part of the everyday work done by the project. You may need to design forms to collect the information and train staff to use the forms. For example, if you are running a VCT centre, you can collect information with a standard form on the characteristics of the clients attending the centre, reasons for using the VCT service, the testing protocol used, whether they return for their test results, etc. In Section 3, we identify some of the routine information you can collect while implementing different HIV responses.

When designing information collection forms, it is important to make sure that they are user-friendly. This means you need to think carefully about what kind of information you need to collect, why you need the information and how you will use it. You also need to ensure that there are no ethical problems with gathering the information. If any of the information is confidential, make sure that it is stored securely.

In addition to a formal system of collecting information for monitoring purposes, ask all field staff to keep detailed notes of their activities in a notebook or diary and to share their notes with other staff during meetings.

Field staffs’ diaries can include a description of activities and comments about the activities. For example, what worked, what did not work, what could be improved, what could be stopped, what could be initiated, constraints, lessons, etc. These diaries are part of your project’s information system.

Analysing information

When you are busy running a project, it is often easier to collect information than to analyse it and use it to improve your work. It helps if you have a regular schedule for collating and analysing the information. Depending on the type of information you are collecting, the schedule can be on a daily, weekly, monthly or even quarterly basis.

Using our example of running a VCT centre, you can tabulate the number of people using the service on a weekly basis. On a monthly basis, you may want to look closely at the kinds of people using the service – for example, what proportion are women? What age groups are using the service? You may also wish to know what proportion of people return for their test results.

Taking a close look at the information can alert you to any problems with the service that you are providing. Sometimes you may need to conduct some research to find out what is really going on. For example, if you found out that only half of those who come in for an HIV test return for their results, you may want to find out why that is so. You may need to check the quality of pre-test counselling that they receive, or the length of time it takes for the results to come back from the laboratory.

It is important to remember that collecting and analysing routine information enables your organisation to track the progress of implementation of your project and also allows you to check the quality of your work.
**Reporting, sharing and displaying project information**

**Reports**

Reporting on your work is an important way of being accountable to project participants including community members, project staff, and funders. The regularity with which you produce progress reports would usually be negotiated between your organisation and the funding agency. Many NGOs report quarterly and annually on their work. Quarterly and annual reports should normally include information on:

- the activity or work area being reported on;
- work planned for the period and work completed;
- progress towards project objectives and targets;
- budgeted and actual expenditure;
- achievements;
- constraints/problems and action taken or recommended;
- lessons learned.

Progress reports should be brief and to the point, using tables, charts and other visual aids to communicate progress.

Try to keep up to date with quarterly and annual reporting requirements. Each quarter, you could have a special workshop where staff and users present reports on progress towards objectives as well as achievements, challenges and lessons. Quarterly reports are written from this information.

A routine format reduces the time that this takes, and word processors make it a simple matter to update the previous report. The progress reports should not be just for the donor agency. They make a useful record of the project for visitors, members of the community and project staff.

**Sharing information**

It is also useful to set aside some time at staff meetings for sharing of information, reflection and discussion. One way to do this is to call for a period of silence while project workers quietly think about recent achievements, problems and lessons. Then ask each person to mention one achievement, one problem and one learning that has occurred since the last meeting. Ask the others not to respond to or discuss what is said. This can be quite frustrating, but does encourage those who may feel shy to mention issues because they fear an argument.

If you hold such a session be sure to provide an opportunity for discussion and follow-up of issues raised. Ask the workers how they feel about the exercise.

Another way to encourage a process of ongoing analysis of project work is to ask different workers to present aspects of their work to the others. This also improves presentation skills, confidence, and cohesion between project activities and stimulates new ideas and suggestions. You can also share project information through a newsletter.

**Displaying project information**

Ask project workers to think of creative and attractive ways to display information about the project so that it is accessible to the wider community. One way might be to have a visual representation of a target on the office wall that is gradually coloured in to show progress towards the target. This might take the form of a road, a snake, or a tree for example, divided into sections to show number of people reached, training workshops held, or orphan households helped.

Another idea is to have a display of photographs and stories about the project that is added to throughout the project. The wall charts, photographs and stories monitoring progress of the project towards its objectives are part of the project information system.
Managing information

A project generates a great deal of documents and information, including reports, correspondence, planning documents, and accounts. It is important to establish a system for managing this information.

Filing may be boring but creating a sensible filing system that is easy to use is one of the most important ways to help a project to run smoothly. An efficient filing system saves a great deal of time and misunderstanding.

If you have a computer, arrange the computer documents in files of the same names and categories as in your filing cabinet. Well-labelled box files are especially useful for documents that you use frequently and which are not confidential.

Evaluating your project

What is evaluation?

Managers and staff are faced with decisions about their project all the time. These decisions relate to ways to improve the project and how best to use resources. In order to make these decisions, you often use your professional judgement to informally assess your work. Your assessment may be based on what staff and other project participants tell you, what you yourself actually observe about the project, or what you know from previous experience with similar projects.

Most managers and project staff, however, recognise that their judgement is subjective. Bias can be reduced and decisions can be improved by more structured data gathering. Project evaluation is a more structured approach to assessing projects.

Evaluation assesses the value of the project to all stakeholders. We can further define project evaluation as the systematic gathering, analysis, and reporting of data about a project to assist in decision-making. Evaluation involves:

- describing the intended project;
- documenting what actually happened;
- describing participant characteristics;
- demonstrating the outcome and impact of the project.

Are there different types of evaluation?

Different types of evaluation are needed at the different stages of the project cycle. Before a project is designed, we conduct a needs assessment or formative evaluation to determine whether a project is needed, who needs the project and how it should be carried out. The process of carrying out a needs assessment is described in Chapters 3 and 4.

Early in the implementation phase, we may need information to answer questions such as: ‘Is implementation consistent with the way the project was planned? How can the project be improved? This type of evaluation which examines how the project is working is called process evaluation.
Once the project is established and early evaluation activities (process evaluation) have indicated that implementation is running smoothly, you may wish to assess the impact the project is having. This is called outcome evaluation. This type of evaluation examines the changes that occurred as a result of your project and whether it is having the intended effects. The following diagram illustrates the relationship between project activities and the different effects of the project.

**FIGURE 13.1: PROJECT ACTIVITIES AND THEIR EFFECTS**

| Inputs and Activities (eg training workshops, condoms, drugs) |
| Outputs (eg number of trained peer educators, number of condoms distributed) |
| Short-term outcomes (changes in knowledge, attitudes, behaviours, service quality and coverage) |
| Long-term outcomes or impact (changes in the health, social, or economic status of individuals and communities) |

**TABLE 13.1: TYPES OF EVALUATION**

<table>
<thead>
<tr>
<th>Purpose of evaluation</th>
<th>Type of evaluation</th>
<th>Examples from the field</th>
<th>Questions answered by the evaluation type</th>
</tr>
</thead>
</table>
| To assess the needs, determine the concept and design of a project | Formative Evaluation/Needs Assessment | ‘Quite a few men and women in our village have died the last few years. They all had children, some of them quite young. The children have been living on their own. The older ones have stopped going to school. We have to find out how many such children there are, how they are surviving and how we can help them.’ | • Is a project/response needed?  
• Who needs the project?  
• How should the project be carried out? |
| To improve the operation of an existing project | Process evaluation (Monitors inputs and outputs; assesses service quality) | ‘Implementation just isn’t going smoothly. My colleagues and I are not exactly sure what the problem is. I’d like to be able to pinpoint the problem in order to correct it and get things back on track.’ | • To what extent are planned activities actually realised?  
• How well are the services provided? |
| To assess the short- and long-term outcomes of a project | Outcome and impact evaluation | ‘The effectiveness of our project is being questioned. We’re sure our project is important and it is already beginning to show results – at least it will if it’s given enough time. The community is telling us that it’s having an impact and staff believe the project is really building momentum. I’d like to demonstrate the results our project is having on its participants and the community as whole.’ | • What short- and long-term outcomes are observed?  
• What do the outcomes mean?  
• Does the project make a difference? |
Who should be involved in monitoring and evaluating your project?

It can be tempting to see monitoring and evaluation as the job of project managers and/or evaluation specialists. It is important that all project participants have a role in monitoring and evaluation. As we have described above, project staff have a crucial role in collecting and analysing the everyday information that makes up the management information system used to monitor project activities.

We would also encourage project planners and staff to experiment with forms of monitoring and evaluation which promote rather than exclude community participation. For example:

- Community members can be regularly asked to give their own accounts of project performance, impact, strengths, weaknesses, lessons etc through oral stories, drawings and photos (even videotape!).
- Community members can be asked to develop social accounts of typical and exceptional instances of project impact etc through photos and/or stories. In this spirit, stories, photos, drawings etc can function as community-based indicators of past, present and desired scenarios. A target can be a desired scenario that is depicted by drawings, photos, a video, a play (that is videoed for example) etc. The project’s progress towards or away from the desired situation can also be shown in similar ways.

Formal evaluations, even if they involve external evaluators, should also be participatory. A participatory approach does not simply mean extracting information from project staff or clients who use services provided by the project. A participatory approach involves key stakeholders in all aspects of the evaluation, from defining the purpose to deciding the key evaluation questions to collecting and analysing the information and agreeing on the decision to take.

This can be done by establishing an evaluation team consisting of project staff, identified community members, and project participants (e.g. clients of services provided by the project). If your project is externally funded, your funding organisation may require or prefer an external, independent evaluator. You may want to invite an external person with expertise in the area of your project work and evaluation.

There are advantages and disadvantages to having one or more external evaluators present. If there are too many highly qualified external consultants present, other members of the Evaluation Team such as community members and project workers may feel intimidated and less likely to contribute their experiences and views.

If the Evaluation Leader who runs the evaluation and is responsible for preparing the report does not support a participatory approach, there is a danger that the evaluation will have little meaning for the local community, and may undermine the confidence of project workers. In the end, the findings of such an evaluation may not be used.

On the other hand, an external evaluator who encourages a participatory approach may increase the confidence and morale of project workers. They may notice achievements and issues that local people might have taken for granted. They can bring useful suggestions and ideas from projects in other settings.

When should evaluations be planned?

Evaluation is an integral part of project management. The plan for process and outcome evaluation should be built into your overall project plan and have sufficient budget allocated to it. Although it is never too late to evaluate your project, you should plan your evaluation as early as you can. Early planning ensures that you will be able to gather the right data at the right time. This is especially important for outcome evaluation.
It is a good idea to formally evaluate your project annually, immediately prior to your annual planning workshop where you set your annual objectives and targets and detailed work plan. You could run an annual ‘participatory evaluation and planning’ workshop. In these workshops, the findings, lessons and recommendations of the evaluation can be immediately fed back into your planning for the next year.

**Preparing for an evaluation**

Project management and staff need to prepare carefully in the weeks before you begin an evaluation. The preparation includes:

- deciding on the Evaluation Team: agreeing on who is going to be involved and making sure that they will be available for the time required;
- drafting the terms of reference and making sure that the Evaluation Team has a chance to comment on it;
- organising and sorting documents from the project information system;
- arranging transport for field visits by the Evaluation Team;
- where necessary, arranging for interpreters to be available for the Evaluation Team.

**What are the steps involved in doing the evaluation**

We present a five-step approach to evaluating HIV projects. The process described here is based on the model described in *Program evaluation tool kit: a blueprint for public health management*:

- Focus the evaluation by determining exactly what you need to know about your project.
- Choose appropriate methods for answering the evaluation questions.
- Develop or modify data collection tools.
- Gather and analyse data.
- Use the answers to your evaluation questions to help make decisions about your project.

**Step 1: Focus the evaluation**

The first step in evaluating your project is deciding the focus of the evaluation. Focussing your evaluation involves:

- defining the purpose of the evaluation;
- creating a logic model of your project;
- consulting with stakeholders about the evaluation;
- determining the evaluation questions.

**Step 1a: Identifying the purpose of the evaluation**

Evaluations cannot explore everything about a project. It is a good idea to think carefully about the purpose of the evaluation. What do you want to achieve by doing the evaluation? It is important to do this before tackling the specific details of how you are going to do the evaluation. Otherwise there is a danger of getting bogged down in the process of developing data collection tools, gathering data, analysing data, trying to interpret that data, thereby losing sight of the bigger picture.

There are many reasons to evaluate a project — to identify strengths and weaknesses, to share experiences, to measure progress, to improve implementation, to see what has been achieved so far, or to make decisions about which aspects of your project should be continued or discontinued. You will probably have more than one reason to evaluate your project, but you should be careful not to take on too many focus areas.

Most of our earlier advice on project planning applies to evaluation planning. Consult with other project participants and stakeholders. What do they want from the evaluation? What are their interests?
Step 1b: Creating a logic model

For most evaluations, it is important to have a clear description of the project to be evaluated. It will help to identify the critical questions for your evaluation. A ‘Logic Model’ is a diagram showing what the project is supposed to do, with whom and why.

**WHAT?** Describes:
- Components of the project
- Activities conducted to achieve the desired outcomes

**WHO?** Describes:
- Target groups – individuals, groups or communities for whom the project’s activities are designed

**WHY?** Describes:
- Outcomes – changes the project hopes to achieve. There are both short-term and long-term outcomes.

To develop a Logic Model, start by describing the Components, Activities and Target groups (CAT) of your project. An example of a CAT Worksheet is shown in Annex 13.1.

Next fill in a SOLO (Short-term Outcomes and Long-term Outcomes) Worksheet (Annex 13.2). Short-term outcomes are the direct results of the project on its participants. They show why the project activities will lead to long-term outcomes. In HIV prevention projects, short-term outcomes may be increased awareness or concern, increased knowledge, increased adoption of healthier attitudes or improved skills.

Long-term outcomes reflect the consequences of your project in the broader community. They tend to be ultimate goals of the project. Long-term outcomes are also referred to as the impact of the project and sometimes take a long time to occur. Projects are rarely held accountable for achieving long-term outcomes because there are so many other forces that can influence outcome. Examples of long-term outcomes for AIDS prevention and care are reduced trends in HIV/AIDS rates, sustained changes in HIV/STI-related risk behaviours, reduced AIDS-related death rates, and sustained changes in societal norms.

Once the worksheets are complete, you are ready to start putting all the program elements together into a logic model. It is a good idea to get others to help you create a logic model. Consider working with project staff at all levels to develop the logic model. Everyone should agree on the way the project is shown in the logic model before going ahead with the evaluation.

An example of a Project Logic Model is shown in Table 13.2 below.
TABLE 13.2: PROGRAM LOGIC MODEL FOR YOUTH PEER EDUCATION PROGRAM

<table>
<thead>
<tr>
<th>COMPONENTS</th>
<th>Reproductive health services for young people</th>
<th>HIV and STI education</th>
</tr>
</thead>
</table>
| ACTIVITIES | • Identify and train young volunteers to provide counselling and distribute condoms at selected health centres  
• Youth counselling volunteers attend peer education sessions in schools to inform young people about their services at the health centres  
• Health care workers at 3 selected centres trained about providing services for young people  
• Procure condoms  
• Distribute condoms to young people attending health centres for STI treatment or family planning advice | • Recruit and train 25 student peer educators – 5 from each 5 selected schools  
• Identify and train one teacher from each participating school as HIV/AIDS Patron  
• Peer educators conduct group session each month  
• HIV patrons meet with peer educators every month to discuss issues or problems  
• HIV patrons observe some of group sessions conducted by peer educators |
| TARGET GROUPS | • Volunteer youth counsellors  
• Health care workers  
• Young people aged 15–24 years | • Young people from 5 high schools  
• Peer educators from 5 high schools  
• Teachers from 5 high schools |
| SHORT-TERM OUTCOMES | • Quality of STI services for young people improved  
• Condoms made available to all young people who request them  
• Sexually active young people using condoms | • Increased participation of high school students in peer education program  
• Increased knowledge of HIV/STI transmission and methods of prevention among young people  
• Improved knowledge of available services/resources for young people  
• Increased ongoing peer support |
| LONG-TERM OUTCOMES | • Changes in STI trends among young people | • Increased number of young people able to adopt safer sexual behaviour |

Decrease in HIV infection among young people aged 15–24 years

BOX 13.7: ACCESS TO INFORMATION AND SERVICES FOR YOUNG PEOPLE

After learning that youth aged 15–24 years are among the fastest growing group to contract HIV infection, an NGO in a Southern African town conducted a study in the four villages it serves. The study found that although around 33% of high school students were sexually active, only 7% used condoms. Only 26% of high students could define HIV/AIDS and only 20% could list ways the disease is transmitted or name three safe sex practices.

To reduce HIV transmission among young people in the villages, the NGO designed a strategy to improve access to information and services for high school students. They trained 25 peer educators to promote awareness among the approximately 2,500 high school students attending five selected schools. One teacher from each school was also trained to support the program as an HIV/AIDS patron. Assuming that each peer educator could conduct one small group session per month for the ten months in the school year, the NGO estimated that 250 educational sessions would be conducted by the end of the school year.

The second part of their strategy was to improve access of students to services at the health centres. The NGO worked with the three health centres to establish youth friendly settings. Young trained volunteers were available at the centres to discuss sexuality and provide condoms when requested.
Remember, a logic model is supposed to demonstrate the logic behind your project. The final step in developing the model is to check the logic. Ask yourselves: ‘Is it reasonable to expect the project’s activities will actually lead to both the project’s short-term and long-term outcomes?’

**Step 1c: Consulting with stakeholders**
When the logic model of your project has been completed, the next step is to consult with stakeholders. These are the individuals or groups who have an interest in the project’s evaluation.

Develop a list of stakeholders by asking yourself: ‘Who will be using the information from the evaluation?’ Try not to serve too many individuals or groups at once. For the evaluation to be credible, it must be focussed on serving the information needs of key users.

For example, the stakeholders of a project which aimed to reduce the risk of young people in Cholo Township to HIV infection were: young people, parents and guardians, school teachers, health care workers at the local clinic, project staff, the local HIV/AIDS program manager, and the funding agency.

It is most important to check the logic model of the project with key stakeholders, in particular project participants who use services provided by the project.

**Step 1d: Determining the evaluation questions**
The next step is to determine the questions the evaluation will seek to answer. Use the logic model to help you to focus on possible evaluation questions. So you can ask questions about the activities, target groups, and outcomes (short-term and long-term) of your project. A checklist for evaluation questions is shown in Table 13.3 below.

For each question, indicate whether it is a high- or low-priority evaluation question for the project staff and key stakeholders. A high priority question is one that absolutely must be answered as soon as possible to help you make decisions about the project. A low-priority question is something that would be ‘nice to know’, but no one actually needs to know the answer right now.

It is very important that we ask the right questions. When you have got your list of priority questions, check the feasibility of the questions by applying the SMART principle to each question. Ask if the question is:

- **Specific:** Is the question specific? Is it clear?
- **Measurable:** Will you be able to answer the question?
- **Actionable:** Will the answers to the question provide you with the information you need to make decisions about your project?
- **Relevant:** Are there any questions that you can identify as simply ‘nice to know’ as opposed to ‘need to know’. For each question, you should be able to know who needs the information, and clearly define why they need it.
- **Timely:** Is it important to ask this question now?

**REMEMBER!!**
The evaluation cannot be all things to all people. It is crucial to limit the evaluation questions to high-priority issues only.
TABLE 13.3: EVALUATION QUESTIONS CHECKLIST

<table>
<thead>
<tr>
<th>QUESTIONS</th>
<th>WHO NEEDS TO KNOW?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>H = High priority</td>
</tr>
<tr>
<td></td>
<td>Project staff</td>
</tr>
<tr>
<td>Activities</td>
<td></td>
</tr>
<tr>
<td>Were activities implemented as planned? (how often, when, where, duration)</td>
<td>H</td>
</tr>
<tr>
<td>How did the activities vary from one site to another?</td>
<td></td>
</tr>
<tr>
<td>Were required resources in place and sufficient?</td>
<td></td>
</tr>
<tr>
<td>Did staff think they are able to implement the activities as planned?</td>
<td></td>
</tr>
<tr>
<td>If not, what factors limited their implementation?</td>
<td></td>
</tr>
<tr>
<td>Did staff and community partners think the partnership was positive?</td>
<td></td>
</tr>
<tr>
<td>Did community partners think the activities were implemented as planned?</td>
<td></td>
</tr>
<tr>
<td>What activities worked well? What activities did not work so well?</td>
<td></td>
</tr>
<tr>
<td>What was the cost of delivering the activities?</td>
<td></td>
</tr>
<tr>
<td>Project Participants (Target Groups)</td>
<td></td>
</tr>
<tr>
<td>How many people were reached?</td>
<td></td>
</tr>
<tr>
<td>Did the program reach the intended target group?</td>
<td></td>
</tr>
<tr>
<td>To what extent did activities reach people outside the target group?</td>
<td></td>
</tr>
<tr>
<td>What proportion of people in need were reached?</td>
<td></td>
</tr>
<tr>
<td>Were potential participants (non-participants) aware of the project?</td>
<td></td>
</tr>
<tr>
<td>Were participants satisfied with the project?</td>
<td></td>
</tr>
<tr>
<td>Does the project have a good reputation?</td>
<td></td>
</tr>
<tr>
<td>How did the participants find out about the project?</td>
<td></td>
</tr>
<tr>
<td>Outcomes</td>
<td></td>
</tr>
<tr>
<td>Have the short-term outcomes been achieved? (List the short-term outcomes of the project from the logic model).</td>
<td></td>
</tr>
<tr>
<td>Have the long-term outcomes been achieved? (List the long-term outcomes of the project from the logic model).</td>
<td></td>
</tr>
</tbody>
</table>

Think about which activities contribute the most to the project’s outcomes. Are there any activities you're particularly concerned about?

Think about who the project is designed for. What do you need to know about who you are reaching and who you are not?

Think about which outcomes are most crucial. Which outcomes are the most difficult to achieve?
**Step 2: Select data collection methods**

The next step after developing key evaluation questions is to determine the best way to answer the questions. You need to decide the specific data you need and the methods you should use to gather them.

**Establishing expectations**

Before you can go ahead and assess achievements in the project, it is important to know what the project was expected to achieve in the first place. Think back to when your project started. You had some idea of what you wanted to see happen in terms of activities and outcomes and a sense of what would constitute success. To define your expectations, you may consider the following questions for each evaluation question:

- What would satisfy you that your program has been operating successfully and achieving what you intended? For example in our example of the HIV prevention program for young people, the primary target group for improving reproductive health services was high school students aged 15–24 years. Your evaluation needs to assess whether you are reaching the intended population group.
- What is the minimum that you would accept before considering making changes to the program?

Apply the following seven considerations to each evaluation question:

- Are the data you need already available?
- What type of data collection tool would provide the data?
- Who could provide the data, if asked?
- Who can gather the data?
- What is the best design?
- From how many people or things should data be collected?
- What is the required time frame for data collection?

When you have answered all these questions, you will have outlined your method for collecting the data in the ‘data collecting plan’.

You can use a worksheet such as the one shown in Annex 13.3 to plan the data collection. The last column in the worksheet is about the feasibility of the data collection method you have described for a particular evaluation question.

The following questions will help you determine whether your plan is feasible, given the resources you have.

- Do you have the expertise and the time in-house to do all parts of the plan?
- Will you require someone outside of your project to do any of the work? If so what will it cost and do you have the money to pay for it?
- What are the other costs involved? For example, if new data collection tools are required, what will it cost to develop them?

The Logistics Worksheet in Annex 13.4 can help you judge the feasibility of your plan.

**Step 3: Develop tools for data collection**

All data collection tools involve asking questions and recording answers. They include questionnaires, telephone surveys, focus groups, face-to-face interviews, activity logs, registration forms and attendance sheets.

**Step 3a: Finding existing tools**

It is important to check if there are existing tools that meet your needs. A number of tools have been developed and used to assess all aspects of HIV/AIDS responses. UNAIDS, WHO, USAID-funded projects MEASURE and HORIZONS and Family Health International have developed and published HIV/AIDS program assessment tools. These are available both in hard copy and as CD-ROMs.
If you do find a good measure or tool, chances are that you will have to make some modifications. Assess how well the tool addresses your unique evaluation questions and how well it will work in your particular situation.

If there are no existing tools, you will have to create a new tool.

**Step 3b: Developing new data collection tools**

The steps in developing data collection tools are:

- draft questions;
- determine the type of response;
- select the response categories;
- put the questions and answers together in a clear and easy-to-understand format.

For each expectation (key evaluation question), write one or more questions you want to ask people who have the data you need. Some expectations will only require one question on a tool. For example, ‘In what year were you born?’ is the individual question for the expectation that 20% of participants are less than 25. Others will require several questions to tap all the dimensions of an issue. To explore participant satisfaction, for example, it may be necessary to ask, ‘How satisfied were you with each of the following aspects of the program: the small group discussions with the peer educator, one-on-one discussions with peer educator, counselling sessions at the clinic, information leaflets?’

Make sure that all questions on your tool relate back to the overall purpose of the evaluation and the specific evaluation questions and expectations.

For each question you draft, you have to select the type of response you expect. There are two ways to record answers to questions, with pre-set categories (closed-ended questions) or in people’s own words (open-ended questions).

The following two examples illustrate two ways of recording closed-ended questions:

**Example 1**

‘I am going to read out some statements about protection against HIV. For each statement please tell me whether you think it is true or not.

People can protect themselves from HIV/AIDS by:

- having a good diet
- staying with one faithful partner
- avoiding public toilets
- using condoms during sexual intercourse
- avoiding touching a person who has AIDS
- avoiding sharing food with a person who has AIDS
- avoiding being bitten by mosquitoes or similar insects
- making sure any injection they have is done with a clean needle
- Other ________________________________’.

**BOX 13.8: TIPS FOR DRAFTING QUESTIONS**

- Use simple and familiar words. Consider the literacy levels of the people from whom you are collecting data.
- Keep questions short and to the point
- Avoid using jargon or technical terms. For example ‘determinants of health’ can be expressed as ‘factors which affect our health’.
- Avoid compound questions – these are questions which ask for more than one piece of information. For example ‘How satisfied were you with the time and location of the education sessions?’ This should be broken down to:

  - How satisfied were you with the time of the education sessions?
  - How satisfied were you with the location of the education sessions?

- Avoid leading questions. They can introduce bias. An example of a leading question is: ‘Some parents believe that educating young people about sex will make them want to have sex. Do you agree?’

This question should be rephrased as follows:

- ‘Do you agree or disagree with the following statement: Educating young people about sex will make them want to have sex?’
Example 2

‘Overall, how would you rate the peer education session?
• excellent
• good
• fair
• poor

Open-ended questions do not have any pre-set response categories. Some data collection tools, such as focus group discussions, consist entirely of open-ended questions. Open-ended questions allow people to express themselves in their own words. When you analyse open-ended questions, you generally don’t count the number of times people say things. Instead you look for broad themes. The following question is an example of an open-ended question:

What did you learn as a result of the peer education sessions?

Step 3c: Assessing the quality of the data collection tool

Once you have put your data collection tool together from scratch, or modified an existing one, it is critical to assess its quality. There are several ways to do this. At a minimum you should assess the content and clarity of the tool.

The content and clarity test will tell you whether the tool is measuring exactly what you want it to measure and whether it is easy to understand. You assess the tool by getting two different groups of people to review the tool. For the evaluation of the Youth HIV/AIDS Program, one group of reviewers will be the teachers at the high school and nurses at the clinics. A second group will be people similar to those who will eventually provide you with real data, in this case high school students.

Ask your reviewers the following questions:
• Does the tool measure what it is supposed to?
• Are there any unnecessary measures included in the tool?
• Are the questions easy to understand?
• Will people be able to answer the questions?
• Will people be able to follow the instructions?
• What is the quality of translation (if applicable?)
• Are there colloquial (slang) expressions that may not be understood?
• Is the font and style easy to read?
• Will people have trouble remembering information needed to answer questions?
• Does the tool read smoothly and flow logically?
• Will the tool hold people’s interest?
• Are there any typographical errors or spelling mistakes?
• Are there any questions that may be culturally inappropriate?

Step 4: Gather and analyse data

Step 4a: Gathering data

Once your tool is developed, it is time to gather data. In Chapter 4 we describe a number of methods for collecting and analysing data. In summary this step involves:

• Selecting data collectors: the term ‘data collectors’ refers to those who are going to get the data you need, for example, a moderator for a series of focus group discussions or an interviewer for a survey.

• Preparing instructions for data collectors: you need a ‘protocol’ to maximise consistency in data collection. The protocol is a set of brief written instructions. The aim is to have the most standardised approach possible among data collectors.

• Training data collectors: Training sessions for data collectors generally cover all of the information contained in the protocol. It is important that everybody
meets together. Explain the roles and responsibilities of the data collectors and then walk data collectors through the task step-by-step. It is important to review the techniques associated with your particular data collection tool.

- **Pre-testing the method:** Despite the most careful and detailed planning, there are things that inevitably get overlooked which can jeopardise the quality of your data. It is essential that your data collectors try out the tool and methods on a small subgroup before you launch into the real thing. The pre-test allows you to look at the following issues:
  - How much time does it take?
  - Are there any problems in selecting the sample?
  - How many people participate?
  - How disruptive is administration of the tool?
  - Do data collectors understand and execute their tasks well?

- **Keeping track of data collection:** It is always important to keep track of your data collection activities. For face-to-face interviews, it sometimes takes several attempts to reach a potential interviewee. Decide in advance when attempts should be made and how many there should be in total.

**Step 4b: Analysing data**

Analysing both quantitative and qualitative data involves a systematic, step-by-step process. Sometimes data can be analysed by hand, other times it is necessary to use a computer.

Qualitative data — ie data collected from focus groups, interviews, observation, chart reviews, open-ended questions on questionnaires, and surveys can be analysed with computer programs such as Ethnograph and NUD.IST.

You can also analyse qualitative data by hand. The Qualitative Data Analysis Worksheet shown in Annex 13.5 can help you analyse your data. Here’s how to do it:

- **Read all the completed tools or notes and transcripts. Use a highlighter to mark the parts that deal with each evaluation question (a different colour for evaluation question).**
- **In the ‘Points’ column on the worksheet, write down each opinion, idea or feeling that pertains to the expectations for that evaluation question. If a point has already been mentioned, don’t rewrite it. Instead, keep a tally of the number of times this opinion, idea, or feeling is mentioned. Quotes sometimes help illustrate or substantiate points. In the column provided on the worksheet, write any quotes that express a point particularly well.**
- **Look at the tallies for each expectation. Take the points that are mentioned by the majority of respondents and write them in the ‘Findings’ column. Organise them by expectations. Don’t report precisely how many respondents agreed with each point. Instead use phrases like: ‘most people felt…’; ‘there was a strong feeling that…’; ‘the majority view was…’**

Most times you won’t report opinions that are expressed by only a minority of respondents. Occasionally, however, the minority view is important. Use your judgement, but always make it clear that only one or a few respondents expressed that opinion. If it is meaningful and won’t jeopardise any guarantees of anonymity, note any distinguishing characteristics of this minority that are relevant.

- **Repeat the above steps for each evaluation question. When you have completed this, you will have the findings from your qualitative data.**

Whenever possible, quantitative data should by analysed by computer. Special programs for statistical analysis such as Epi-Info, and SPSS can be used to analyse quantitative data. You may have to consult people with training in using these computer programs to help you with your analysis.
Step 5: Making decisions
This is the most creative part of the evaluation process – combining the systematic gathering and analysis of data with wisdom and experience to make good decisions about your project. Like all the steps in the evaluation process, this is a job for the whole Evaluation Team.

Step 5a: Interpreting the findings and drawing conclusions
Use the Interpretation of Findings Worksheet (Annex 13.6) to lead you through the process.

Look at the expectations that you established for your project. Compare them to your findings to determine whether or not they were met. Indicate in ‘Expectations Met’ whether the expectation was met; choose yes, no, or no but acceptable. It is important to consider whether the expectations were in fact realistic.

Next, think about the expectations that were not met. Consider all the possible explanations why. In the ‘Why’ column, write down the most plausible explanations. You might want to highlight your success by providing some explanation for expectations that were met or exceeded.

When thinking about the possible and the most plausible explanations, consider patterns of evidence, discrepancies, internal and external factors, plus any unexpected findings.

Patterns of evidence: Patterns are similarities in the findings from different sources. They help to confirm a finding or explain why a project did not achieve the intended result. For example, a study of behaviours of young people in relation to HIV/STI risk might find that young people reported engaging in unsafe sex when they had drunk large quantities of alcohol.

Discrepancies: These are findings that contradict each other or are inconsistent with findings from previous evaluations. Exploring these differences can help shed light on what is happening in your project, and indicate possible changes. For example, if staff delivering the project think it is going well, but participants do not, then it suggests staff are not in tune with participants. The project could be improved by providing an opportunity for staff and participants to interact more effectively.

Internal factors: Internal factors in your organisation/project can have either a positive or negative impact on the likelihood of your project meeting its expectations. Some questions to ask are:
• Was there a change in the allocation of staff or resources to the project?
• Was there a change in the priorities of the project?
• Was there a change in staff during the project?

External factors: External factors can also have a positive or negative impact on your project. Some questions to ask are:
• Have community needs changed?
• Does the problem for which the project was developed still exist?
• Did new problems arise?
• Did any gaps in service arise which must compete for existing resources?
• Is another organisation in the community providing a similar project?
• Has new research become available on the efficiency and effectiveness of the strategies used in your project?

Unexpected findings: Sometimes your evaluation will uncover something that you didn’t even think to ask in the first place. Ask yourself, ‘Did I learn anything beyond the evaluation questions?’
When you have considered possible explanations for your findings, you are in a position to draw some conclusions for your project. The conclusions are a summary of what you have learned from the project, both positive and negative. This is the ‘bottom line.’ Ask the following questions as you summarise your interpretations and write them in the ‘Conclusions’ column of the Interpretation of Findings Worksheet:

- Overall, is the project worthwhile?
- What is working well?
- What problems have been identified?

**Step 5b: Making decisions and preparing an action plan**

We have now come full circle. We defined evaluation as the systematic gathering, analysis and reporting of data about a project to assist in decision-making. Unless we use the findings of the evaluation to make decisions about the project, the whole process would have been wasted.

The decisions that you reach will be based on the purpose of the evaluation and your conclusion. For example, in the Youth Peer Education Project, the purpose of the evaluation could have been to decide whether or not to continue to offer the project. You may have concluded that the project was worthwhile and to continue with it. However, you may have identified problems in the peer education process. Work through whether and how you will address the problems.

From the findings of the evaluation, consider once again any internal and external factors, asking yourselves the following questions:

- Are they still factors?
- Will they continue to have an effect on the project?
- Are there new internal or external factors that you should consider?

Consider a range of alternative options and present the pros and cons of each before choosing a course of action. Among the options to consider are:

- Make small, inexpensive adjustments (list what they are).
- Make large modifications, which may or may not have resource implications (list modifications).
- Stop the project and do not replace it.
- Stop the project and begin planning to develop a new one.

Select your preferred options according to importance and feasibility. Decide on the time frame for implementing the changes required based on:

- the urgency of the need to correct the problem to improve the program;
- the magnitude of the change proposed;
- the significance of the decisions on staff and resources.

Your Action Plan for implementing your decisions should identify the tasks that need to be done, who will be responsible for and/or carry out each task, and an estimate of the resources required. You can use the Decisions and Action Plan Worksheet in Annex 13.7 to plan how you will implement decisions.

**Step 5c: Reporting on your evaluation**

A report of your evaluation is a record of the evaluation that can be used by others. Depending on the purpose of the evaluation, you may not need to prepare a formal written report. If you conducted the evaluation for internal needs, then the worksheets that you completed during the course of the evaluation may be sufficient.

In many cases, you may be required to draft a formal report. When doing so, you must consider the audience of the report. You will need to relate the findings to their specific knowledge, experience and concerns, and use language familiar to them. As part of planning the evaluation, the Evaluation Team should discuss and agree on the distribution of the findings.
To accommodate the various audiences, you may need to create more than one version of a written report. Also consider other ways of presenting the material. In this way, you can highlight the issues of interest to different readers, or present them in another way audiences may find more useful.

However you decide to report on your evaluation, there are a few things to remember:

- **Be timely**: Produce the report within a reasonable time after the data collection.
- **Be specific**: Limit the content to what is really needed.
- **Be simple**: Keep the report free of jargon. Use simple examples. Use pictorial methods (graphs, tables, photographs etc) to describe and explain data. Remember: ‘A picture is worth a thousand words’!

The format for a written report is shown in Box 13.9 below.

Apart from sending the written report to interested parties, you can distribute the results of the evaluation in a number of ways:

- conduct verbal presentation for project participants, including staff, clients, community leaders etc;
- use an in-house newsletter to highlight key portions – or all of the report for a wider audience;
- assist related external organisations to distribute the report.

### Planning for sustainability of the project

Whether or not your project has external funding, you will probably want communities to be able to continue to work towards the project objectives (or some other relevant objectives) when the project ceases sooner or later. Here are some general ways you can increase the chances that your project will be sustainable.

- By including key local stakeholders in your project planning team.
- By building a sense of ‘this is our idea’, ‘this is our project’ among project communities and other key stakeholders during planning, implementation, monitoring and evaluation.
- By building the capacity of project participants to plan, implement, monitor and evaluate HIV/STI responses (including proposal writing).
- By building the capacity of project participants to carry on the project activities or other worthwhile activities if the situation and priorities change.
- By building the capacity of project participants to train others.
BOX 13.9: STRUCTURE OF A FORMAL EVALUATION REPORT

**Executive Summary** (if the report is longer than about 10 pages)
This should be about one to three pages long. Include a brief description of the purpose of the evaluation, evaluation questions, methods, key findings, conclusions and decisions about the program.

**Introduction**
In this section, introduce the background and purpose of your evaluation. Be very brief. Leave the details to the rest of the report.

**Program Description**
Write a brief description of your project. Include the Project Logic Model from Step 1b.

**Evaluation Questions**
List the evaluation questions that were selected in Step 1d.

**Methods**
Briefly outline the methods you used for gathering the data (Step 2). You might include copies of the blank data collection tools in the report’s appendix. If it was necessary to develop new tools for gathering your data or if you modified existing tools, provide an outline of the steps taken.

**Findings**
In this section, briefly describe what you found when the data was analysed (Step 4). The findings should be grouped under each evaluation question. Use tables and graphs to present data clearly. The written text should not repeat everything in the tables but rather highlight key points.

**Discussion and Conclusions**
Select the key findings and briefly describe why they occurred (Step 5a). The conclusions that you reached should be listed here.

**Program Decisions**
Summarise your decisions about the project and include an outline of your action plan for implementation.

**Acknowledgements**
In this section, acknowledge anyone who provided data or helped you complete the evaluation.

**Appendix**
Include data collection tools
<table>
<thead>
<tr>
<th>Components</th>
<th>Activities</th>
<th>Target Groups</th>
</tr>
</thead>
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### QUALITATIVE DATA ANALYSIS WORKSHEET

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<th>Findings:</th>
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Chapter 14

Community action: profiles of some community responses

by Tamara Kwarteng and Tim O’Shaughnessy

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Introduction

At the beginning of 2004, there are signs that HIV prevention programs are working in a number of countries, with significant reductions in the prevalence of infection, including Uganda, Rwanda, Thailand, and Cambodia. The Global HIV Prevention Working Group reported in May 2003 that the hallmarks of an effective response to HIV included the following:

- high-level bipartisan political commitment;
- engagement with civil society and involvement of people living with HIV/AIDS;
- effective reduction of stigma and discrimination;
- good surveillance system;
- focus on preventing transmission in the most vulnerable groups in the population.

In this chapter, we focus on community action on HIV, an essential element of the civil society response. In the first and main part of the chapter, we describe a number of community responses to HIV in different settings. Community-level action has always played a major role in the global response to AIDS. In many countries, community action on HIV began before government action.

Most of the responses described here emerged from concerns of community groups about the effect of the epidemic on their community. Others were the result of collaboration between government and non-government organisations. One resulted from collaboration between government and the private sector. It is included to remind us that the workplace is an important site for facilitating community action.

We draw out important lessons for facilitating community action, including a central lesson for all HIV responses: effective HIV prevention and care requires action within communities themselves.

Community development has an important role to play in HIV prevention, treatment and care. Actions within communities themselves, undertaken with or without outside support, are essential for HIV prevention and can be called ‘community development’. Community development funded by external donors can help to increase the capacity of communities to organise and take action on HIV themselves.

An African proverb states that ‘one who does not cultivate one’s field will die of hunger’. Governments and communities, including people infected with HIV, can cultivate effective HIV prevention, treatment and care.
Responding to the needs of children

Kwasha Mukwenu: A Children-in-Distress (CINDI) program in Urban Lusaka, Zambia

This project, which aims to reduce the distress of children affected by HIV, was started by members of the women’s group of St Mary’s Catholic Church in Matero, a suburb of the Zambian capital Lusaka. The name of the project is Kwasha Mukwenu which means ‘help your friend’ in Tonga, one of the local Zambian languages. The project is affiliated with the Society for Women and AIDS in Zambia (SWAAZ).

Many of the Matero residents have moved there from other parts of Zambia. The Women’s Group members became aware that the number of households headed by children in the area was increasing as a result of many prime-age adults dying from AIDS. Many of the children could not provide for their basic needs to an extent that their very survival was at risk. Because most of these families had moved from their ‘hometown’ to the city, the extended family network which would normally have stepped in to look after the orphaned children was not available.

Kwasha Mukwenu was started to provide care and support for children affected by HIV in Matero. Members of the women’s group volunteered to be a ‘caretaker parent’ to between three and five families of orphans. Each caretaker parent ensures that the children under her care attend school and have food, shelter, clothes and the attention of a caring adult. Wherever possible, the children are supported to remain in their own home. This is possible if there is more than one child in the family and one of the siblings is old enough to provide some care to the younger ones.

From responding to a crisis in the care of children in their community after the death of their parents, members of Kwasha Mukwenu have extended their services to care and support of people living with HIV. They provide material and moral support and help those with children to plan for the welfare of their children after their death. Kwasha Mukwenu has also taken on a role to educate the local community about HIV and the plight of orphans, for example by producing a play about children affected by HIV in the community.

One of the most remarkable aspects about Kwasha Mukwenu is that many of the volunteers struggle to look after their own families financially. Yet they willingly take on the added responsibility of looking after the orphaned children. They have recreated, to an extent, the extended family network which exists in most African communities, but is strongest in rural communities and more fragile in urban areas.

In addition to caring for the affected children, the members of Kwasha Mukwenu raise funds for their work through income-generating activities. They have established a micro-enterprise centre at the hall donated by the local Catholic church where they cook, sew and tie and dye fabrics. The cooking project has contracts with several local schools and provides these institutions with biscuits and bread daily. Clothes and uniforms made by the sewing group, and cloth produced by the tie and dye project, are sold through local retail shops.

Kwasha Mukwenu: strengths of the response

- The Kwasha Mukwenu project is an excellent example of a group of community members responding to the pressing needs for care and support of children affected by AIDS in their community.
- This spontaneous response emerged from, and is sustained by, the community group. External funding and material support enhances the effectiveness of the project. However, the most important elements are the spirit of generosity and compassion of the members and their sense of responsibility for the survival of the community.
The project has established a system of social support in a country without a functioning government social welfare program. This provides a good example from which other communities with similar problems can learn.

Positive action: advocacy for the rights of HIV-positive people

Kenya AIDS Society (KAS)\(^1\)

The Kenya AIDS Society is a non-government organisation (NGO) founded in 1989 by a group of HIV-positive Kenyans to support people affected by the virus. The founders of KAS were among the first people with AIDS in Kenya to speak publicly about their condition. The organisation operates mainly in urban areas.

KAS is primarily an organisation for people living with HIV. The main goal of the organisation is to reduce the discrimination and stigma associated with HIV infection. To realise this goal, the organisation:

- provides care and support to people living with HIV;
- encourages and supports people with HIV to be involved in counselling, outreach, community education and advocacy;
- promotes the self-organisation of people with or affected by HIV so they share experiences and learn from each other about living positively with HIV;
- collaborates with, and encourages support from, the community at large;
- develops and maintains supportive relationships with other community organisations.

Providing care and support for people living with HIV is one of the most important functions of KAS. Many HIV-positive people are impoverished by the disease and have problems securing adequate food, housing and medical care. Many are also unable to support their families and pay for their children’s school fees. KAS has established relationships with numerous other organisations to whom they refer people who come to them for assistance. However, in a country with ever-increasing numbers of people affected by the epidemic, welfare agencies cannot meet the increasing demand for care and support.

KAS believes that its community education and counselling activities are paying dividends. More and more people are requesting educational materials, using the KAS hotline and, according to KAS counsellors, engaging in safer sex by using condoms and having fewer partners.

Kenya AIDS Society: strengths of the response

- self-organisation of people infected with HIV;
- facilitation of peer care and support of people with HIV;
- strong linkages between care, support and prevention established.

KAS clients report that ‘they feel free at heart’ to talk openly about HIV in the group therapy sessions. They say that some people have changed by becoming spiritually committed and that many have started to take measures to avoid the spread of HIV by using condoms. This change in sexual behaviour has been most notable among sex workers. Sex workers are also trying to find alternative means of earning a living.
**The Lawyers’ Collective**

The Lawyers’ Collective is a group of practising lawyers who defend the human rights of people on issues such as housing, the environment, gender and labour relations. They work from two offices in Mumbai and New Delhi. Members of the Lawyers’ Collective became involved in India in HIV work in 1989 when they were asked to represent a young man from Goa, who was jailed when he was discovered to be infected with HIV after donating blood. The young man, Dominic D’Souza, was placed in solitary confinement because the Goa Public Health Act required anyone considered to be a threat to public health to be placed in quarantine. The Lawyers’ Collective challenged these terms of the Goa Public Health Act in court. Subsequently the Act was changed so that it was no longer mandatory to detain people with HIV.

Since that first case, the Lawyers’ Collective has continued to represent, without charge, people with human rights problems related to HIV. These have included issues such as HIV testing and confidentiality in the health care setting, and discrimination with regard to employment and the custody of children. The story in the text box below describes one such case.

In addition to acting on behalf of people who have suffered discrimination because they are HIV-positive, the Lawyers’ Collective is also working to change the laws against homosexuality, sex work and injecting drug use. They recognise that laws treating these behaviours as criminal acts hinder HIV prevention efforts.

The Collective is extending its work to all parts of India by recruiting and training a network of lawyers from different parts of the country in HIV/AIDS Ethics and the Law. They organised a national workshop in 1994 which produced a 10-point program on legal and social reforms for protecting the basic rights of people with HIV/AIDS.

**Lawyers’ Collective: strengths of the response**

- The focus on the human rights of people infected and affected by HIV is a real strength of the Lawyers’ Collective response. This often neglected area is crucial for encouraging people with HIV to live positively and act responsibly to prevent further spread of the virus.
- It is an excellent example of a community group – professionals – using their comparative advantage to address an area of need. It exemplifies an expansion of the response beyond the health and welfare fields where AIDS responses are located in most countries.
- It illustrates that advocacy is an important tool for change, one which could be used more often in HIV responses.

An important outcome of the advocacy carried out by the Collective with national politicians is that the Indian government has abandoned plans for mandatory testing and forced isolation of people with HIV.

**BOX 14.1: FIGHTING AGAINST DISCRIMINATION IN EMPLOYMENT AGAINST HIV-POSITIVE PEOPLE**

Amol began working as a casual labourer for a large corporation in Bombay in 1986. He had always hoped to be taken on as a permanent employee, which would give him and his family a degree of security.

In 1994, he was interviewed for a permanent post, and to his delight was informed that he had been selected, subject to the results of a medical test. But his joy was short-lived. The Personnel Manager informed him that he would not be appointed after all, because he had tested HIV-positive the previous year, when he had applied for a different job in the same company.

Amol was shocked to learn that he had been tested for HIV without his knowledge, and wrote to the Executive Director of the company asking for an explanation. He did not receive a reply to his letter.

The Lawyers’ Collective filed a petition on behalf of Amol in the Bombay High Court, requesting that he be allowed to appeal against the company’s decision without having to reveal his identity in the course of proceedings. The High Court issued a suppression order which allowed Amol to sue under a pseudonym.

Amol did not win the case and left the company. However the case has paved the way for people with HIV to seek justice in the court of law without revealing their identities.

Source: Adapted from Broadening the front (1996)
Working with sex workers

The Sonagachi STD/HIV Intervention Programme

Sonagachi is one of the oldest and largest red-light areas in Kolkata, with an estimated 4,000 sex workers living and working in 370 brothels. The livelihood of the community depends on the approximately 20,000 men who visit the brothels every day. There is a regular influx of young girls from remote parts of India into the brothels.

The STD/HIV Intervention Project (SHIP) began in 1992 as a collaboration between the National AIDS Control Organisation (NACO), WHO, the All India Institute of Hygiene and Public Health and two NGOs – Health & Eco-Defence Society (HEDS) and Human Development and Research Institute (HDRD). Since 1995, the sex workers forum, called the Durbar Mahila Samanwya Committee (DMSC), has been an active partner of the project.

The primary objective of the project is to assist sex workers and their clients to practise safer sex. At the start, sex workers had to be convinced that the aim of the project was not intended to stop them earning their living but rather to assist them to protect their health and that of their clients. The partnership with the sex workers in developing appropriate strategies has been crucial to the success of the project. The major components of the project are provision of health care services, information, education and communication (IEC) and condoms.

Provision of health care services

A health care centre was opened in the heart of the red-light district. Sex workers and their families receive free health care at the centre. Particular attention is paid to ensuring that sex workers who become infected with STIs receive prompt treatment. All sex workers attending the clinic are screened for syphilis, and the clinic uses the syndromic STI management approach (Chapter 4). The opening hours of the clinic are set to the times when sex workers are not busy with clients. The clinic treats on average 35 to 40 clients daily – the majority of them are sex workers and their family members.

Condom promotion and information, education and communication

A peer education approach was adopted to provide sex workers with information and skills for preventing HIV and other STIs. The project recruited sex workers as peer educators, and trained them over a six-week period in HIV and STI prevention.

Following the training, peer educators work from 10 am to 1 pm daily making contact with 40 to 50 sex workers and 10 to 15 madams. Using flip-charts, leaflets, videos, slide shows and puppets, they provide sex workers with information about how to prevent STIs and HIV infection. Peer educators also encourage sex workers to attend the clinic for regular health checks. In addition, they promote and distribute condoms to sex workers and the brothel owners.

Effects of the project

The project has made some impressive changes in the lives of sex workers in Sonagachi in a relatively short time. A number of surveys have shown that the awareness of sex workers about HIV and STIs has increased significantly. In 1992, only 30% of sex workers interviewed were aware of their risk of becoming infected with HIV. By 1995, this percentage had grown to 97%. This awareness increased the demand for and use of condoms. Condom demands grew from 3,592 at the start of the project in 1992 to 110,328 in December 1996. A survey in 1992 found that only about 2.7% of sex workers reported using condoms.
A similar survey of sex workers in 1995 showed that 30% of respondents reported that they always used condoms and 50% reported that they often used condoms. Sex workers also stated they felt more confident in motivating their clients to use condoms and sometimes to turn away clients who refused to comply.

Perhaps the most important outcome of the project has been the positive impact on the self-respect, dignity and social identity of the sex workers. They now feel that they can negotiate better with clients and the police, and are more able to resist oppression and exploitation.

Sex workers have enough self-confidence to press for improvements in their legal and social position, including:

• repeal of the Prevention of Immoral Traffic Act, which criminalises sex work;
• the right to privacy and confidentiality;
• the right to have a self-regulatory board.

**Sonagachi: strengths of the project**

• The government and NGOs worked together effectively with a sex worker organisation to make the project a success.
• Building the capacity of sex-workers to become HIV educators was important in helping their sex-worker colleagues to understand and adopt the prevention messages.
• The harm reduction approach (see ‘Glossary’) taken to prevent STI/HIV infection among sex workers was important for getting the sex workers to accept and participate fully in the project. It was crucial for sex workers to know that the project sought to protect their health and that of their clients, and did not aim to stop the sex work itself.
• Improving the self-confidence and dignity of the sex workers has enabled them to fight against other forms of discrimination and achieve self-regulation.

**Integrating HIV/AIDS responses into existing community development activities**

**The Afar Pastoralist Development Association**

The main transport routes between the ports of Djibouti and Assab, Eritrea to Addis Ababa in Ethiopia pass through an area that is home to the Afar pastoralists. Off the main road there is little infra-structure, and government services are confined to major towns. The health facilities which exist beyond the regional capital are poorly equipped and staff do not speak the Afar language. The majority of the people who live in this region are nomadic or semi-nomadic pastoralists. During the four months of the dry season people often do not have enough to eat. The health status of the Afar people is poor. For example, 35% of children die before their fifth birthday from respiratory infections, malaria, tuberculosis or diarrhoea, and 150 out of every 1,000 pregnant women die in childbirth. Some of the reasons for the high maternal mortality rate include:

• poor health status
• difficulties in growing enough food
• lack of access to safe drinking water
• lack of money to buy food and other necessities
• insufficient access to government health services
• poverty.
A growing HIV epidemic is now adding to this already bleak situation. The virus is thought to have entered this vulnerable, marginalised population through men having unsafe sexual relations with sex workers in trading settlements along the transport routes. The number of AIDS deaths among Afar males is increasing.

The Afar Pastoralist Development Association (APDA) is a community organisation working to improve health and literacy, key community priorities. Since 1996, APDA has developed a Primary Health Care and Literacy Program in close consultation with Afar religious and traditional leaders and supported by Oxfam/Community Aid Abroad. HIV prevention is integrated into both the health and the literacy program.

Illiteracy is viewed as the single greatest cause of underdevelopment in the Afar region. Less than two percent of Afar can read or write, and this rate is even lower among women. Culturally, women have low status in the traditional clan structure, and Afar women are not involved in decision-making. A famous Afar proverb states that ‘One should always give an ear to women but not the final decision’. Clan leaders now recognise the link between illiteracy and maternal and child health, poor nutrition, child spacing and reproductive rights.

Through APDA’s literacy program Afar men, women and children learn to read, write, count and calculate in their own language.

Teachers are selected for training by the clan and, once trained, bring their skills back to the community. Traditional birth attendants (TBA), most of whom have had no formal training, are encouraged to join the literacy classes. The teaching materials used in the literacy classes include specially written health sheets which cover the main health issues affecting the Afar. Topics include HIV, hygiene, home remedies for diarrhoea and fever, use of medicines, respiratory infections, tuberculosis, nutrition during pregnancy, and use and maintenance of mosquito nets.

The program seeks to benefit women by increasing their skills, knowledge and confidence. However, to date, women’s involvement remains below the desired level. Of the 3,500 Afar pastoralists who have mastered Afar literacy and basic numeracy, only 670 are women. Since it is not culturally acceptable for married women to learn alongside men, special classes are now conducted for women only in the more established project areas where the communities have come to view women’s education as of community value.

TBAs that have joined the literacy classes embrace their new-found health knowledge as they realise it will enhance their practice. They now use more hygienic methods, such as sterilisation of razor blades and other basic equipment to reduce the risk of infection during birth. And though the first female graduates of the literacy classes were not health workers, they recognised the value of the health information used in their classes. The TBAs requested a booklet on disease prevention which would enable them to transfer this new-found knowledge to others in their communities.

The low status of women, the poor health status of the population and the proximity of their lands to transport routes and trading centres with a high prevalence of HIV make the Afar extremely vulnerable to HIV. In the coming year, APDA will step up their efforts to prevent the spread of HIV among the Afar by conducting a major community education program about HIV using a variety of information channels including posters, leaflets, videos, and songs. Health care workers will also be trained in counselling.
The pace of change is slower than hoped for. It takes time, especially in a traditional society, to gain the confidence of the community and convince them of the benefits of literacy training for women. Once this has been achieved, interest in literacy grows rapidly. The position of women in Afar society is changing as they gain skills and knowledge that are deemed important to the society.

**The Afar Pastoralist Development: strengths of the program**

- The program addresses needs identified by the community, including the religious and traditional leaders. The program is responding to the spread of HIV in the community by addressing some of the key factors underlying the vulnerability of the Afar people – a low literacy rate, low status of women and low health status.
- Ownership of the program is firmly grounded in the community. Each household contributes one goat per year to maintain stocks of medicines and other renewable supplies.
- Literacy teachers and health workers are chosen by the community and return to the clan to share the skills and knowledge gained with others.
- Those involved in communicating information about HIV/AIDS are accepted and trusted by the community.

**Responding to dual epidemics of injecting drug use and HIV**

**SHALOM project: a community response to AIDS in Churachandpur**

The SHALOM project is an indigenous community-based response to the dual epidemic of injecting drug use and HIV in Churachandpur, a district of the state of Manipur, located in the north-east of India and bordering Myanmar. Initiated in 1995, it has come to be recognised by the Government of India and UNAIDS as a model project representing a ‘best practice’ response to the epidemic in the context of injecting drug use.

Though only 0.2% of India’s population lives in Manipur, the region has contributed 17% of reported HIV infections in India. HIV was first reported in the state in 1989; since then the number of HIV infections has increased rapidly. As a consequence of the extensive practice of sharing injection equipment, the majority of those infected with HIV are male injecting drug users. Subsequently HIV has spread to their sexual partners and the wider community. Now, 2.3% of women attending antenatal clinics are infected with HIV.

The HIV epidemic in Churachandpur is directly linked to an epidemic of injecting drugs which began in the early 1980s. An estimated 7% of the population injects drugs. As heroin has been trafficked through India from Myanmar since the early 1980s, heroin is readily available in a cheap and pure form. Sero-prevalence studies among injecting drug users in Churachandpur have revealed that a staggering 80% are infected with HIV.

To support regular drug use, young people were increasingly engaging in crime and sex work. Thus, many injecting drug users were in prison, either because of criminal activities or as an attempt to enforce abstinence.

In the decade prior to the introduction of HIV infection into Churachandpur, the different ethnic communities responded to the problem of drug use and drug addiction by establishing many residential rehabilitation units. An attempt was made in these units to wean addicts from drug dependence by locking them up and enforcing abstinence.
They had a low success rate. The SHALOM project thus emerged in a context where the epidemic was well established among injecting drug users and their sexual partners, and where the need for a more effective response was high.

After careful consultation with community leaders, injecting drug users, their partners and families, the SHALOM project developed a carefully planned response to the epidemic. Project leadership and staff were indigenous to the area and represented most of the twelve tribal and language groups of the region. This is important to the project’s success, as the region is prone to inter-tribal conflict.

The project developed a program which was comprehensive in nature from the outset. Its main components are:

- community- and school-based drug and HIV education;
- confidential HIV testing with counselling;
- home-based care and counselling;
- home-based drug detoxification;
- drug rehabilitation provided through residential units;
- harm reduction through syringe and needle exchange and condom distribution;
- vocational training and employment creation.

A major feature of the SHALOM project is the adoption of harm reduction strategies to complement other services. The syringe and needle exchange established by SHALOM in 1995 was the first of its kind in India. A sero-prevalence study was initiated to determine the contribution of this component to reducing HIV transmission among injecting drug users.

The success of the SHALOM project makes it into a potential model response for surrounding states and countries which face similar injecting drug-fuelled HIV epidemics. In recognition of the early successes of the SHALOM approach, the government of India is seeking to adapt such responses more widely in the north-east of India in its donor-assisted bilateral Indo-Australian program.

Soon after the SHALOM program began, harm reduction strategies were included in a newly developed State AIDS Policy. Subsequently the state government has sought assistance to develop similar comprehensive programs for other seriously affected areas of the state. The neighbouring state of Mizoram has also established a similar project in the capital city of Aizwal in a desire to see the SHALOM model adopted more widely in that city and throughout the state. The project also supports the development of similar comprehensive responses in the northern state of Kachin, Myanmar, through the provision of technical support and provision of a study tour.

The application of the SHALOM project model elsewhere in India (including its harm-reduction approach) is an example of ‘scaling-up’ or broadening the scope of the project or its approach (see Chapter 5).

The SHALOM project was well supported with skilled human resources and adequate funds from the outset. In its first three years, an international agency provided technical assistance, while funding came from AusAID. Further, the project was a member unit of a large national health care NGO and thus could draw on guidance and direction from a very well recognised and experienced national agency.
SHALOM: strengths of the project

• The extensive consultation at the start of the project was important for getting the community to discuss the links between an acknowledged injecting drug use problem and the hidden and stigmatised HIV epidemic which accompanied it.
• Project leadership and staff were indigenous to the area and represented most of the twelve tribal and language groups of the region. This is especially important for the project’s success, as the region is prone to inter-tribal conflict.
• The project provided a comprehensive response to the epidemic, ensuring care and support for those infected and affected by the epidemic at the same time as undertaking extensive community education to increase awareness of the virus.
• The adoption of harm reduction strategies to complement other services is a major contribution of the SHALOM project.
• The SHALOM project was well supported with skilled human resources and adequate funds from the outset.
• The project included ways to assist others to learn from the project’s experience – the application of the SHALOM project model elsewhere in India (including its harm-reduction approach) is an example of ‘scaling-up’ or broadening the scope of the project or its approach.

Integrated care and prevention

Salvation Army HIV/AIDS Care and Prevention Project
The Salvation Army Chikankata Mission Hospital is a 250 bed hospital in rural Zambia which serves a scattered rural population of about 100,000. In 1987, in response to an increasing number of HIV infected patients attending the hospital, a strategy for care was developed which built on community strengths such as the existence of extended family system, a well-structured community, and a cultural tradition emphasising the importance of mutual accountability. The Chikankata HIV/AIDS Care and Prevention Program has four main elements:
• home-based care
• community counselling
• schools health education/promotion
• AIDS management training seminars.

Home-based care
Home-based care is divided into four stages:
• diagnosis and counselling
• planned discharge
• home-based care
• hospital care for the seriously ill.

Home-based care is the foundation of both the care and prevention program. It provides an entry point into the homes of infected and affected people, thus enabling the multidisciplinary team to assess and provide for patients’ physical, psychological, social and spiritual needs. The team counsels and educates people in the patient’s social environment and promotes voluntary and confidential tracing of sexual partners.

The multi-disciplinary, home-based care team consists of a clinical officer, a nurse, and a counsellor/health educator. The team visits clients once a month. While the medical team members assist the patient with nursing, treatment and counselling, the health educator/counsellor and other team members talk to family members and neighbours to help reduce stigma, ignorance and hostility.
Community counselling

Involvement of family members and the community in home visits provides an essential link between care and prevention. Home visits are the main starting point of the community counselling process. The concept of community counselling was first described by the Chikankata AIDS team, and entails the transfer of responsibility for behaviour change from others (including health care workers) to the community. The Chikankata community counselling process has been described as follows:\(^6\)

- **Selecting the community**: The community often takes the initiative to invite the team; alternatively, the team may facilitate such an invitation.
- **Establishing and building a relationship between the community and Chikankata team**: The process of building trust and gaining the ‘right to speak’ goes on throughout the counselling process.
- **Exploring the problem**: discovering together the whole problem, or different aspects of a particular problem. This includes an exploration of options for solutions, including perspectives from different sections of the community.
- **Forming a strategy**: developing ideas that address the problems and give rise to actions.
- **Decision-making**: exploring options and possible actions that could solve the problem(s) and deciding which actions are to be taken.
- **Implementing**: acting on the decisions and carrying out plans. This requires a high degree of ongoing community participation.
- **Evaluating**: leading to deeper levels of exploration of the problem and of other problems.

In the brief description above – and in more detailed accounts of the project’s approach\(^7\) – it appears that ‘community counselling’ involves the application of mainstream, community-development methods.

The first communities participating in the community counselling process made strategies relating to:\(^8\)

- training of community-selected community counsellors (or facilitators);
- abolition of a recognised high-risk behaviour, namely ritual cleansing of a widow or widower through sexual intercourse;
- re-institution of traditional teaching and ceremonies at village level;
- establishment of a church to bring the community together and influence lifestyle.

**School health education/promotion program**

The aim of this component of the AIDS Care and Prevention program is to provide communities, school pupils and teachers with knowledge about HIV and promote responsibility for AIDS care and prevention.

The program trains teachers from the 28 schools in the catchment area in basic counselling and as HIV educators. The teachers provide AIDS education to school pupils and support the formation of Anti-AIDS clubs by the students.

The program has trained 268 teachers from all 28 schools in the area; 4,997 students have received counselling and information about HIV, and Anti-AIDS clubs have been formed in all the schools in the area.

Positive results to which the school education program has contributed include:

- reduction of 40% in the number of school girl pregnancies between 1990 and 1994;
- increased number of pupils asking for and receiving counselling on sexuality;
- increased contribution of Anti-AIDS clubs to AIDS education in the area.
AIDS Management Training Seminars (AMTS)
The success of the Chikankata home-based care and community counselling program generated many requests from health personnel in other parts of the country to learn from the program. The AIDS Management Training Seminars (AMTS) program was developed as a vehicle for transferring the concepts underlying the successful management of AIDS in Chikankata. The objectives of the AMTS are as follows:
• to facilitate the transfer of principles of management, including teamwork, integration, decentralisation, and behaviour change;
• to cover basic theory in the areas of IEC, counselling, project design, administration, clinical diagnosis and care, nursing care, pastoral care, and home-based care;
• to provide skills training such that participants can continue to develop their skills after the seminar and transfer the skills to others in their workplace;
• to enable participants to form an action plan in AIDS management based on their own cultural, political and social situations, and their health care system.

Chikankata – Salvation Army HIV/AIDS Care and Prevention: strengths of the response
• The prevention and care strategy was consistent with existing community values and capacities.
• The integration of prevention and care arguably resulted in a larger impact than could be achieved by either prevention or care activities on its own.
• The response included a community development approach to HIV prevention and care (under the name ‘community counselling’), an approach advocated by UN and other multilateral agencies for many years now (e.g. WHO, UNRISD, FAO, World Bank).
• The response included a focus on youth through its school health education program – young women and men are now acknowledged as a key focus for prevention efforts.
• Training school teachers to influence the attitudes and practices of school children was a powerful method of broadening the response’s scope and impact.
• Training school teachers in behaviour change communications and counselling was a way of institutionalising HIV-related health promotion among youth in schools.
• AIDS Management Training Seminars broadened the response’s scope and impact through sharing skills and learning with other workers and agencies.

Community action by women
Women in sub-Saharan Africa have been most seriously affected by the HIV epidemic. In most countries in the region, more women are infected with the virus than men. Women have also been at the forefront of the response to the epidemic. In many communities women’s groups have rallied to the need for care and support of people infected and affected by the epidemic. Spontaneous community responses such as KIWAKKUKI (described below) and Kwasha Mukwenu, the orphan care project in Zambia, have been activated in all countries affected by the epidemic.

Kilimanjaro Women’s Group in the Fight Against AIDS in Tanzania (KIWAKKUKI)9
KIWAKKUKI is the acronym for Kilimanjaro Women’s Group in the Fight Against AIDS. It is a community-based organisation founded in 1990 by a group of women in northern Tanzania who felt compelled to join the fight against HIV/AIDS because the negative effects of the epidemic were rapidly increasing in their community.

The first step in the formation of KIWAKKUKI was taken in December 1990, when a group of women got together informally to organise an AIDS Week in the town.
of Moshi. The theme for the week’s activities was ‘Women and AIDS,’ which was the theme for the World AIDS Day that year. Following the success of the week’s activities, a number of these local women decided they would form a women’s organisation in Kilimanjaro in response to the HIV epidemic.

KIWAKKUKI’s founders felt that women were the most vulnerable and affected group within the population and that they needed to mobilise to protect themselves, their children, and the whole community from being infected with HIV and to care for those already infected/affected.

Although KIWAKKUKI is a women’s organisation, its target group is the entire population in the area: all age groups, sexes, and religions. Their objectives include:
• raising awareness and educating the community, particularly women and young people, about HIV;
• helping restore dignity, self-respect, and purpose to the lives of individuals and families affected by HIV through the formation of a self-help group;
• promoting understanding and developing a sense of responsibility within communities for HIV prevention;
• identifying the physical and psychological needs of HIV-infected people and their families, and coordinating efforts to provide for these needs;
• raising the status of women in family and community life so that women can conduct their lives with dignity and without threat to their physical and mental well-being;
• cooperating with other groups and organisations dealing with HIV/AIDS, including the sharing of information and resources.

KIWAKKUKI staff believe that through their mobilisation of women to carry out community-based activities for HIV prevention and care they can bring about social change. At the village level, many women – especially those who are members of KIWAKKUKI – have been empowered to discuss HIV prevention with their husbands and children. Volunteers believe that their support to people living with HIV helps to give the infection a human face and contributes to reducing the stigma and discrimination surrounding the epidemic.

KIWAKKUKI: strengths of the response
• A group of local women speedily and effectively mobilised and rallied support within their own community.
• The group’s focus on the whole community as well as on particular groups such as people living with HIV: effective community groups and community action rarely focuses only on particular groups in the community. We’ll return to this point later in the chapter.
• The voluntary spirit of its members, who carry out HIV prevention and care activities during their free time, is the life force of the project.

Responsible employers: the workplace as a site for community action

INDENI Petroleum Refinery Company HIV response
The INDENI Petroleum Refinery Company, located in Zambia’s Copperbelt Province, is participating in the Zambian Ministry of Labour and Social Security’s (MLSS) effort to promote HIV education and prevention in the workplace. In Zambia, workers employed in the formal sector represent a large, accessible population who are directly experiencing the impact of HIV. Because the workplace is an organised community, it offers important opportunities for HIV education and prevention.
In 1979, the MLSS initiated a project to introduce family planning information and services into the workplace. By the early 1980s, the MLSS recognised the need to introduce a component dealing with sexually transmitted diseases. It was logical, therefore, that when HIV became recognised as a health concern in Zambia, the project was further expanded to include HIV prevention and care activities.

INDENI’s prevention and care services, which are part of a company-wide broad health program, are available to all its employees. Activities include information, education and communication to increase HIV awareness, promotion and provision of condoms, counselling, inpatient and outpatient medical care for persons with HIV-related illness, and community outreach services for employees’ families, particularly their spouses and sexual partners.

These efforts have resulted in increased awareness and knowledge about HIV among INDENI employees. Most of the employees interviewed for the case study said they were aware that HIV is a major social problem and health threat. They also knew the main symptoms of AIDS and that the primary mode of transmission in Zambia is heterosexual intercourse. And while project staff still feel a large gap remains between knowledge and behaviour change, there is some evidence of positive change. When the project began, workers were reluctant to accept condoms. Now, whenever there is a project-sponsored event, staff have to bring many boxes of condoms because ‘they are going like hotcakes.’

**Mobilising communities in a cross-border context**

**World Vision Thai/Burma Border HIV/AIDS Project**

Over the last two decades, the rapid economic growth in Thailand has attracted thousands of migrant labourers from its poorer neighbouring countries. A great majority of them have come from Myanmar and have entered Thailand illegally through several border crossings. Cross-border trading between the two countries has increased dramatically. Traders from both countries make frequent trips to the border towns on both sides.

Ranong–Kawthaung is one of the four major crossing points between the two countries and the only one separated by the sea. Many of the large mobile population of Ranong are fishermen from Tanintharyi Division in Myanmar.

The Ranong AIDS Prevention and Care Project (the main focus of this example) began in May 1992 with the implementation of HIV intervention measures among commercial sex workers who, at that time, were assessed as the most vulnerable to transmission. Fishermen, primarily Burmese, soon became the second target group upon which interventions were focussed.

The project began with four project staff, one project coordinator, one Burmese physician, a bookkeeper and a Thai caseworker. It operated in an extremely complex, and often dangerous, environment characterised by organised crime, prison-like brothels and national health and social policies that were struggling to come to terms with prostitution and illegal migrant populations.

A year later, realising that problems related to HIV transmission could not be contained on one side of the border, the Kawthaung HIV/AIDS prevention and care project began implementation through World Vision Myanmar. With the establishment of this project the first elements of cross-border cooperation were born. Seeing the need to
address similar situations in other areas of the border, the World Vision Foundation of Thailand received funding for a further HIV project in Mae Sai in the north of Thailand. Once again, World Vision Myanmar applied for and received funding for a cross border intervention in Tachilek. Later, funded by AusAID, World Vision Myanmar started to work in Mae Sot, Myanmar, a second major border-crossing point close to Mae Sai in Thailand.

Beginning as more ‘traditional’ programs of information dissemination and condom distribution to ‘high-risk’ target groups, both projects developed into far more comprehensive HIV programs that have engendered a high level of community participation. This is especially significant in Ranong where many of the target population do not hold any legal status within Thailand.

The program involves six components:
1 a community development approach whereby communities are assisted to identify their needs and possible responses and existing or new community groups are assisted to develop and to respond to needs using community-friendly tools (eg PLA techniques described in Chapter 5);
2 a comprehensive training and support program designed to build the capacity of the three levels of staff involved in the project: Ministry of Public Health (MOPH), project staff, and community participants (including peer trainers and frontline social networkers);
3 an umbrella project, the Thai-Burma Border HIV Project funded by AusAID, which includes action research to help program participants to understand and to respond to the broader economic, social and political circumstances of the program areas and the interplay between these circumstances with the spread of HIV/STIs;
4 provision of technical support to component projects;
5 facilitation of collaboration between World Vision projects, communities and government agencies in both countries;
6 Behaviour development and change communication (BDCC) approach, ie HIV information and skills development within a broader life skills curriculum.

Achievements of the program include:
• identification and reduction of the dangerous practice (widespread among Burmese fishermen in Ranong) of injecting hair oil into the penis in order to enlarge it (this practice increased risk of genital ulcers, increasing risk of HIV infection);
• identification and reduction of dangerous heroin injecting practices (such as using and sharing unclean needles) by Burmese fishermen themselves;
• Burmese fishermen assisted to develop a BCC strategy, including production of a video and use of fishermen as peer HIV/STI trainers;
• education of STI prevalence among pregnant women attending project-supported antenatal clinic;
• integration of HIV with STI diagnosis and treatment, both integrated into a primary health care approach;
• increased understanding about prevention and care for people living with HIV in border areas;
• percentage of fishermen who could name at least two ways that HIV is transmitted increased from 46% to 74% between 1994 and 1996;
• percentage of fishermen who could cite at least two methods of prevention rose to 64% in 1996;
• evidence of commercial sex workers saying ‘no’ to condom-free sex with clients;
• increased cross-border collaboration (eg sharing information on problems, responses, lessons etc; facilitation of the return home of illegal migrants from Thailand to Burma, including sex workers; cross-border referral of patients with HIV and other illnesses to better facilities; facilitation of cross-border meetings between Thai and Burmese health staff).
World Vision’s response in Ranong and Kawthaung, as well as in other areas in Thailand and Myanmar in which it works, has evolved from a ‘traditional’ top-down, information and condom distribution approach to a more bottom-up, community development approach.

The program focus is now on facilitating a response to HIV by individuals, communities and appropriate local NGOs. It has grown into a program that listens rather than instructs and helps communities to define how HIV is affecting them and how best to respond, within the context of their own realities. The program’s goal is to implement programs that work with communities to define and develop an enabling environment in which behavioural change can occur and be sustained.

**World Vision Thai/Burma Border HIV/AIDS Project: strengths of the response**

- Bottom-up community development approaches are usually more effective than top-down programs focusing on disseminating information.
- Focussing attention on the health risks to men of unsafe sex with sex workers may discourage these men to have unsafe casual sex with other girls and women in the community.
- Complementing the focus on ‘high-risk groups’ by a community-wide focus on safe and healthy practices (e.g., people having sex with non-regular partner should use a condom, whether or not the non-regular partner is a member of a high-risk group).
- Collaboration between the participants of different HIV/STI responses promotes mutual learning and planning and facilitates the provision of technical support.

**Elements of successful projects and related challenges**

**Ingredients for success**

The experiences of the projects described above show clearly that local people – including people living with HIV – can become dynamic agents for changing attitudes and providing support to those in need within their communities. An important question is what elements these projects share that contribute to their success.

Elements of successful community action on HIV include:

- strong and committed leadership
- strong community participation – for the community, by the community
- reaching out – creating links with other organisations
- valuing volunteers
- access to health care
- training and support.

**Strong foundations:** Foremost among the elements of success is the role of strong and determined people in getting things off the ground. In developed countries too – particularly the United States – the response of governments to HIV has often been criticised as ‘too little, too late’, and effective action was spearheaded by highly committed, resourceful and energetic individuals and private organisations.

**By the community, for the community:** Many of the examples described in this chapter show community action by local community members focussing on the needs of particular sections of the community (e.g., orphaned children, people living with HIV) in the context of the whole community. One of the essential ingredients of effective HIV prevention is action within communities themselves! We’ll return to this crucial point later in the chapter.
Reaching out: No matter how tireless or committed such individuals may be, the survival and growth of the projects described above also depended on creating links with a range of other institutions. Most of these projects have now established liaisons with the National AIDS Control Program in their respective countries, and supportive relationships with both governmental and non-governmental organisations and the private sector. These institutions are a major source of information, educational materials, commodities, expertise and, in some cases, financial support.

The role of volunteers: While some organisations do operate with the assistance of paid staff, in almost every case the work of volunteers is invaluable for carrying out project activities. These efforts demonstrate that community members provided with appropriate training, supervision and support can play a vital role in educating their peers and caring for people with HIV. However, even committed volunteers need to receive some form of incentive in order to continue their active involvement. Projects thus do not only face the challenge to provide salaries to paid employees, but also to create incentives to sustain their volunteers’ engagement and enthusiasm.

Access to health care: People with HIV have a great deal of health care needs and the population at large needs to know where they can go for HIV testing and counselling. By establishing links with local health facilities, projects are offering an important service to their clients by providing access to services and medication that might not otherwise be available to them. However, in situations where the health care infrastructure is already overstretched and suffering from shortages of staff and commodities, projects struggle with an almost perpetual need to find new and varied sources of care for their clients.

Training and support: One important element present in varying degrees in all the projects studied is counselling. By providing clients with opportunities to participate in individual, family and group counselling sessions, projects are helping to dispel the sense of isolation and frustration often experienced by those affected by HIV, and assist them to find ways to cope with the many consequences of HIV.

Common constraints

Next to these shared strengths, the projects described above also have a number of challenges and difficulties in common. Despite their success, they all operate under significant constraints in terms of resources. Funding is often insufficient, sporadic or at times absent, and there is a perpetual shortage of materials and commodities. Home-based care programs lack medicines and supplies for their patients, while IEC programs lack educational materials – especially materials that are culturally appropriate and written in local languages and simple, easy to understand formats. Project staff often lack the transport needed to effectively carry out their work.

Besides trying to meet the immediate needs of their clients, all projects grapple with the growing phenomenon of orphaned children. Infected parents are haunted by the question of who will care for their children when they die and provide for their school fees. The traditional resilience of the extended family is hard pressed to meet these needs – especially in urban areas where people often live far from their kin. One of the greatest challenges these organisations face is how to establish substitute mechanisms beyond giving support to family networks caring for these children in need, which can build the community’s capacity to provide children with the physical, emotional and social support they need.
Community development

Defining community development

The case studies presented above underline the importance of community action for HIV prevention and care. Let’s turn now to put the case studies in the broader context of community development, describe some of the core values and principles of community development and present a few tips for planning HIV responses using a this approach.

It is probably impossible to define ‘community development’ in a way that includes all the diverse forms, purposes and focuses of ‘community development’ practised around the world.

The terms ‘community’ and ‘community development’ have been defined in many different ways.

For example, the word ‘community’ has often been used to refer to people living in a particular locality (such as an urban neighbourhood or a rural village) – see, for example, Eisen and Oakley.

Community is also often used to refer to ‘one of more groups of people who share a common identity on the basis of location, ethnicity, occupation or sexual preference’.

A recent international review of community development theory and practice has identified a number of common social values and principles underlying community development in practice.

Social values and principles of community development

Common social values and principles that underlie the practice of community development include the following:

- Cooperative, responsible, and active communities of involved men and women should be nurtured, and mobilised for the purposes of mutual aid, self-help, problem-solving, social integration, and/or social action.

- At all levels of society, down to the very lowest, participation must be enhanced, and the ideal of participatory democracy must be fostered, in order to counter the apathy, frustration, and resentment that often arise from feelings of powerlessness and oppression in the face of unresponsive power structures.

- As much as possible and feasible, community development should rely on the capacity and initiatives of relevant groups and local communities to identify needs, define problems, and plan and execute appropriate courses of action; in this, the goals are to foster confidence in community leadership, to increase competency, and to reduce dependence on state, institutional, and professional interventions.

- Community resources (human, technical, and financial) and, where necessary, resources from outside the community (in the form of partnerships with governments, institutions, and professional groups) should be mobilised and

BOX 14.2: COMMUNITY DEVELOPMENT

From an international perspective, it is clear that community development has been one of the most significant social forces in the process of planned change (Chekki, 1979). This was certainly true for the first development decades of the 1950s and 1960s, when, under the direction of the UN and its affiliated organisations, community development was actively promoted throughout the developing world as part of the nation-building process and as a means of raising standards of living among the poor ...

Simply put, community development is a demonstration of the ideas, values, and ideals of the society in which it is carried out. From a humanitarian perspective, it may be seen as a search for community, mutual aid, social support, and human liberation in an alienating, oppressive, competitive, and individualistic society. In its more pragmatic institutional sense, it may be viewed as a means for mobilising communities to join state or institutional initiatives that are aimed at alleviating poverty, solving social problems, strengthening families, fostering democracy, and achieving modernisation and socio-economic development.

Source: Campfens (1997) pp 20 and 25
deployed in an appropriate manner in order to ensure balanced, sustainable forms of development.

- Community integration should be promoted in terms of two sets of relations:
  - ‘social relations’ among diverse groups distinguished by social class or significant differences in economic status, ethnicity, culture, racial identity, religion, gender, age, length of residence, or other such characteristics that may cause tensions or lead to open conflict;
  - ‘structural relations’ among those institutions – such as public sector agencies, private sector organisations, not-for-profit or charitable organisations, and community organisations and associations – that take care of social challenges at the community level. Regarding the latter, the aim is to avoid unnecessary competition, lack of coordination, and duplication of services.

- Activities, such as circles of solidarity, should be organised that empower marginal or excluded population groups by linking them with the progressive forces in different social sectors and classes in the search for economic, social, and political alternatives.

- Those who are marginalised, excluded, or oppressed should be given the essential tools that will enable them to critically analyse and become conscious of their situation in structural terms, so that they can envisage possibilities for change.

In a particular situation, the emphasis accorded to any of these social values and principles of community development depends greatly on whether the practice involves a social movement, a process of change, or a concrete program. Also the sponsorship may come from an organised citizen’s group, a particular profession, an NGO, an institution, or a state agency, or any combination of these; each of these has its own particular and sometimes contradictory interests and priorities. These differences in sponsorship and emphasis make it particularly difficult to offer a general definition of community development that includes all possible practice situations.

**Planning tips for community development**

Many suggestions and hints for people planning HIV responses have been made earlier in the manual. Here are a few that focus directly on community and community development (sources include: Oakley 198911; Campfens 199712; and Etchepare 199813). They are particularly addressed to community development planners and facilitators who are external to the project communities they are assisting. They are, of course, relevant to internal community development planners and facilitators, but most of the answers to the questions will be already known.

It is important to learn a lot about the community or communities to be involved and/or affected in a HIV response, including:

- the type of social bonds and identity that bind a ‘community’ together (eg workplace, class, caste, ethnicity, locality, sexual identity, shared pastimes etc);
- the strength of the social ‘bonds’ and ‘identity’ that bind them together;
- the durability of the bonds and relationships (eg short-term in the case of temporary migrant mine or sex workers);
- the similarities and differences within particular communities (what binds and what divides each community?);
- the similarities and differences between communities;

---

1 ‘Circles of solidarity’ refers to developing social support for marginalised groups, from other people and organisations at local, district, province, national and international levels, including options of global networking and advocacy through the Internet.
• what are the resources and capacities of the community or communities to contribute to HIV responses materially, socially, intellectually etc;
• the type and level of community organisations or associations;
• the government’s formal and informal stance on community development and community organisations.

Here are some suggestions on how an HIV response based on community development principles might be focussed.

• The **continuum** focus: links action at individual, group, community and international levels (eg in relation to the human rights of people living with HIV and AIDS; scaling-up of response models, methods and lessons; using project experience to advocate changes in law, policy or level of funding).

• The **group or cooperative** focus: on people and community organisations providing mutual aid and/or engaging in social action (eg community organisations providing aid and support to people living with HIV and AIDS; most of the responses described in this chapter included a cooperative focus).

• The **locality** focus: where a particular geographical area is viewed as a physical, social, economic and political unit in its own right; the focus is on improving the sustainable livelihoods of local communities (eg World Vision’s community-based Area Development Programs often include health and HIV components with agriculture, income-generation, education and training; a strength of a locality focus is that it can focus on a range of immediate and longer-term risk factors).

• The **integrative** focus: in which community is used to increase the cohesion, cooperation and synergy between the various policy sectors and stakeholders – different levels of government, private enterprise, not-for-profit agencies, community-based organisations (eg the workers and health staff at the INDENI Petroleum Refinery Company (above) could be linked with other stakeholders and other local HIV/STI programs and responses to explore the possibility of collaborative actions).

• The **categorical or population-group** focus: in which community development is part of a broader strategy to prevent or alleviate a social problem – such as poverty or HIV/STI – which disproportionately affects certain social groups – eg ‘high-risk groups’ such as sex workers and their clients, injecting drug users, truck drivers, migrant workers, youth etc (eg most of the examples described in this chapter included a population-group focus).

• The **self-management** focus: where community takes a bottom-up, empowering approach to the development of groups or communities (eg Salvation Army’s ‘community counselling’; KIWAKKUKI; Afar Pastoralist Development Association, Kwasha Mukwena project etc).

• The **social learning or education** focus: where professional ‘experts’ learn together with local residents through a ‘learning-by-doing’ approach (the INGO project proposal described in Chapter 5 exemplified this community development focus).

• The **intergroup** focus: relies on mutual understanding and conflict resolution (eg where people living with HIV and AIDS are assisted to organise and to negotiate changes to the way they are treated by health staff or by police).

**Community development tips**

• Communities have their own ideas about HIV, health, development etc – you need to find out what they think and do and work with them as far as possible.

• The community development organisation should be local, indigenous and based on existing community structures and mechanisms; be created, where possible, as a result of local initiatives; be representative of the interests of the groups in the community whom you are trying to involve; be able to develop as a legitimate and formal representative body.
Community development in HIV responses should be linked as far as possible to other existing community development initiatives in health and other sectors; where possible, community development focusing on marginalised categories of people should explore ways to empower and to integrate these groups into mainstream community life.

Some contexts are more favourable to community development approaches than others; for example, some governments discourage the creation of community-based organisations, working instead through government-sponsored ‘mass’ organisations at village, district, province and national levels; cohesive or dynamic communities are usually more open to community development approaches than divided or apathetic communities.

You may need to work to open up government staff to the values and principles of community development including the ideas and realities of community participation and organisation – you could build workshops on community development for government staff and key community leaders.

What can you do against HIV?

Just a few ideas to get you started

- Action days in schools
- Advertising spots on television
- AIDS hotlines in schools, workplaces, universities
- Auctions or tombolas to raise funds
- Banners and flags about AIDS prevention
- Bar owners distribute information and condoms to clients
- Become a ‘buddy’ to a person living with HIV/AIDS
- Benefit concerts to raise funds and awareness
- Bicycle rallies
- Billboard posters at railway and bus stations
- Board games on AIDS
- Book readings in stores and libraries
References


4 This project description was contributed by Liz Mann, Project Officer, Horn Africa, Community Aid Abroad.

5 Project profile provided by Peter Deutschmann, Project Director, Burnet Institute.


8 The following information about the Salvation Army’s HIV/AIDS care and prevention is drawn from the Salvation Army’s publication: Finding hope in the river of life, cited above.


10 Eisen A. Survey of neighbourhood-based comprehensive community empowerment initiatives. Health Educ Q 21(2).


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Appendix 1: Glossary

Activity
Event carried out by a project, such as training, materials development, product design and dissemination, education sessions, condom distribution, etc.

Adherence
The extent to which the patient continues the agreed-upon mode of treatment or intervention as prescribed.

Affected community
Persons living with HIV and AIDS and other related individuals, including their families, friends, and advocates whose lives are directly influenced by HIV infection and its physical, psychological, and sociological ramifications.

AIDS Service Organisation (ASO)
A health association, support agency, or other service actively involved in the prevention and treatment of AIDS.

AIDS Wasting Syndrome
The involuntary weight loss of 10 percent of baseline body weight plus either chronic diarrhoea (two loose stools per day for more than 30 days) or chronic weakness and documented fever (for 30 days or more, intermittent or constant) in the absence of a concurrent illness or condition other than HIV infection that would explain the findings.

ANC
Antenatal clinic; most common site for sentinel surveillance of STIs and HIV.

AIDS
Acquired Immune Deficiency Syndrome (AIDS) is the end result of infection with HIV. The body’s immune system has been seriously damaged, leaving it vulnerable to infections that can ultimately result in death.

Antibody
A protein produced in the blood to fight infection.

Antibody test
When blood is tested for HIV, it is tested for the presence of antibodies. There are two commonly used tests: ELISA and Western Blot. The ELISA test detects antibodies in response to HIV infection.

Antibody-positive
Antibody-positive or Ab positive or sero-positive or HIV positive refers to a person whose blood is found to be carrying HIV antibodies. Those found to be Ab positive are at risk of developing AIDS though the probability of progression is unknown.

Antibody-negative
Antibody-negative or Ab negative or sero-negative or HIV negative refers to a person whose test indicates that their blood is not carrying HIV antibodies.

Antifungal
A substance that kills or inhibits the growth of a fungus.

Antiretroviral drugs
Substances used to kill or inhibit the multiplication of retroviruses such as HIV.

Assessment
The process of collecting information for program planning and establishing a baseline against which progress can be measured.

Asymptomatic
Without symptoms. Usually used in the HIV/AIDS literature to describe a person who has a positive reaction to one of several tests for HIV antibodies but who shows no clinical symptoms of the disease.
At risk Practising behaviours which can lead to becoming infected with HIV; for example: unprotected sex; sharing of unsterilised injecting equipment.

Attainment Measure the status of a situation at one point in time. Attainment Indicators targets usually refer to a particular number or percentage of people or things attaining a specified standard or state by a particular time. They are particularly useful when ‘pre-program’ or earlier data are unavailable. See also ‘indicators’, ‘comparative indicators’ and ‘targets’.

AZT Antiviral agent whose chemical action is to inhibit replication of HIV. Now named zidovudine, formerly azidothymidine. Its trade name is Retrovir.

Body fluids Any fluid in the human body, such as blood, urine, saliva (spit), sputum, tears, semen, mother’s milk, or vaginal secretions. Only blood, semen, mother’s milk, and vaginal secretions have been linked directly to the transmission of HIV.

Baseline data Data about characteristics, figures, of people/places, collected before a program/project starts and which can be collected again in the same manner during, or at the end of a program/project to determine what changes have occurred.

Bisexual men Men who have sex with both women and men. This includes men who normally relate sexually to men but who may also have sex with women, as well as men who may be married to or normally have sex with women but who may also have sex with men.

Blood transfusion The process of receiving blood, or parts of the blood (plasma, serum, red blood cells, etc).

Budget A plan that details the resources and the costs for carrying out a project.

Chancroid A highly contagious sexually transmitted disease caused by the Haemophilus ducreyi bacterium with symptoms appearing three to five days after exposure.

CMV (cytomegalovirus) Infection with CMV is not uncommon for people who have AIDS. The virus can lead to disease of the lungs, bowel, brain, liver and eyes. In mild manifestations it can cause aching, fever, sore throat, fatigue and enlarged lymph nodes. In severe infections it can cause blindness, chronic diarrhoea and death. CMV can be sexually transmitted.

Cohort Group of people, often of the same age, who are involved in a research study over time.

Co-factors for HIV disease Substances or elements of lifestyle or environment which could possibly contribute to the development of HIV disease. Examples include alcohol use, smoking, poor diet, high stress or repeated viral infections. Smoking is the only one which has been proved to be related to disease progression to date.

Comparative Facilitate the monitoring of change over time and require two or more indicators comparable data collections. They commonly begin with the phrases ‘change in number of’ or ‘change in percentage of’. Use data collected on two or more occasions during the project or intervention.
Condom
Also called nirodh, rubber or prophylactic. A latex sheath used to cover the penis during intercourse to help prevent pregnancy and the transmission of sexually transmitted diseases, including AIDS.

Contact tracing
The process of informing people at risk from an individual who has a notifiable, communicable disease, e.g., tuberculosis, so that they can be treated.

Commercial sex
The selling of sexual services for compensation; prostitution

Dementia
A condition which can occur in category 4 AIDS. The symptoms may include memory loss, visual disturbances, motor impairment and personality changes.

Disaggregate
To analyse data by different groups (e.g., gender, age, etc.) to show the differences between them thus reflecting true variations within a sample.

Diagnosis
The process of determining the cause and nature of an illness.

Drug resistance
The ability of some disease-causing micro-organisms, such as bacteria, viruses, and mycoplasma, to adapt themselves, to grow, and to multiply even in the presence of drugs that usually kill them.

Early intervention
The interruption of disease progression at the early stages of infection in order to prevent anticipated illness.

Effectiveness
The extent to which program outcomes are achieving program objectives. The effectiveness of a program should be distinguished from the adequacy of administration of the program, which concerns efficiency.

Efficiency
The extent to which program inputs are minimised for a given level of program outputs or, the extent to which outputs are maximised for the given level of inputs. Efficiency is concerned with the processes (activities/strategies/operations) by which the program is delivered and which produce the outputs of the program.

ELISA test (enzyme-linked immunosorbent assay)
A screening test to detect antibodies to HIV. A positive result indicates the presence of antibodies. Another test, such as the Western Blot, is done for all positive ELISA results to confirm the findings. A negative test implies that no HIV antibodies have been detected. This does not mean that a person has not been infected as it may take the body up to 12 weeks or longer to produce antibodies. The ELISA test does not detect AIDS.

Epidemic
A disease that spreads rapidly through a demographic segment of the human population, such as everyone in a given geographic area; or similar population unit; or everyone of a certain age or sex, such as the children or women of a region. Epidemic diseases can be spread from person to person or from a contaminated source such as food or water.

Epidemic, concentrated
An HIV epidemic in a country in which 5% or more of individuals in groups with high risk behaviour, but less than 5% of women attending urban antenatal clinics, are infected.

Epidemic, generalised
An HIV epidemic in a country in which 5% or more of women attending urban antenatal clinics are infected; infection rates among individuals with high risk behaviour are also likely to exceed 5% in countries with a generalised HIV epidemic.
Epidemic, nascent An HIV epidemic in a country in which less than 5% of individuals in groups with high-risk behaviour are infected.

Epidemiologic surveillance The ongoing and systematic collection, analysis, and interpretation of data about a disease or health condition. Most countries have established a surveillance system to monitor the HIV epidemic. Collecting blood samples for the purpose of surveillance is called sero-surveillance.

Epidemiology The study of the distribution of a disease and of the factors which influence the distribution.

Evaluation The process of collecting and analysing information on the effectiveness of a project. It includes assessing the impact of the project in order to detect and solve problems in both the current project and to help in planning future projects.

False negative In an AIDS antibody test, a result that reads negative when there is actually antibody in the blood. A type of erroneous result.

False positive In an AIDS antibody test, a result that reads positive when there is actually no antibody in the blood. A type of erroneous result.

Gatekeeper Someone such as a government official, community or religious leader, in charge of, and therefore grantor of access to another group, such as street children or IDUs.

Gay men A subgroup of homosexual men who identify themselves with the gay community. It is a reference to membership of a community sharing a common identity more than to behaviour.

Goal A broad statement of what a program/project intends to achieve.

Haemophilia Haemophilia is a lifelong bleeding disorder which affects males and is transmitted through the female line. All daughters of men with haemophilia will be obligatory carriers. It can also occur in families with no history of the disorder. The disorder is caused by a deficiency in one of the normal clotting factors of the blood. The severity of the disorder varies from a mild condition which shows up only under surgery or trauma, to a severe condition where bleeding, particularly internal bleeding, is a constant threat. Because of their frequent need for blood factor replacement, people with haemophilia are at risk of HIV infection where there is no screening of blood supplies. In Australia the blood supply has been safe since April 1985, with donor screening, the testing of all blood, and heat treatment of the replacement factors.

Health promotion The process of using information, education and channels of communication and community mobilisation to influence the health behaviour of individuals and groups.

High-risk behaviour Unprotected sexual intercourse (ie without a condom), with many partners or sharing unsterilised injecting equipment.
 Highly Active Antiretroviral Therapy (HAART)  The name given to treatment regimens recommended by leading HIV experts to aggressively suppress viral replication and progression of HIV disease. The usual HAART regimen combines three or more different drugs, such as two nucleoside reverse transcriptase inhibitors (NRTIs) and a protease inhibitor, two NRTIs and a non-nucleoside reverse transcriptase inhibitor (NNRTI), or other combinations. These treatment regimens have been shown to reduce the amount of virus so that it becomes undetectable in a patient’s blood.

HIV Human Immunodeficiency Virus (HIV)  The virus that causes AIDS.

HIV-positive  Having antibodies to HIV.

HIV-related illness  The range of illnesses which may occur as a result of HIV infection. It replaces previously used expressions such as AIDS-related condition (ARC) and includes those illnesses referred to as AIDS.

HIV testing  Screening the blood for HIV antibodies. At this point in time, the two most popular tests are the ELISA and Western Blot.

HIV infection  The state of being infected with HIV as indicated by a positive HIV antibody or antigen test. Initial infection is frequently accompanied by a brief flu-like illness (Category 1) followed by a period of asymptomatic infection of variable duration (Category 2) to mild immune impairment (Category 3) to severe immune impairment with opportunistic infection or cancer (Category 4).

HIV transmission  The passing of HIV from one person to another. HIV is transmitted through: sexual contact with an infected person involving the exchange of semen, blood or vaginal fluids; transfusion of contaminated blood and blood products; transmission from an infected mother to her child before or during birth and during breastfeeding; or unsterile injecting equipment and sharing of needles and syringes, especially among injecting drug users.

HIV is not spread through coughing, sneezing, sharing eating or drinking utensils, shaking hands, or being near an infected person. HIV is not spread through everyday activities, such as working in an office, eating in a cafeteria, or using public toilet facilities. Unlike colds or flu, HIV is not spread through the air.

Homosexual  Men/women whose sexual orientation is towards the same sex.

Human immunodeficiency  The retrovirus isolated and recognised as the etiologic (ie Virus Type 1 (HIV-1) causing or contributing to the cause of a disease) agent of AIDS. HIV-1 is classified as a lentivirus in a subgroup of retroviruses. The genetic material of a retrovirus such as HIV is the RNA itself. HIV inserts its own RNA into the host cell's DNA, preventing the host cell from carrying out its natural functions and turning it into an HIV factory.

Immune system  The body's mechanism to resist infection. It includes certain white blood cells. Lymphocytes are a type of white blood cell which recognises and destroys antigens. In HIV-related illness, a type of lymphocyte, T-cell, is affected by HIV causing immune deficiency.

Immunity  A natural or acquired resistance to a specific disease. Immunity may be partial or complete, long lasting, or temporary.
<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Immunosuppression</strong></td>
<td>A state of the body in which the immune system is damaged and does not perform its normal functions. Immunosuppression may be induced by drugs (eg in chemotherapy) or result from certain disease processes, such as HIV infection.</td>
</tr>
<tr>
<td><strong>Impact</strong></td>
<td>An expression of the ultimate changes brought about as a result of a program/project which was specifically undertaken to produce those changes. Impact is the <strong>outcome</strong> of the program/project effects and is a reflection of the degree to which long-term objectives have been achieved. An impact may be intended or unintended, and it may be either positive or negative.</td>
</tr>
<tr>
<td><strong>Incidence</strong></td>
<td>The number of new cases (eg of a disease) occurring in a given population over a certain period of time.</td>
</tr>
<tr>
<td><strong>Incubation period</strong></td>
<td>The time interval between the initial infection with a pathogen (eg HIV) and the appearance of the first symptom or sign of disease.</td>
</tr>
<tr>
<td><strong>Indicator</strong></td>
<td>An observable measure of the progress made towards achieving goals, objectives and targets.</td>
</tr>
<tr>
<td><strong>Infection</strong></td>
<td>Invasion by a disease-causing agent.</td>
</tr>
<tr>
<td><strong>Infectious</strong></td>
<td>A disease or disease agent that can be passed on to other people.</td>
</tr>
<tr>
<td><strong>Informed consent</strong></td>
<td>The permission granted by a participant in a research study (including medical research) after receiving comprehensive information about the study. This is a statement of trust between the institution performing the research procedure and the person (eg a patient) on whom the research procedures are to be performed.</td>
</tr>
<tr>
<td><strong>Input</strong></td>
<td>The resources such as manpower, materials, services, etc which are required for achieving the stated objectives by producing the intended outputs through relevant activities.</td>
</tr>
<tr>
<td><strong>Injecting drug use (IDU)</strong></td>
<td>Injection of non-prescribed, recreational drugs such as heroin, cocaine or speed. HIV can be transmitted to IDUs through sharing of unsterilised needles and syringes.</td>
</tr>
<tr>
<td><strong>Kaposi's sarcoma</strong></td>
<td>An example of an opportunistic illness in people with HIV disease. It is a cancer and the cells are probably derived from blood vessels. It manifests as raised red or purple blotches on or in the body. It can be treated with chemotherapy or interferon.</td>
</tr>
<tr>
<td><strong>Lentivirus</strong></td>
<td>‘Slow’ virus characterised by a long interval between infection and the onset of symptoms. HIV is a lentivirus.</td>
</tr>
<tr>
<td><strong>Logical framework</strong></td>
<td>A logical illustration describing the structure of the project and its various elements.</td>
</tr>
<tr>
<td><strong>Low-risk individuals</strong></td>
<td>Individuals practising behaviour that puts themselves and their partners at low risk of HIV infection; depending on the extent to which they mix with high-risk individuals, however, they may nevertheless be at high risk of becoming infection.</td>
</tr>
<tr>
<td><strong>Men who have sex with men (MSM)</strong></td>
<td>Homosexual, bisexual, and heterosexual men who have sex with other men.</td>
</tr>
</tbody>
</table>
Microbicide
An agent (e.g., a chemical or antibiotic) that destroys microbes. Research is being carried out to evaluate the use of rectal and vaginal microbicides to inhibit the transmission of sexually transmitted infections, including HIV.

Monitoring
The process of regularly collecting and analysing information about the implementation of a project so that problems can be identified and corrective action taken.

Mother-to-child transmission (MTCT) of HIV
Refers to the transmission of HIV from an infected woman to her baby during pregnancy, at delivery, or after birth through breastfeeding. Also ‘Perinatal transmission’ and ‘Parent-to-child transmission’.

Needs assessment
See below, ‘situation analysis’.

Nosocomial
Infection acquired though being in a hospital/clinic environment.

Notification
A legal requirement to inform the health authorities of the name, particulars and social or sexual contacts of any individual with a communicable disease. Diseases are declared notifiable in most countries under Public Health legislation, and/or under international health regulations.

Objectives
Concise, realistic, outcomes-oriented statements of what a program, sub-program or other element of the program structure aims to achieve.

Opportunistic infections
An infection by a micro-organism that may be common in the environment but causes disease only in a host with a weak immune system, such as a person with HIV.

Outcomes/impacts
Changes which result from the outputs; may be short-term/intermediate (e.g., more young people know about and/or value the benefits of using condoms), or longer term and more permanent (e.g., lower rate of HIV transmission).

Outputs
The products or services which are produced and delivered by a program in order to achieve the program’s outcomes.

Palliative care
An approach to life-threatening chronic illnesses, especially at the end of life, that combines active and compassionate treatments to comfort and support patients and their families. Palliative care strives to meet physical needs through pain relief and maintaining quality of life while emphasising the patient’s and family’s rights to participate in informed discussion and to make choices. This patient- and family-centred approach provides a comprehensive continuum of care including spiritual and emotional needs.

Pandemic
An epidemic occurring simultaneously in many countries.

Parent-to-child transmission (PTCT) of HIV
We use the term ‘parent-to-child transmission’ (PTCT) when talking of public health and policy aspects to acknowledge the role of the father in transmission of HIV from mother to child. See ‘mother-to-child transmission’ and ‘perinatal transmission’.

Performance indicator
A specific and measurable result that a project component tries to achieve.

Perinatal transmission of HIV
Transmission of HIV, from mother to baby before, during, or after the birth process.
**APPENDIX 1: GLOSSARY**

**Performance**  
The efficiency and effectiveness with which outcomes are being achieved against the objectives program, the appropriateness and quality of the processes, and the probity with which processes are conducted to achieve the outcomes.

**Pneumocystis carinii**  
This is a common opportunistic infection. It is caused by a pneumonia (PCP) parasite, *Pneumocystis carinii*, which characteristically lives in the lungs and in the presence of a normal immune system it causes no harm. However, the infection is life-threatening to people with immunosuppression.

**Prevalence**  
The proportion of a defined population infected at any one given point in time. Prevalence is dependent on 'incidence' and people leaving the infected pool (either through death or migration out of the sample area).

**Probability sample**  
A random sample in which all members (or ‘units’) of a specified population have an equal chance of being selected (see the different types of random sampling under ‘sampling’).

**Problem analysis**  
A process of analysing the reasons for the existing problem situation in a systematic and analytical way whereby the connections between different causes and effects are clearly presented. In the planning system presented in these guidelines the outcome of the problem analysis is normally a problem tree indicating the cause-effect relationships. The problem analysis should normally be a joint planning process between various parties involved with the project.

**Process**  
The means to produce the outputs designed to bring about the outcomes.

**Program**  
A group of related projects or services directed toward the attainment of specific (usually similar or related) objectives. A long-term, phased project can often be seen as a program.

**Prognosis**  
The expected outcome of a disease is called a prognosis. A good prognosis indicates a high probability of cure or recovery; a poor prognosis, a low probability.

**Project**  
A planned undertaking designed to achieve certain specific objectives within a given budget, project organisation and specified period of time.

**Project cycle**  
The system whereby a project advances from one stage to another in a certain order.

**Purposive sample**  
A non-random sample in which you use your own judgement to select a sample of people (see different types of non-random sample under ‘sampling’).

**PWA**  
A ‘person with AIDS’. Many people with AIDS prefer this term to others such as AIDS victim, or AIDS patient. They would rather see themselves as active participants in their treatment and healing, not just helpless victims who passively wait to die.

**Qualitative indicator**  
An indicator which uses subjective questions (e.g., how satisfactory was the service at the clinic) to measure progress.
Quantitative indicator  An indicator is a number but more often a proportion (expressed as a percentage) that reflects how many people are infected, have certain knowledge, or practise certain behaviour.

Qualitative research  A flexible and open-ended method of building up an in-depth picture of a situation, community, etc; methods used include observation and discussion.

Quantitative research  Used to collect data which can be analysed in a numerical form; things are therefore either measured or counted, or questions are asked according to a defined questionnaire so that the answers can be coded and analysed numerically.

Questionnaire  A series of questions listed in a specific order, used to gather information from a range of people. See also ‘survey’.

Response analysis  See below, ‘situation analysis’.

Retrovirus  Family of viruses containing only RNA, which combines with host cell (in humans the T-Cell) DNA to replicate.

Risk  An external or internal factor which has a relatively high probability and potential of endangering the implementation or the results of the project.

Safer sex  Sexual activity where transmission of HIV by semen, blood, vaginal or cervical secretions is minimised. This may be through a change in sexual practices or through the correct use of quality condoms.

Sampling  A selection of ‘units’ chosen to represent the total population you wish to research or evaluate. ‘Units’ can be individuals, households or villages depending on your project design and the type of sampling you choose. In random sampling, the method of selection is based on chance and all units in the target population have a known chance of being selected. In non-random sampling, the method of selection is based at least partly on the judgement of the researcher or interviewer. See also ‘surveys’, ‘questionnaire’, ‘probability sample’, ‘purposive sample’.

Sentinel surveillance  Screening of a key group in the population to gain an idea of the extent of an infection or other problem; eg screening pregnant women or STI patients for HIV to see how many have HIV at a given point in time; repeat screening later would show how fast HIV was spreading in this population.

Sero-conversion  The appearance of antibodies to the HIV virus. This usually occurs between 6 and 12 weeks after infection.

Sero-prevalence  The proportion of a given population with a particular marker in the blood, such as antibody to HIV, at a specific time.

Sex worker  Someone who offers sexual services for money.

Sexually transmitted infection (STI)  Sexually transmitted infections are infections spread by the transfer of organisms from person to person during sexual contact. In addition to the ‘traditional’ STIs (syphilis and gonorrhoea), the spectrum of STIs now includes HIV infection, which causes AIDS. The complexity and scope of STIs have increased dramatically since the 1980s; more than 20 micro-organisms and syndromes are now recognised as belonging in this category.
<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Side effects</td>
<td>The actions or effects of a drug (or vaccine) other than those desired. The term usually refers to undesired or negative effects, such as headache, skin irritation, or liver damage.</td>
</tr>
<tr>
<td>Situation analysis</td>
<td>Also called ‘needs assessment’ or ‘formative research’ is research carried out before a project begins covering all aspects of the situation relevant to the project, ie people, place, policies, cultural beliefs and attitudes etc and in its second stage (called ‘response analysis’) looks at what is/is not already being done, who is doing it and with or for whom.</td>
</tr>
<tr>
<td>Social marketing</td>
<td>Marketing of programs designed to raise condom use by improving the social condoms acceptability of condoms, making them more widely available through non-traditional outlets and offering them for sale at subsidised prices.</td>
</tr>
<tr>
<td>Stakeholders</td>
<td>People, organisations or groups with an interest or stake in the program and/or its outcomes and in the evaluation of the program.</td>
</tr>
<tr>
<td>Strategy</td>
<td>A planned approach for achieving an objective. A strategy tells you the way in which the objective will be achieved and therefore guides the selection of specific activities to be carried out by the project.</td>
</tr>
<tr>
<td>Sub-projects</td>
<td>Concrete and logical entities covering certain project sectors. Sub-projects are used in large projects in order to break down the project into manageable pieces. Sub-projects usually consist of several components.</td>
</tr>
<tr>
<td>Survey</td>
<td>A survey usually relies on a questionnaire with a list of questions that should be asked exactly as written on the survey guide (ie the questionnaire). Surveys can be ‘one-shot’ (ie a one-off survey at one particular point of time) or ‘repeat’ (ie surveys involving repeated data collection over time). Repeat sampling methods include: panel survey (survey involving repeat visits to the same fixed sample over time; useful to monitor change over time) repeat survey (survey involving fresh sampling, same questionnaire each time) rotating survey (survey involving changing a fraction of the sample each time).</td>
</tr>
<tr>
<td>Susceptible</td>
<td>Vulnerable to becoming infected.</td>
</tr>
<tr>
<td>Sustainability</td>
<td>The extent to which the result of the project will last and the development continue after project assistance is over.</td>
</tr>
<tr>
<td>Symptomatic</td>
<td>Exhibiting sufficient symptoms to require medical treatment.</td>
</tr>
<tr>
<td>Synergism, Synergistic</td>
<td>An interaction between two or more treatments (eg drugs) that produces or enhances an effect that is greater than the sum of the effects produced by the individual treatments.</td>
</tr>
<tr>
<td>Syphilis</td>
<td>A primarily sexually transmitted infection resulting from infection with the spirochete (a bacterium), <em>Treponema pallidum</em>. Syphilis can also be acquired in the womb during pregnancy.</td>
</tr>
<tr>
<td>Targets</td>
<td>A target is a measurable standard that the project participants choose or are asked to meet. ‘Attainment’ targets can be expressed as straight numbers or percentages (with no reference to a pre-existing situation). ‘Comparative’ targets are expressed as an increase or reduction of a phenomenon vis-a-vis an earlier, baseline situation. Some guidelines on indicators distinguish between ‘indicators’ and ‘targets’ and others collapse them into an ‘objectively verifiable indicator’ (OVI).</td>
</tr>
</tbody>
</table>
Target group  
The specific group for whose benefit the project or program is undertaken, that is, the direct beneficiaries of the project.

Thrush  
Sore patches in the mouth caused by the fungus *Candida albicans*. Thrush is one of the most frequent early symptoms or signs of an immune disorder. The fungus commonly lives in the mouth, but only causes problems when the body’s resistance is reduced either by antibiotics that have reduced the number of competitive organisms in the mouth, or by an immune deficiency such as HIV disease. See ‘Candidiasis’.

Triangulation  
Asking the same question in different ways or using different sources to get answers to the same question.

Tuberculosis (TB)  
A bacterial infection caused by *Mycobacterium tuberculosis*. TB bacteria are spread by airborne droplets expelled from the lungs when a person with active TB coughs, sneezes, or speaks. Exposure to these droplets can lead to infection in the air sacs of the lungs. The immune defenses of healthy people usually prevent TB infection from spreading beyond a very small area of the lungs. If the body’s immune system is impaired because of HIV infection, aging, malnutrition, or other factors, the TB bacterium may begin to spread more widely in the lungs or to other tissues. Most cases of TB occur in the lungs (pulmonary TB). However, the disease may also occur in the larynx, lymph nodes, brain, kidneys, or bones (extrapulmonary TB). Extrapulmonary TB infections are more common among persons living with HIV.

Virus  
One of the simplest forms of life. Microscopic in size, viruses require a living cell of a host in order to reproduce. When viruses reproduce they invade living cells and use the infected cells as ‘factories’ to make more viruses. This process often causes death of the infected cells, resulting in disease.

Window period  
The time between infection and the appearance of antibodies to HIV in the blood system. An infected person can test antibody negative because no (or insufficient) antibodies have yet been produced by the immune system. This can vary greatly in length. The window period usually lasts between two and twelve weeks; in this time the infected person can pass the virus on to others.

Workplan  
A detailed description that lists all the activities that need to be completed during the project, how each one will be done, who will do it, and when each activity will begin and end.
Appendix 2: List of organisations and useful websites

**Australian organisations**

**Adventist Development and Relief Agency (ADRA)**
PO Box 129
Wahroonga NSW 2076
Tel: +61 2 9489 5488
Fax: +61 2 9489 7790
Email: adra.info@adra.org.au
Website: www.adra.org.au

**AIDS Council of New South Wales (ACON)**
PO Box 350
Darlinghurst NSW 1300
Tel: +61 2 9206 2000
Fax: +61 2 9206 2069
Email: acon@acon.org.au
Website: www.acon.org.au

**Australian Agency for International Development (AusAID)**
62 Northbourne Avenue
GPO Box 887
Canberra ACT 2601
Tel: +61 2 6206 4000
Fax: +61 2 6206 4880
Email: info@ausaid.gov.au
Website: www.ausaid.gov.au

**Australians Care for Refugees (AustCare)**
Locked Bag 15
Camperdown NSW 1450
Tel: +61 2 9565 9111
Fax: +61 2 9550 4591
Email: info@austcare.org.au
Website: www.austcare.org.au/

**Australian Research Centre in Sex, Health & Society**
Faculty of Health Sciences
La Trobe University
First floor, 215 Franklin Street Melbourne 3000
Tel: +61 3 9285 5382
Fax: +61 3 9285 5220
Email: arcs@latrobe.edu.au
Website: www.latrobe.edu.au/arcs

**National Council of Churches in Australia**
Locked Bag 199
Sydney NSW 1230
Tel: +61 2 9299 2215
Fax: +61 2 9262 4514
Email: gensec@ncca.org.au
Website: www.ncca.org.au

**Australian Council for International Development (ACFID)**
[formerly ACFOA]
Private Bag 3
Deakin, ACT 2600
Tel: +61 2 6281 9216
Fax: +61 2 6285 1720
Email: main@acfid.asn.au
Website: www.acfid.asn.au/

**Australian Federation of AIDS Service Organisations (AFAO)**
PO Box 51
Newtown NSW 2042
Tel: +61 2 9557 9399
Fax: +61 2 9557 9867
Website: www.afao.org.au

**Australian People for Health, Education and Development Abroad (APHEDA)**
Level 3/377 Sussex Street
Sydney NSW 2000
Tel: +61 2 9264 9343
Fax: +61 2 9261 1118
Email: apheda@labor.net.au
Website: www.apheda.org.au

**Australian Red Cross**
155 Pelham Street
Carlton South Vic 3053
Tel: +61 3 9345 1800
Fax: +61 3 9348 2513
Website: www.redcross.org.au

**Australian Volunteers International**
71 Argyle Street
Fitzroy Vic 3065
Tel: +61 3 9279 1788
Fax: +61 3 9419 4280
Email: info@australianvolunteers.com
Website: www.australianvolunteers.com
International organisations and networks

Asian Harm Reduction Network (AHRN)
72/8 Moo 1 Cholprathan Road
T. Changpuak A Muang
Chiang Mai 50300 Thailand
Tel: +6653 893 175, 893 144
Fax: +6653 893 176
Email: clearinghouse@ahrn.net
Website: www.ahrn.net
Head office:
PO Box 18, Chiangmai University, Chiangmai 50202, Thailand

Asia Pacific Council of AIDS Service Organisations (APCASO)
No.12, Jalan 13/48A The Boulevard Shop Office
Off Jalan Sentul, 51000 Kuala Lumpur, Malaysia
Tel: +603 4043 9602
Fax: +603 4044 9615
Email: apcaso@pd.jaring.my
Website: www.apcaso.org

Asia Pacific Network of People Living with HIV and AIDS (APN+)
Secretariat: Paul Toh, APN+ Coordinator
62B Race Course Road
Singapore, 218568
Tel: +65 295 1153
Fax: +65 295 5567
Email: paultoh@pacific.net.sg

Centres for Disease Control and Prevention (CDC)
1600 Clifton Road
Atlanta Georgia 30333 USA
Tel: +1 404 639 3311
Fax: +1 770 488 7829
Website: www.cdc.gov

Children and AIDS International NGO Network (CAINN)
CAINN held its first planning meeting in London, England from 13 to 16 November 1996. The meeting identified the priority children-and-AIDS issues the network plans to address and developed a work plan for participating NGOs.
For more information about CAINN, contact Bruce Waring at ICAD: tel: (613) 788-5107; fax: (613) 788-5052; Email: ICAD@web.net
Family Health International (FHI)
2101 Wilson Boulevard, Suite 700
Arlington, Virginia 22201 USA
Tel: +703 516 9779
Fax: +703 516 9781
Website: www.fhi.org

François-Xavier Bagnoud Center for
Health and Human Rights
Harvard School of Public Health
651 Huntington Avenue, 7th floor
Boston, MA 02115 USA
Tel: +1-617-432-0656
Fax: +1-617-432-4310
Email: fxbcenter@igc.org
Website: www.hsph.harvard.edu/fxbcenter

Global Network of People Living with
HIV/AIDS (GNP+)
PO Box 11726 1001 GS
Amsterdam
The Netherlands
Tel: +31 20 423 41 14
Fax: +31 20 423 42 24
Email: infognp@gnpplus.net
Website: www.gnpplus.net

HealthLink Worldwide
Cityside 40 Adler Street
London E1 1EE, UK
Tel: +44 20 7539 1570
Fax: +44 20 7539 1580
Email: info@healthlink.org.uk
Website: www.healthlink.org.uk

International Council of AIDS Service
Organisations (ICASO)
Secretariat – 65 Wellesley Street East, Suite 403
Toronto, Ontario M4Y1G7 Canada
Tel: +1 416 921 0018
Fax: +1 416 921 9979
Email: icaso@icaso.net

International Planned Parenthood
Federation
Regent’s College, Inner Circle, Regent’s Park
London NW1 4NS, UK
Tel: +44 20 7487 7900
Fax: +44 20 7487 7950
Email: info@ippf.org
Website: www.ippf.org

Network of African People Living with
HIV and AIDS
NAP+ Secretariat: Michael Angaga, NAP+
Coordinator
P O Box 30218, Nairobi, Kenya
Tel: +2542 228 776
Fax: +2542 251 324
Email: nap@africaonline.co.ke

Save the Children Fund UK
1 St. John’s Lane
London, EC1M 4AR UK
Website: www.savethechildren.org.uk

Southern Africa AIDS Information
Dissemination Service (SafAIDS)
P O Box A509
Avondale, Harare, Zimbabwe
Tel: 263 4 336193/4
Fax:263 4 336195
Email: info@safaids.org.zw
Website: www.safaids.org.zw

Thai NGOs Coalition on AIDS
61/54 Soi Thaweemit 8,
Rama 9 Road
Huaykhwang Bangkok 10320
Tel: +66 2 246 8701
Website: www.signposts.uts.edu.au/contacts/
Thailand/NGO/170.html

United Nations organisations
and multi-lateral banks

International Labor Organisation (ILO)
4 route des Morillons
1211 Geneva 22, Switzerland
Tel: +41 22 799 6111
Fax: +41 22 798 8685
Email: ilo@ilo.org

UNAIDS (Joint United Nations
Programme on HIV/AIDS)
Head Office:
20 avenue Appia
CH-1211 Geneva 27 Switzerland
Tel: +41 22 791 3666
Fax: +41 22 791.4187
Email: unaid@unaid.org
Website: www.unaids.org
Asia Pacific Intercountry Team (APICT)
UNESCAP Building (B359)
Rajadamnern Nok Avenue
Bangkok 10200
Tel: +66 2 288 2179
Fax: +66 2 288 1092
Email: unaids-apict.unescap@un.org

West Africa Intercountry Team
UNAIDS Inter-Country Team for West and Central Africa (UNAIDS ICT/WCA)
Immeuble Avodire, 1st Floor
Rue des Jardins, II Plateaux Vallons
04 BP 1900, Abidjan 04, Côte d’Ivoire
Tel: +225 22 40 44 01 / 22 40 44 11 / 22 44 43 95
Fax: +225 22 40 44 09 / 22 40 44 13
Email: eip.onusida@aviso.ci / eip2.onusida@aviso.ci

United Nations Development Programme (UNDP)
Room DC 1-2092 1 United Nations Plaza,
New York, NY 10017 USA
Tel: +1 212 906-3687
Fax: +1 212 906-5023/5857
Email: monica.sharma@undp.org

UNDP/UNOPS
Partnership for the Future
Programme Management Office
PO Box 21642
Nicosia - Cyprus
Tel: +357 22 445060
Fax: +357 22 445061
Email: pff@undp-unops@undp.org

United Nations Children’s Fund (UNICEF)
UNICEF House
3 United Nations Plaza,
New York, NY 10017 USA
Tel: +1 212 326 7000
Fax: +1 212 887 7465
Website: www.unicef.org

United Nations Office on Drugs and Crime
Head office:
Vienna International Centre
PO Box 500, A-1400 Vienna, Austria
Street Address
Vienna International Centre
Wagramer Strasse 5
A-1400 Vienna, Austria
Tel: +43 1 26060 0
Fax: +43 1 26060 5866
Email: unodc@unodc.org

United Nations Educational Cultural & Scientific Organisation (UNESCO)
7, place de Fontenoy
75352 Paris 07 SP, France
Tel: +33 (0)1 45 68 10 00
Fax: +33 (0)1 45 67 16 90
Website: www.unesco.org

United Nations Fund for Population Activities
220 East 42nd Street,
New York, NY 10017 USA
Tel: +1 212 297-5256/5249
Fax: +1 212 297-4915
Email: mehta@unfpa.org

The World Bank
1818 H Street, NW,
Washington DC 20433, USA
Tel: +1 202 473 1000
Fax: +1 202 477 6391
Email: dzewdie@worldbank.org
Website: www.worldbank.org

World Health Organization (WHO)
20 Avenue Appia,
1211 Geneva 27, Switzerland
Tel: +41 22 791 4645/4657
Fax: +41 22 791 4834
Email: mpanjuw@who.ch
Website: www.who.int
Useful websites

**ACT UP: www.actupny.org**
ACT UP is a diverse, non-partisan group of individuals united in anger and committed to direct action to end the AIDS crisis.

**ÆGiS: www.aegis.com**
ÆGiS, using a combination of FidoNet® (connecting over 32,000 electronic bulletin boards in 66 countries) and website communication tools, seeks to relieve some of the suffering and isolation caused by HIV/AIDS by fostering the understanding and knowledge that will lead to better care, prevention, and a cure. It offers a vast range of information, from clinical information to late-breaking news, with chat facilities.

The AIDS Economics Website is managed by the World Bank on behalf of UNAIDS. It aims to collect and link to the most useful tools for economic understanding of the HIV/AIDS epidemic. It is intended as an information resource for researchers and policymakers dedicated to defining and implementing effective AIDS policy.

**The Albion Street Centre: www.sesahs.nsw.gov.au/albionstcentre**
The Albion Street Centre, a facility of the South Eastern Sydney Area Health Service, promotes the well-being of people affected by HIV and high-impact current and emerging infectious diseases.

**CDC Division of HIV/AIDS Prevention (DHAP): www.cdc.gov/hiv/dhap.htm**
CDC's HIV mission is to prevent HIV infection and reduce the incidence of HIV-related illness and death, in collaboration with community, state, national, and international partners.

**CRIN – The Rights of Children Living with HIV/AIDS: www.crin.org**
CRIN is a global network of organisations sharing their experiences of information on children’s rights. Its website includes the full text of briefing and position papers on the rights of children living with HIV/AIDS and links to a list of relevant publications.

**Drum Beat: www.comminoit.com/drum_beat.html**
This is an email and web network from THE COMMUNICATION INITIATIVE partnership with The Rockefeller Foundation, UNICEF, USAID, WHO, BBC World Service, CIDA, Johns Hopkins Center for Communication Programs, Soul City, The Panos Institute, and UNFPA. It offers information, ideas, and dialogue on communication, development and change, including sexual health and HIV/AIDS issues.

**ELDIS: www.eldis.org**
ELDIS, a Gateway to Information Sources on Development and the Environment, offers an easy route to the latest information on development and environmental issues as both a directory and an entry point to electronic information resources. Recent new entries related to HIV/AIDS include materials on the impact of HIV/AIDS on the elderly.

**Galaxy – AIDS and HIV: www.galaxy.com/b/d?n=33733**
Galaxy is a searchable website directory that provides links to various websites about HIV/AIDS.

**HIVpositive.com: www.HIVpositive.com**
HIVpositive.com is an online collection of resources to improve the quality of life of HIV-positive people. It covers all aspects of living with HIV/AIDS.
Information Center for Research on Women (ICRW): www.icrw.org
Founded in 1976, ICRW is a private, nonprofit organisation dedicated to promoting social and economic development with women’s full participation. ICRW advocates with governments and multilateral agencies, convenes experts in formal and informal forums, and engages in an active publications and information program to advance women’s rights and opportunities.

The International HIV/AIDS Alliance (the Alliance): www.aidsalliance.org
An international development non-governmental organisation which was set up in 1993 by a consortium of international donors. The Alliance was established to respond to the need for a specialist, professional intermediary organisation which would work in effective partnership with non-governmental and community-based organisations in developing countries, as well as with national governments, private and public donors and the UN system. The Alliance’s mission is to support communities in developing countries to play a full and effective role in the global response to AIDS.

SEA-AIDS: unaidasapict.inet.co.th/
Information support services for people living or working with HIV/AIDS in the Asia-Pacific region, provided by the UNAIDS Asia Pacific Intercountry Team, based in Bangkok, Thailand.

Sexually Transmitted Infections: www.who.int/csr/en
This WHO Communicable Disease Surveillance and Response site includes information on HIV/AIDS and sexually transmitted infections as well as links to many other AIDS-related sites.

Straight Talk in Uganda: www.swiftuganda.com/~strtalk
Straight Talk Foundation, which originated out of the UNICEF-funded Straight Talk newspaper first published in 1993, is a communication NGO that been produces IEC materials for adolescents and young adults. Its broad objective is to contribute to the improved mental, social and physical development of these groups in Uganda. The program also aims to keep its target audience safe from HIV/STI infection and any early pregnancy, through its communications projects by increasing the understanding of adolescence, sexuality and reproductive health, and to promote the adoption of safer sex practices.

Strategies for Hope: www.stratshope.org
Strategies for Hope is a series of books and videos which focus mainly on sub-Saharan Africa, and also includes the training package ‘Stepping Stones’. Issues covered include counselling, home-based care, workplace-based prevention, orphans, young people and gender issues.

The Body: www.thebody.com
One of the largest HIV/AIDS websites on the Internet, with many valuable resources, including 15 doctors online to answer patients questions, a lively BBS, as well as over 40,000 documents on a wide assortment of HIV-related subjects. Also, there is a terrific selection of prevention materials, including an interactive section where people can ask expert questions.
History will surely judge us harshly if we do not respond with all the energy and resources that we can bring to bear in the fight against HIV and AIDS.

Nelson Mandela
XVth International AIDS Conference, 2004