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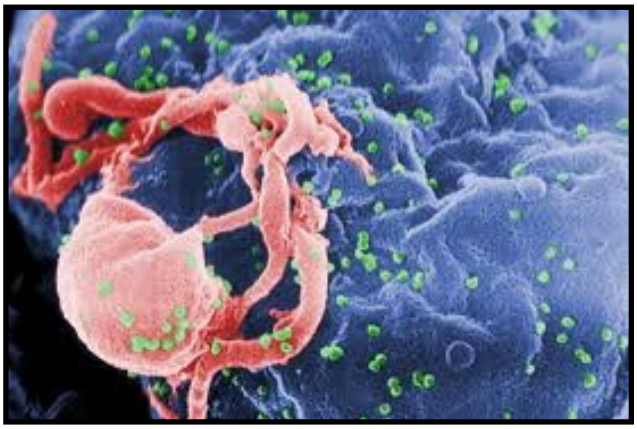
1. Introduction



HIV stands for Human Immunodeficiency Virus. It weakens a person's immune system by destroying important cells that fight disease and infection. No effective cure exists for HIV. But with proper medical care, HIV can be controlled. Some groups of people in the United States are more likely to get HIV than others because of many factors, including their sex partners, their risk behaviors, and where they live.

The acquired immunodeficiency syndrome (AIDS) was first recognized in 1981 and has since become a major worldwide pandemic. AIDS is caused by the human immunodeficiency virus (HIV). By leading to the destruction and/or functional impairment of cells of the immune system, notably CD4+ T cells, HIV progressively destroys the body's ability to fight infections and certain cancers. A retrovirus, the Human Immunodeficiency Virus (HIV) was identified in 1983 as the pathogen responsible for the Acquired Immunodeficiency Syndrome (AIDS). AIDS is characterized by changes in the population of T-cell lymphocytes that play a key role in the immune defense system.

A person infected with HIV is diagnosed with AIDS when he or she has one or more opportunistic infections (which occur when your immune system is damaged by HIV), such as pneumonia or tuberculosis, and has a dangerously low number of CD4+ T cells (less than 200 cells per cubic millimeter of blood). An HIV-infected person is diagnosed with AIDS when his or her immune system is seriously compromised and manifestations of HIV infection are severe. The Centers for Disease Control and Prevention (CDC) currently defines AIDS in an adult or adolescent age 13 years or older as the presence of one of 26 conditions indicative of severe immunosuppression associated with HIV infection, such as Pneumocystis carinii pneumonia (PCP), a condition extraordinarily rare in people without HIV infection. Most other AIDS-defining conditions are also "opportunistic infections"

which rarely cause harm in healthy individuals. A diagnosis of AIDS also is given to HIV-infected individuals when their CD4+ T-cell count falls below 200 cells/cubic millimeter (mm3) of blood. Healthy adults usually have CD4+ T-cell counts of 600-1,500/mm3 of blood. In HIV-infected children younger than 13 years, the CDC definition of AIDS is similar to that in adolescents and adults, except for the addition of certain infections commonly seen in pediatric patients with HIV.

General Definitions

- HIV refers to the human immunodeficiency virus. There are two types of HIV: HIV-1 and HIV-2. HIV-1 is responsible for the vast majority of HIV infections globally.
- Acute infection is the period between a person being infected with HIV and HIV antibodies being detectable by a serological assay.

Key populations are groups that have a high risk and disproportionate burden of HIV in all epidemic settings. They frequently face legal and social challenges that increase their vulnerability to HIV, including barriers to accessing HIV prevention, treatment and other health and social services. Key populations include (1) men who have sex with men, (2) people who inject drugs, (3) people in prisons and closed settings, (4) sex workers and (5) transgender people.

Vulnerable populations are groups of people that are vulnerable to HIV in certain situations or contexts, such as adolescents (especially adolescent girls in sub-Saharan Africa), orphans, people with disabilities and migrant and mobile workers. They may also face social and legal barriers to accessing HIV prevention and treatment. These populations are not affected by HIV uniformly in all countries and epidemics and may include key populations. Each country should define the specific populations that are vulnerable and key to their epidemic and response, based on the epidemiological and social context.

The term diagnosis of HIV infection is defined as a diagnosis of HIV infection regardless of the stage of disease (stage 0, 1, 2, 3 [AIDS], or unknown) and refers to all persons with a diagnosis of HIV infection. The term HIV infection, stage 3 (AIDS) and its condensed version—stage 3 (AIDS)—refer specifically to persons with diagnosed HIV whose infection was classified as stage 3 (AIDS) during a given year (for diagnoses) or whose infection has ever been classified as stage 3 (AIDS) (for prevalence and deaths).

Human immunodeficiency virus (HIV) is a lentivirus (a member of the retrovirus family) that can lead to acquired immunodeficiency syndrome (AIDS), a condition in humans in which the immune system begins to fail, leading to life-threatening opportunistic infections. This condition progressively reduces the effectiveness of the immune system and leaves individuals susceptible to opportunistic infections and tumors. HIV is transmitted through direct contact of a mucous membrane or the bloodstream with a bodily fluid containing HIV, such as blood, semen, vaginal fluid, preseminal fluid, and breast milk. This transmission can involve anal, vaginal or oral sex, blood transfusion, contaminated hypodermic needles, exchange between mother and baby during pregnancy, childbirth, or breastfeeding, or other exposure to one of the above bodily fluids.

Apart from psychological impact, HIV infection has direct effects on the central nervous system, and causes neuropsychiatric complications including HIV encephalopathy, depression, mania, cognitive disorder, and dementia, often in combination. Infants and children with HIV infection are more likely to experience deficits in motor and cognitive development compared with HIV negative children. Cognitive impairment in HIV/AIDS has been associated with greatly increased mortality, independent of other factors such as baseline clinical stage, CD4+ cell count, and serum hemoglobin concentration, antiretroviral treatment, and social and demographic characteristics.

Although treatments for AIDS and HIV can slow the course of the disease, there is currently no vaccine or cure. Antiretroviral treatment reduces both the mortality and the morbidity of HIV infection, but these drugs are expensive and routine access to antiretroviral medication is not available in all countries. Due to the difficulty in treating HIV infection, preventing infection is a key aim in controlling the AIDS epidemic, with health organizations promoting safe sex and needle-exchange programs in attempts to slow the spread of the virus.

Signs and symptoms

The symptoms of HIV vary depending on the stage of infection. Though people living with HIV tend to be most infectious in the first few months, many are unaware of their status until later stages. The first few weeks after initial infection, individuals may experience no symptoms or an influenza-like illness including fever, headache, rash, or sore throat.

As the infection progressively weakens the immune system, an individual can develop other signs and symptoms, such as swollen lymph nodes, weight loss,

fever, diarrhea and cough. Without treatment, they could also develop severe illnesses such as tuberculosis, cryptococcal meningitis, severe bacterial infections and cancers such as lymphomas and Kaposi's sarcoma, among others.

Transmission

HIV can be transmitted via the exchange of a variety of body fluids from infected individuals, such as blood, breast milk, semen and vaginal secretions. Individuals cannot become infected through ordinary day-to-day contact such as kissing, hugging, shaking hands, or sharing personal objects, food or water.

Risk factors

Behaviors and conditions that put individuals at greater risk of contracting HIV include:

- Having unprotected anal or vaginal sex;
- Having another sexually transmitted infection such as syphilis, herpes, chlamydia, gonorrhoea, and bacterial vaginosis;
- Sharing contaminated needles, syringes and other injecting equipment and drug solutions when injecting drugs;
- Receiving unsafe injections, blood transfusions, tissue transplantation, medical procedures that involve unsterile cutting or piercing; and
- Experiencing accidental needle stick injuries, including among health workers.

Diagnosis

Serological tests, such as RDTs or enzyme immunoassays (EIAs), detect the presence or absence of antibodies to HIV-1/2 and/or HIV p24 antigen. No single HIV test can provide an HIV-positive diagnosis. It is important that these tests are used in combination and in a specific order that has been validated and is based on HIV prevalence of the population being tested. HIV infection can be detected with great accuracy, using WHO prequalified tests within a validated approach. It is important to note that serological tests detect antibodies produced by an individual as part of their immune system to fight off foreign pathogens, rather than direct detection of HIV itself.

Most individuals develop antibodies to HIV within 28 days of infection and therefore antibodies may not be detectable early, during the so-called window period. This early period of infection represents the time of greatest infectivity; however HIV transmission can occur during all stages of the infection.

Testing and diagnosis of HIV-exposed infants has been a challenge. For infants and children less than 18 months of age, serological testing is not sufficient to identify HIV infection – virological testing must be provided (at 6 weeks of age, or as early as birth) to detect the presence of the virus in infants born to mothers living with HIV. However, new technologies are now becoming available to perform the test at the point of care and enable return of the result on the same day to accelerate appropriate linkage and treatment initiation.

HIV testing services

HIV testing should be voluntary and the right to decline testing should be recognized. Mandatory or coerced testing by a health care provider, authority, or by a partner or family member is not acceptable as it undermines good public health practice and infringes on human rights.

New technologies to help people test themselves are being introduced, with many countries implementing self-testing as an additional option to encourage HIV diagnosis. HIV self-testing is a process whereby a person who wants to know his or her HIV status collects a specimen, performs a test and interprets the test results in private or with someone they trust. HIV self-testing does not provide a definitive HIV-positive diagnosis – instead, it is an initial test which requires further testing by a health worker.

The sexual partners and drug injecting partners of people diagnosed with HIV infection have an increased probability of also being HIV-positive. WHO recommends assisted HIV partner notification services as a simple and effective way to reach these partners, many of whom are undiagnosed and unaware of their HIV exposure, and may welcome support and an opportunity to test for HIV.

All HIV testing services must follow the 5 Cs principles recommended by WHO:

- ✓ Informed Consent
- ✓ Confidentiality
- ✓ Counseling
- ✓ Correct test results
- ✓ Connection (linkage to care, treatment and other services).

Prevention

Individuals can reduce the risk of HIV infection by limiting exposure to risk factors. Key approaches for HIV prevention, which are often used in combination, are listed below.

- ✓ **Male and female condom use**: Correct and consistent use of male and female condoms during vaginal or anal penetration can protect against the spread of sexually transmitted infections, including HIV. Evidence shows that male latex condoms have an 85% or greater protective effect against HIV and other sexually transmitted infections (STIs).
- ✓ **Testing and counseling for HIV and STIs:** Testing for HIV and other STIs is strongly advised for all people exposed to any of the risk factors. This way people learn of their own infection status and access necessary prevention and treatment services without delay. WHO also recommends offering testing for partners or couples. Additionally, WHO is recommending assisted partner notification approaches so that people with HIV receive support to inform their partners either on their own, or with the help of health care providers.
- ✓ **Testing and counseling, linkages to tuberculosis care:** Tuberculosis (TB) is the most common presenting illness and cause of death among people with HIV. It is fatal if undetected or untreated and is the leading cause of death among people with HIV, responsible for 1 of 3 HIV-associated deaths. Early detection of TB and prompt linkage to TB treatment and ART can prevent these deaths. TB screening should be offered routinely at HIV care services and routine HIV testing should be offered to all patients with presumptive and diagnosed TB. Individuals who are diagnosed with HIV and active TB should urgently start effective TB treatment (including for multi-drug resistant TB) and ART. TB preventive therapy should be offered to all people with HIV who do not have active TB.
- ✓ **Voluntary medical male circumcision (VMMC):** Medical male circumcision, reduces the risk of heterosexually acquired HIV infection in men by approximately 60%. This is a key prevention intervention supported in 15 countries in Eastern and Southern Africa (ESA) with high HIV prevalence and low male circumcision rates. VMMC is also regarded as a good approach to reach men and adolescent boys who do not often seek health care services.
- ✓ **Antiretroviral drug use for prevention:** Prevention benefits of ART: A trial has confirmed that if an HIV-positive person adheres to an effective ART regimen, the risk of transmitting the virus to their uninfected sexual partner can be reduced by 96%. The WHO recommendation to initiate ART in all people living with HIV will contribute significantly to reducing HIV transmission.

- ✓ **Pre-exposure prophylaxis (PrEP) for HIV-negative partner:** Oral PrEP of HIV is the daily use of ARV drugs by HIV-negative people to block the acquisition of HIV. More than 10 randomized controlled studies have demonstrated the effectiveness of PrEP in reducing HIV transmission among a range of populations including serodiscordant heterosexual couples (where one partner is infected and the other is not), men who have sex with men, transgender women, high-risk heterosexual couples, and people who inject drugs. WHO recommends PrEP as a prevention choice for people at substantial risk of HIV infection as part of a combination of prevention approaches. WHO has also expanded these recommendations to HIV-negative women who are pregnant or breastfeeding.
- ✓ **Post-exposure prophylaxis for HIV (PEP):** Post-exposure prophylaxis (PEP) is the use of ARV drugs within 72 hours of exposure to HIV in order to prevent infection. PEP includes counseling, first aid care, HIV testing, and administration of a 28-day course of ARV drugs with follow-up care. WHO recommends PEP use for both occupational and non-occupational exposures and for adults and children.
- ✓ **Harm reduction for people who inject and use drugs:** People who inject drugs can take precautions against becoming infected with HIV by using sterile injecting equipment, including needles and syringes, for each injection and not sharing drug using equipment and drug solutions. Treatment of dependence, and in particular opioid substitution therapy for people dependent on opioids, also helps reduce the risk of HIV transmission and supports adherence to HIV treatment. A comprehensive package of interventions for HIV prevention and treatment includes:
    - ➡ Needle and syringe programs;
    - ➡ Opioid substitution therapy for people dependent on opioids and other evidence-based drug dependence treatment;
    - ➡ HIV testing and counseling;
    - ➡ HIV treatment and care;
    - ➡ Risk-reduction information and education and provision;
    - ➡ Access to condoms; and
    - ➡ Management of STIs, tuberculosis and viral hepatitis.
- ✓ **Elimination of mother-to-child transmission of HIV (EMTCT):** The transmission of HIV from an HIV-positive mother to her child during pregnancy, labour, delivery or breastfeeding is called vertical or mother-to-child transmission (MTCT). In the absence of any interventions during these stages, rates of HIV transmission from mother-to-child can be between 15–=45%. MTCT can be nearly fully prevented if both the mother and the baby are

provided with ARV drugs as early as possible in pregnancy and during the period of breastfeeding.

Treatment

HIV can be suppressed by combination ART consisting of three or more ARV drugs. ART does not cure HIV infection but suppresses viral replication within a person's body and allows an individual's immune system to strengthen and regain the capacity to fight off infections.

The WHO released the second edition of the Consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection. These guidelines recommend to provide lifelong ART to all people living with HIV, including children, adolescents and adults, pregnant and breastfeeding women, regardless of clinical status or CD4 cell count.

Recent guidelines include new alternative ARV options with better tolerability, higher efficacy, and lower rates of treatment discontinuation when compared with medicines being used currently: dolutegravir and low-dose efavirenz for first-line therapy, and raltegravir and darunavir/ritonavir for second-line therapy. Transition to these new ARV options has already started in more than 20 countries and is expected to improve the durability of the treatment and the quality of care of people living with HIV. Despite improvements, limited options remain for infants and young children. For this reason, WHO and partners are coordinating efforts to enable a faster and more effective development and introduction of age-appropriate pediatric formulations of antiretrovirals.

In addition, 1 in 3 people living with HIV present to care with advanced disease, at low CD4 counts and at high risk of serious illness and death. To reduce this risk, WHO recommends that these patients receive a “package of care” that includes testing for and prevention of the most common serious infections that can cause death, such as tuberculosis and cryptococcal meningitis, in addition to ART.

Expanding access to treatment is at the heart of a new set of targets which aim to end the AIDS epidemic by 2030.

Causes

AIDS is the most severe acceleration of infection with HIV. HIV is a retrovirus that primarily infects vital organs of the human immune system such as $CD4^+$ T cells (a subset of T cells), macrophages and dendritic cells. It directly and indirectly destroys $CD4^+$ T cells. Once HIV has killed so many $CD4^+$ T cells that there are fewer than 200 of these cells per microliter (μL) of blood, cellular immunity is lost. Acute HIV infection progresses over time to clinical latent HIV infection and then to early symptomatic HIV infection and later to AIDS, which is identified either on the basis of the amount of $CD4^+$ T cells remaining in the blood, and/or the presence of certain infections.

Sexual transmission

Sexual transmission occurs with the contact between sexual secretions of one person with the rectal, genital or oral mucous membranes of another. Unprotected receptive sexual acts are riskier than unprotected insertive sexual acts, and the risk for transmitting HIV through unprotected anal intercourse is greater than the risk from vaginal intercourse or oral sex.

However, oral sex is not entirely safe, as HIV can be transmitted through both insertive and receptive oral sex. Sexual assault greatly increases the risk of HIV transmission as protection is rarely employed and physical trauma to the vagina occurs frequently, facilitating the transmission of HIV. Other sexually transmitted infections (STI) increase the risk of HIV transmission and infection, because they cause the disruption of the normal epithelial barrier by genital ulceration and/or microulceration; and by accumulation of pools of HIV-susceptible or HIV-infected cells (lymphocytes and macrophages) in semen and vaginal secretions. Epidemiological studies from sub-Saharan Africa, Europe and North America suggest that genital ulcers, such as those caused by syphilis and/or chancroid, increase the risk of becoming infected with HIV by about fourfold. There is also a significant although lesser increase in risk from STIs such as gonorrhea, Chlamydial infection and trichomoniasis, which all cause local accumulations of lymphocytes and macrophages *(Appay V, Sauce D,"Immune activation and inflammation in HIV-1 infection: causes and consequences". J. Pathol).*

Transmission of HIV depends on the infectiousness of the index case and the susceptibility of the uninfected partner. Infectivity seems to vary during the course of illness and is not constant between individuals. An undetectable plasma viral load does not necessarily indicate a low viral load in the seminal liquid or genital secretions. However, each 10-fold increase in the level of HIV in the blood is

associated with an 81% increased rate of HIV transmission. Women are more susceptible to HIV-1 infection due to hormonal changes, vaginal microbial ecology and physiology, and a higher prevalence of sexually transmitted diseases. People who have been infected with one strain of HIV can still be infected later on in their lives by other, more virulent strains. Infection is unlikely in a single encounter. High rates of infection have been linked to a pattern of overlapping long-term romantic relationships. This allows the virus to quickly spread to multiple partners who in turn infect their partners. A pattern of serial monogamy or occasional casual encounters is associated with lower rates of infection. HIV spreads readily through heterosexual sex in Africa, but less so elsewhere. One possibility being researched is that schistosomiasis, which affects up to 50 per cent of women in parts of Africa, damages the lining of the vagina *(Appay V, Sauce D, "Immune activation and inflammation in HIV-1 infection: causes and consequences". J. Pathol).*

Exposure to blood-borne pathogens

This transmission route is particularly relevant to intravenous drug users, hemophiliacs and recipients of blood transfusions and blood products. Sharing and reusing syringes contaminated with HIV-infected blood represents a major risk for infection with HIV. Needle sharing is the cause of one third of all new HIV-infections in North America, China, and Eastern Europe. The risk of being infected with HIV from a single prick with a needle that has been used on an HIV-infected person is thought to be about 1 in 150. Post-exposure prophylaxis with anti-HIV drugs can further reduce this risk. This route can also affect people who give and receive tattoos and piercings. Universal precautions are frequently not followed in both sub-Saharan Africa and much of Asia because of both a shortage of supplies and inadequate training. The World Health Organization (WHO) estimates that approximately 2.5% of all HIV infections in sub-Saharan Africa are transmitted through unsafe healthcare injections. Because of this, the United Nations General Assembly has urged the nations of the world to implement precautions to prevent HIV transmission by health workers. The risk of transmitting HIV to blood transfusion recipients is extremely low in developed countries where improved donor selection and HIV screening is performed. However, according to the WHO, the overwhelming majority of the world's population does not have access to safe blood and between 5% and 10% of the world's HIV infections come from transfusion of infected blood and blood products.

Perinatal transmission

The transmission of the virus from the mother to the child can occur *in utero* during the last weeks of pregnancy and at childbirth. In the absence of treatment, the transmission rate between a mother and her child during pregnancy, labor and

delivery is 25%. However, when the mother takes antiretroviral therapy and gives birth by caesarean section, the rate of transmission is just 1%. The risk of infection is influenced by the viral load of the mother at birth, with the higher the viral load, the higher the risk. Breastfeeding also increases the risk of transmission by about 4 %.

Summary of Causes

The risk of getting HIV varies widely depending on the type of exposure or behavior (such as sharing needles or having sex without a condom). Some exposures to HIV carry a much higher risk of transmission than other exposures. For some exposures, while transmission is biologically possible, the risk is so low that it is not possible to put a precise number on it. But risks do add up over time. Even relatively small risks can add up over time and lead to a high lifetime risk of getting HIV. In other words, there may be a relatively small chance of acquiring HIV when engaging in a risk behavior with an infected partner only once; but, if repeated many times, the overall likelihood of becoming infected after repeated exposures is actually much higher.

The table below lists the risk of transmission per 10,000 exposures for various types of exposures.

Estimated Per-Act Probability of Acquiring HIV from an Infected Source, by Exposure Act*

Type of Exposure	Risk per 10,000 Exposures
Parenteral	
Blood Transfusion	9,250
Needle-Sharing During Injection Drug Use	63
Percutaneous (Needle-Stick)	23
Sexual	
Receptive Anal Intercourse	138
Insertive Anal Intercourse	11
Receptive Penile-Vaginal Intercourse	8
Insertive Penile-Vaginal Intercourse	4
Receptive Oral Intercourse	Low
Insertive Oral Intercourse	Low
Other	
Biting	Negligible
Spitting	Negligible
Sharing Sex Toys	Negligible

* *Factors that may increase the risk of HIV transmission include sexually transmitted diseases, acute and late-stage HIV infection, and high viral load. Factors that may decrease the risk include condom use, male circumcision, antiretroviral treatment, and pre-exposure prophylaxis. None of these factors are accounted for in the estimates presented in the table.*

* *HIV transmission through these exposure routes is technically possible but unlikely and not well documented.*

Misconceptions

A number of misconceptions have arisen surrounding HIV/AIDS. Three of the most common are that AIDS can spread through casual contact, that sexual intercourse with a virgin will cure AIDS, and that HIV can infect only homosexual men and drug users. Other misconceptions are that any act of anal intercourse between gay men can lead to AIDS infection, and that open discussion of homosexuality and HIV in schools will lead to increased rates of homosexuality and AIDS.

Pathophysiology

The pathophysiology of AIDS is complex, as is the case with all syndromes. Ultimately, HIV causes AIDS by depleting $CD4^+$ T helper lymphocytes. This weakens the immune system and allows opportunistic infections. T lymphocytes are essential to the immune response and without them, the body cannot fight infections or kill cancerous cells. The mechanism of $CD4^+$ T cell depletion differs in the acute and chronic phases.

During the acute phase, HIV-induced cell lysis and killing of infected cells by cytotoxic T cells accounts for $CD4^+$ T cell depletion, although apoptosis may also be a factor. During the chronic phase, the consequences of generalized immune activation coupled with the gradual loss of the ability of the immune system to generate new T cells appear to account for the slow decline in $CD4^+$ T cell numbers.

Although the symptoms of immune deficiency characteristic of AIDS do not appear for years after a person is infected, the bulk of $CD4^+$ T cell loss occurs during the first weeks of infection, especially in the intestinal mucosa, which harbors the majority of the lymphocytes found in the body. The reason for the preferential loss of mucosal $CD4^+$ T cells is that a majority of mucosal $CD4^+$ T cells express the CCR5 co-receptor, whereas a small fraction of $CD4^+$ T cells in the bloodstream do so.

Continuous HIV replication results in a state of generalized immune activation persisting throughout the chronic phase. Immune activation, which is reflected by the increased activation state of immune cells and release of proinflammatory cytokines, results from the activity of several HIV gene products and the immune response to ongoing HIV replication. Another cause is the breakdown of the immune surveillance system of the mucosal barrier caused by the depletion of mucosal $CD4^+$ T cells during the acute phase of disease.

This results in the systemic exposure of the immune system to microbial components of the gut's normal flora, which in a healthy person is kept in check by the mucosal immune system. The activation and proliferation of T cells that results from immune activation provides fresh targets for HIV infection. However, direct killing by HIV alone cannot account for the observed depletion of $CD4^+$ T cells since only 0.01-0.10% of $CD4^+$ T cells in the blood are infected. A major cause of $CD4^+$ T cell loss appears to result from their heightened susceptibility to apoptosis when the immune system remains activated. Although new T cells are continuously produced by the thymus to replace the ones lost, the regenerative capacity of the thymus is slowly destroyed by direct infection of its thymocytes by HIV. Eventually, the minimal number of $CD4^+$ T cells necessary to maintain a sufficient

immune response is lost, leading to AIDS *(Source: The World Health Organization)*.

2. Statistics and Epidemiology

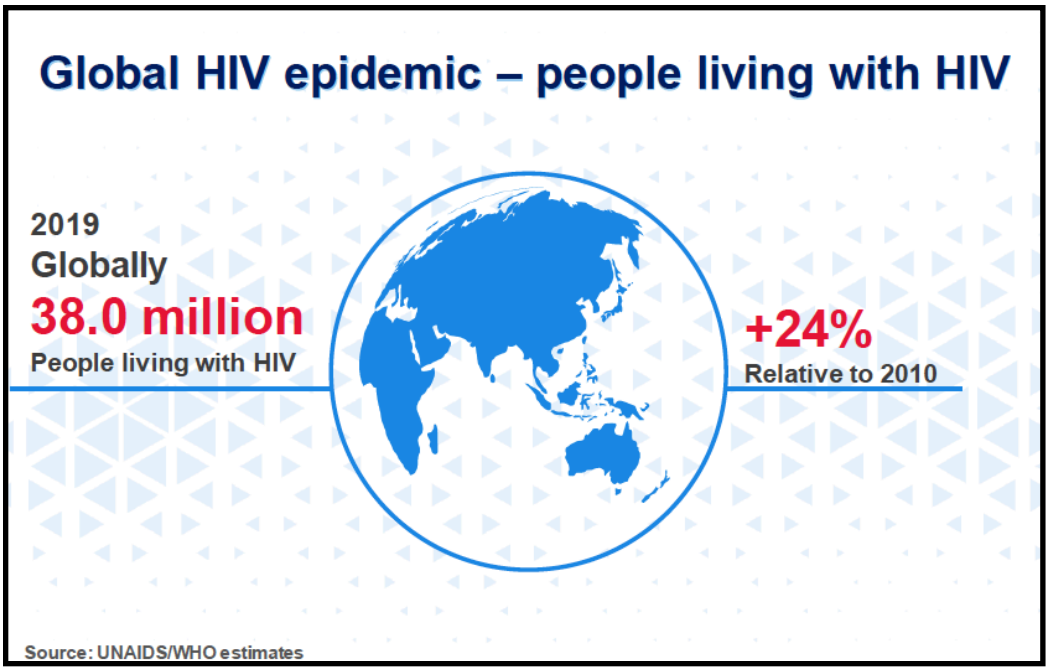
Global HIV & AIDS statistics — 2020 facts

- ➡ 26 million [25.1 million–26.2 million] people were accessing antiretroviral therapy as of the end of June 2020.
- ➡ 38.0 million [31.6 million–44.5 million] people globally were living with HIV in 2020.
- ➡ 1.7 million [1.2 million–2.2 million] people became newly infected with HIV in 2020.
- ➡ 690 000 [500 000–970 000] people died from AIDS-related illnesses in 2020.
- ➡ 75.7 million [55.9 million–100 million] people have become infected with HIV since the start of the epidemic (2020).
- ➡ 32.7 million [24.8 million–42.2 million] people have died from AIDS-related illnesses since the start of the epidemic (2020).

People living with HIV

- ✓ In 2019, there were 38.0 million [31.6 million–44.5 million] people living with HIV.
    - ○ 36.2 million [30.2 million–42.5 million] adults.
    - ○ 1.8 million [1.3 million–2.2 million] children (0–14 years).
- ✓ 81% [68–95%] of all people living with HIV knew their HIV status.

✓ About 7.1 million people did not know that they were living with HIV.



People living with HIV accessing antiretroviral therapy

✶ As of the end of June 2020, 26.0 million [25.1 million–26.2 million] people were accessing antiretroviral therapy.

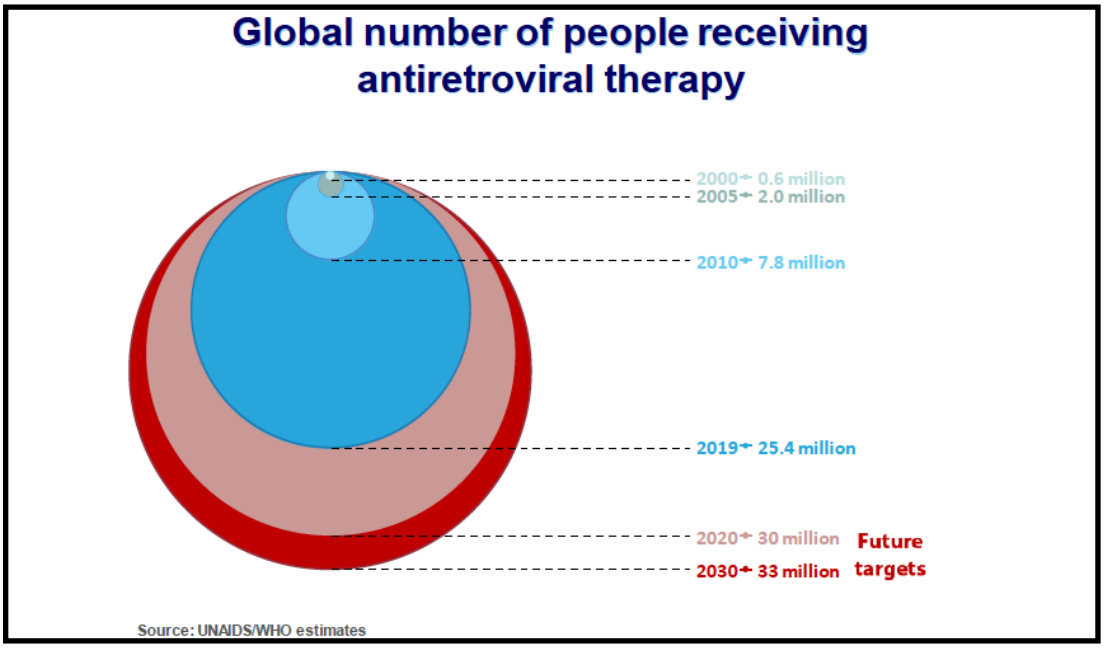
✶ In 2019, 25.4 million [24.5 million–25.6 million] people were accessing antiretroviral therapy, up from 6.4 million [5.9 million–6.4 million] in 2009.

✶ In 2019, 67% [54–79%] of all people living with HIV were accessing treatment.

- 68% [54–80%] of adults aged 15 years and older living with HIV had access to treatment, as did 53% [36–64%] of children aged 0–14 years.

- 73% [60-86%] of female adults aged 15 years and older had access to treatment; however, just 61% [48-74%] of male adults aged 15 years and older had access.

- 85% [63–100%] of pregnant women living with HIV had access to antiretroviral medicines to prevent transmission of HIV to their child in 2019.



New HIV infections

- New HIV infections have been reduced by 40% since the peak in 1998.
    - In 2019, around 1.7 million [1.2 million–2.2 million] people were newly infected with HIV, compared to 2.8 million [2.0 million–3.7 million] people in 1998.
- Since 2010, new HIV infections have declined by 23%, from 2.1 million [1.6 million–2.9 million] to 1.7 million [1.2 million–2.2 million] in 2019.
    - Since 2010, new HIV infections among children have declined by 52%, from 310 000 [200 000–500 000] in 2010 to 150 000 [94 000–240 000] in 2019.

AIDS-related deaths

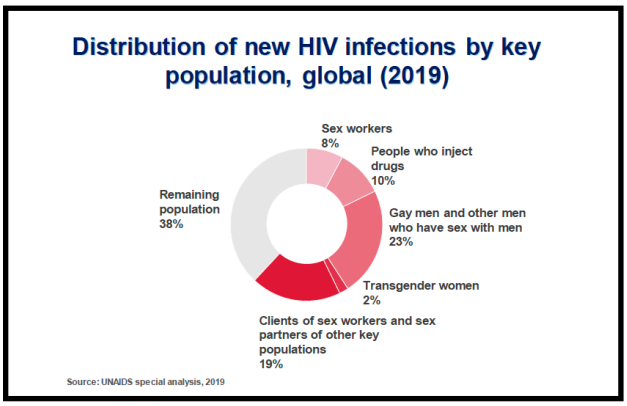
- AIDS-related deaths have been reduced by 60% since the peak in 2004.
    - In 2019, around 690 000 [500 000–970 000] people died from AIDS-related illnesses worldwide, compared to 1.7 million [1.2 million–2.4 million] people in 2004 and 1.1 million [830 000 –1.6 million] people in 2010.
- AIDS-related mortality has declined by 39% since 2010.

Women

- Every week, around 5500 young women aged 15–24 years become infected with HIV.
    - In sub-Saharan Africa, five in six new infections among adolescents aged 15–19 years are among girls. Young women aged 15–24 years are twice as likely to be living with HIV than men.
- More than one third (35%) of women around the world have experienced physical and/or sexual violence by an intimate partner or sexual violence by a non-partner at some time in their lives.
    - In some regions, women who have experienced physical or sexual intimate partner violence are 1.5 times more likely to acquire HIV than women who have not experienced such violence.
- Women and girls accounted for about 48% of all new HIV infections in 2019. In sub-Saharan Africa, women and girls accounted for 59% of all new HIV infections.

Key populations

- Key populations and their sexual partners account for:
    - 62% of new HIV infections globally.
    - 99% of new HIV infections in eastern Europe and central Asia.
    - 97% of new HIV infections in the Middle East and North Africa.



- ○96% of new HIV infections in western and central Europe and North America.
- ○98% of new HIV infections in Asia and the Pacific.
- ○77% of new HIV infections in Latin America.
    - 69% of new HIV infections in western and central Africa.
    - 60% of new HIV infections in the Caribbean.
    - 28% of new HIV infections in eastern and southern Africa.
- The risk of acquiring HIV is:
    - 26 times higher among gay men and other men who have sex with men.
    - 29 times higher among people who inject drugs.
    - 30 times higher for sex workers.

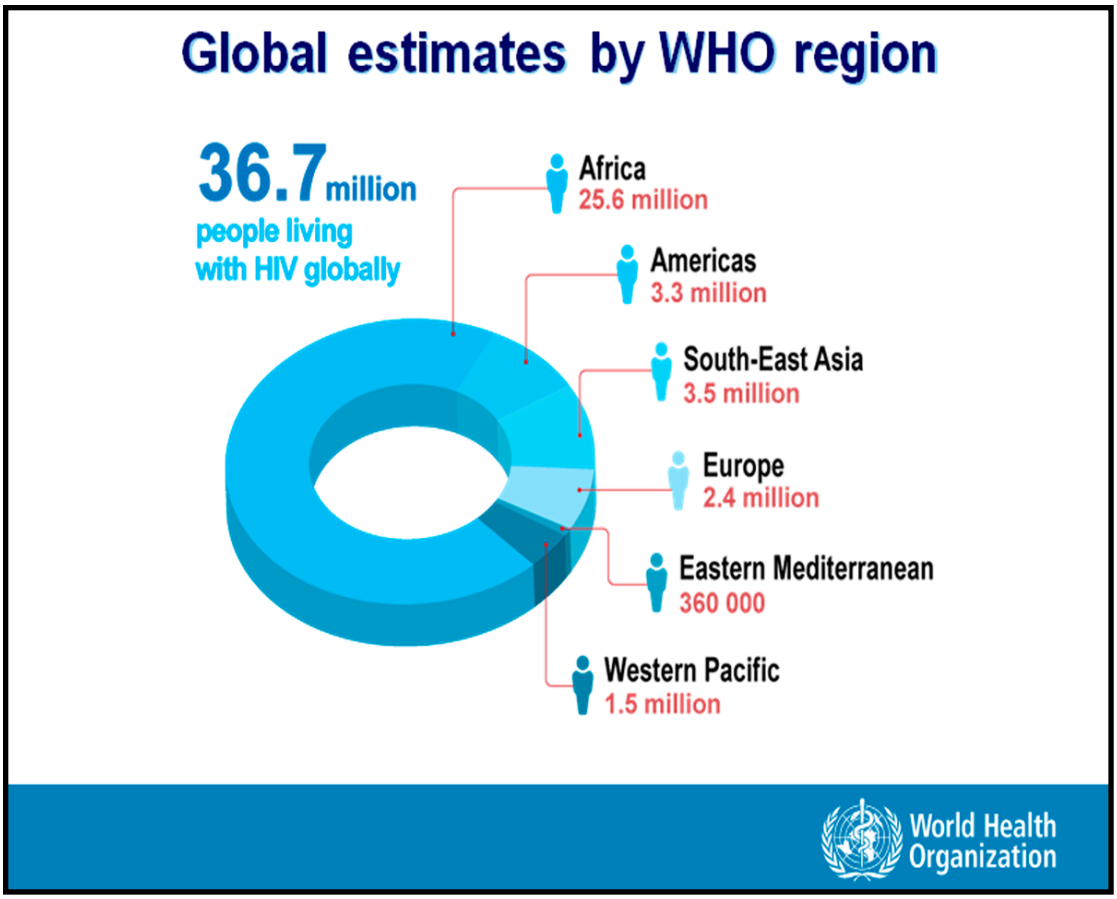
- 13 times higher for transgender people.

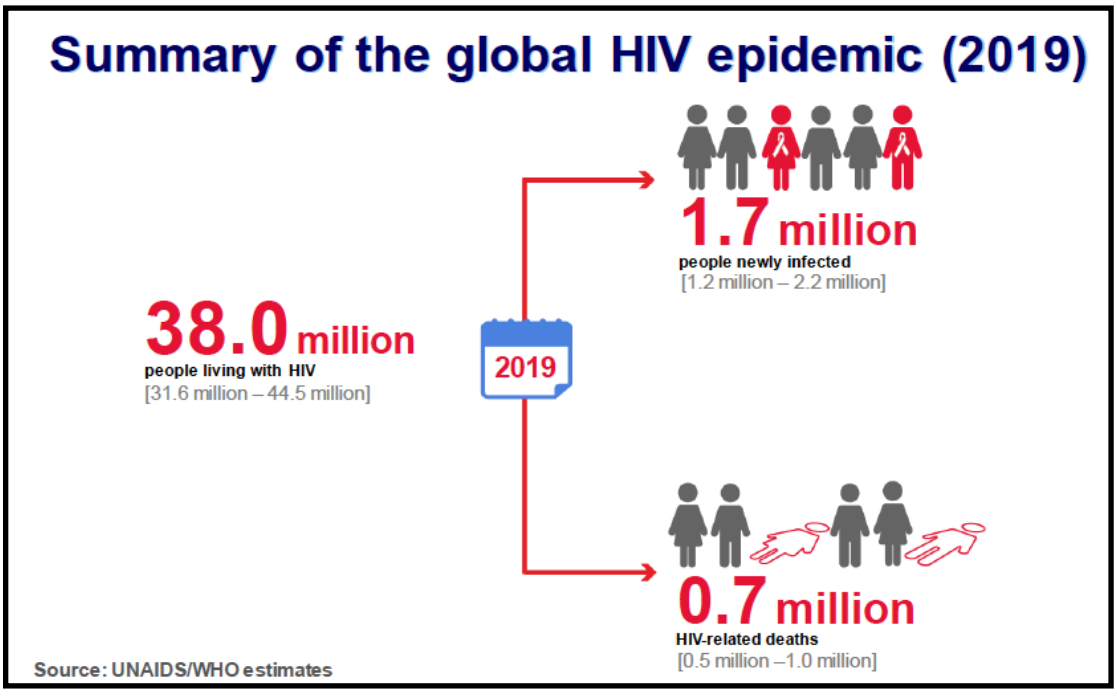
HIV/tuberculosis (TB)

- TB remains the leading cause of death among people living with HIV, accounting for around one in three AIDS-related deaths.
- In 2018, an estimated 10.0 million [9.0 million–11.1 million] people developed TB disease, approximately 9% of whom were living with HIV.
  - People living with HIV with no TB symptoms need TB preventative therapy, which lessens the risk of developing TB and reduces TB/HIV death rates by around 40%.
  - 1.8 million people living with HIV across 65 countries started preventive treatment for TB in 2018.
- It is estimated that 44% of people living with HIV and TB are unaware of their coinfection and are therefore not receiving care.

Investments

- At the end of 2019, US$ 18.6 billion (constant 2016 dollars) was available for the AIDS response in low- and middle-income countries, almost US$ 1.3 billion less than in 2017.
  - Around 57% of the total resources for HIV in low- and middle-income countries in 2019 were from domestic sources.
- UNAIDS estimates that US$ 26.2 billion (constant 2016 dollars) will be required for the AIDS response in 2020.

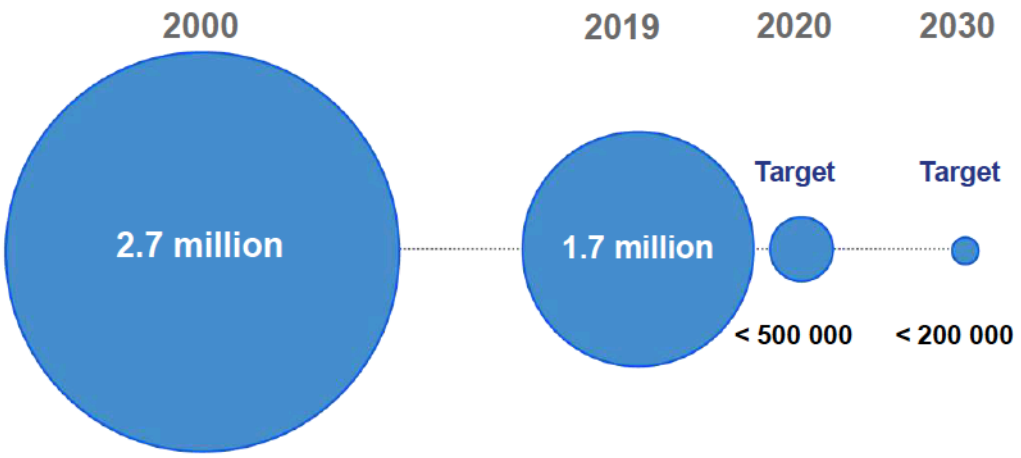

Global estimates by WHO region
36.7 million
people living with HIV globally
Africa
25.6 million
Americas
3.3 million
South-East Asia
3.5 million
Europe
2.4 million
Eastern Mediterranean
360 000
Western Pacific
1.5 million
World Health Organization


Summary of the global HIV epidemic (2019)
1.7 million
people newly infected
[1.2 million – 2.2 million]
38.0 million
people living with HIV
[31.6 million – 44.5 million]
2019
0.7 million
HIV-related deaths
[0.5 million –1.0 million]
Source: UNAIDS/WHO estimates

New HIV infections by region, 2018–2019

WHO region	Number of new HIV infections 2018	Number of new HIV infections 2019	New HIV infections all ages (per 1000 uninfected population) 2018	New HIV infections all ages (per 1000 uninfected population) 2019
Africa	1 000 000 [760 000-1 400 000]	970 000 [730 000-1 300 000]	1	0.94
Americas	170 000 [110 000-240 000]	170 000 [110 000-240 000]	0.17	0.17
South-East Asia	170 000 [120 000-220 000]	160 000 [110 000-210 000]	0.08	0.08
Europe	190 000 [150 000-230 000]	190 000 [160 000-240 000]	0.2	0.21
Eastern Mediterranean	41 000 [31 000-63 000]	44 000 [33 000-67 000]	0.07	0.07
Western Pacific	110 000 [70 000-150 000]	110 000 [71 000-150 000]	0.06	0.06
Global	1 700 000 [1 200 000-2 300 000]	1 700 000 [1 200 000-2 200 000]	0.23	0.22

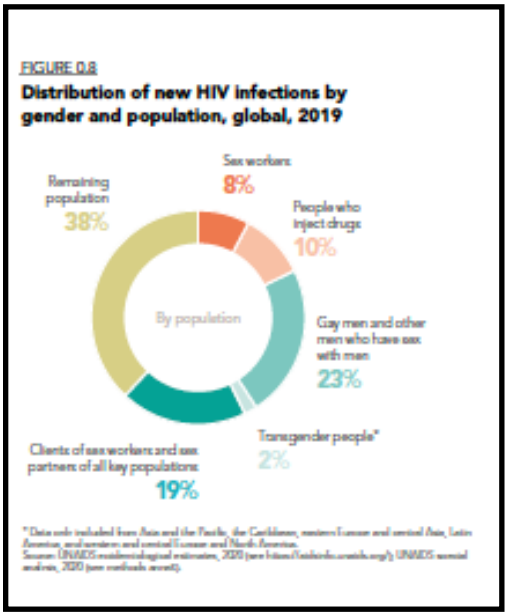
Global number of people newly infected with HIV



Source: UNAIDS/WHO estimates

Gaps expose entrenched inequalities

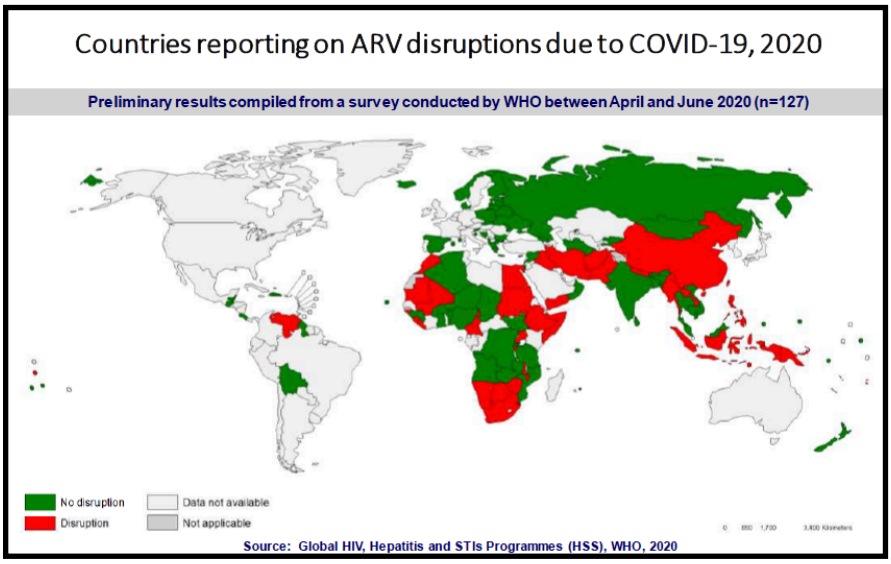
The gaps in HIV responses and resulting HIV infections and AIDS-related deaths lie upon fault lines of inequality. Data from 46 countries in sub-Saharan Africa show a positive relationship between HIV prevalence and income disparity. After controlling for education, gender inequality and income per capita, a one-point increase in a country's 20:20 ratio corresponds to a two-point increase in HIV prevalence. Unequal gender norms that limit the agency and voice of women and girls, reduce their access to education and economic resources, and stifle their civic participation contribute to the higher HIV risk faced by women in settings with high HIV prevalence. Younger women are at particular risk. In subSaharan Africa, adolescent girls and young women (aged 15 to 24 years) accounted for 24% of HIV infections in 2019, more than double their 10% share of the population (Figure 0.9). Women and girls of all ages accounted for 59% of new HIV infections in sub-Saharan Africa. Outside of sub-Saharan Africa, older adult men (aged 25 and above) account for the majority of new HIV infections (Figure 0.10). A considerable proportion of these men are gay men and other men who have sex with men. Transgender people are also at extremely high risk of acquiring HIV: on average, they have a 13 times greater risk of infection than adults in the general population. Gender norms in many cultures—including binary concepts of gender and taboos about sexuality—also perpetuate stigma, homophobia and transphobia. Lesbian, gay, bisexual, transgender and intersex (LGBTI) persons and marginalized women (such as sex workers or women who use drugs) who fear judgement, violence or arrest struggle to access sexual and reproductive health services, especially those related to contraception and HIV prevention. Additional key populations at higher risk of HIV infection include people who inject drugs, sex workers and prisoners. Although they are a small proportion of the general population, key populations and their sexual partners accounted for more than 60% of new adult HIV infections globally in 2019.



COVID-19 amplifies inequalities

The COVID-19 pandemic is affecting the lives and livelihoods of people everywhere, but the impact is especially severe among people who are socioeconomically disadvantaged and marginalized, and among people with underlying medical conditions.

The COVID-19 crisis is amplifying the deep inequalities that thwart the realization of individual and collective health rights. In some contexts, efforts aimed at controlling the spread of COVID-19 have penalized the most vulnerable in society, such as women, the homeless, those living in poverty, or those who are already marginalized, stigmatized or criminalized. Extended confinement measures and restrictions on movement—compounded by economic and social stresses brought on by the pandemic—have coincided with reports in many countries of increased numbers of women and girls facing abuse. Country-wide school closures implemented to fight the spread of the virus in more than 190 countries have led to more than 1.57 billion learners being out of school, including 743 million girls. The impact of this period of disrupted education will be far-reaching, and it is likely to hit marginalized girls the hardest. Lessons learned from the Ebola crisis show that school closures can lead to increases in gender-based violence, teenage pregnancies, child marriage, exploitation and other forms of abuse against adolescent girls (including online sexual exploitation and grooming). School closures may be especially devastating for girls with greater vulnerabilities, such as refugees, internally displaced persons, returnees and girls living with disabilities.



There have been alarming reports of police powers being used to harass, harm and arrest vulnerable and criminalized groups, such as sex workers, people who use

drugs, people living with HIV and LGBTI people. Sex workers all over the world are reporting increased discrimination and harassment, with reports of punitive crackdowns against sex workers resulting in raids on homes, compulsory COVID-19 testing, and arrests and threatened deportation of migrant sex workers.

Restrictions created for the response to COVID-19 have also been specifically used to target marginalized communities, such LGBTI people in some countries, undermining public health objectives and threatening the health and safety of these groups. In Panama, for example, where a gender-based confinement regulation called for men and women to stay at home on alternating days, transwomen have reported experiencing harassment or even being detained for allegedly being a male out on the wrong day. In Hungary, the state of emergency was used to propose a new bill to remove the right of people to change their gender and name on official documents in order to ensure conformity with their gender identity, which is a clear breach of international human rights to the legal recognition of gender identity.

As the new coronavirus spreads in sub-Saharan African countries with high HIV prevalence, there is evidence that people living with HIV should be considered a high-risk group for COVID-19 responses. In Western Cape, South Africa, patient data from more than 3.4 million adults between March and June 2020 show that people living with HIV had a modestly increased risk of COVID-19 death compared to HIV-negative patients, irrespective of viral suppression. The study was not able to assess the effects of socioeconomic status of the patients. Data from population-based surveys from eight countries with a high burden of HIV suggest that people living with HIV have a greater likelihood of living in conditions that make physical distancing difficult. A preliminary analysis of Demographic Health Survey data from Angola, Haiti, Malawi, Mozambique, Rwanda, South Africa, Zambia and Zimbabwe suggests that people living with HIV have significantly higher odds of living in a household with a shared toilet and higher odds of living in a household without a radio.

Accelerating innovations to minimize COVID-19 disruptions to HIV services

As the spread of the new coronavirus threatens to overwhelm health system capacities and lockdowns limit movement and strain economies, people living with HIV and people at higher risk of HIV infection are facing life-threatening disruptions to health and HIV services. VMMC, condom production and distribution, PrEP, HIV testing and treatment, and other programs have all been negatively affected.

Such disruptions could see the global HIV response fall further behind on its 2020 commitments. Recent modeling has estimated that a total disruption of antiretroviral therapy for six months could lead to more than 500 000 [471 000–673 000] additional deaths from AIDS-related illnesses (including tuberculosis) in sub-Saharan Africa in 2020–202. An interruption of antiretroviral therapy for 20% of people living with HIV for six months would result in more than 110 000 additional AIDS related deaths. HIV and other critical health services must be maintained as communities, cities and countries respond to this new pandemic.

Countries around the world are accelerating HIV response innovations to minimize disruptions. HIV service delivery models that emphasize client autonomy and self-care—and that minimize physical contact with health facilities—are proving critical during a time when health facilities need to cater for the influx of COVID-19 patients, while at the same time maintaining vital health services without putting other clients at risk of COVID-19 infection.

HIV self-testing, which empowers people to choose for themselves the circumstances in which they take an HIV test, has the advantage of decongesting health facilities and increasing access to HIV testing to populations at higher risk of HIV infection. Burundi, Eswatini, Guatemala and Myanmar are among the countries that have reported expanding HIV self-testing during the COVID-19 pandemic.

Community-based services are also growing in importance. In Nigeria's Cross River State, for example, community treatment management teams have been responsible for 92% of HIV diagnoses since lockdown measures were put in place in March 2020.

In many countries, community organizations of people living with HIV and people at higher risk of HIV infection are playing leading roles in efforts to bring HIV prevention tools and information, self-test kits, antiretroviral medicines and other essential medications to the people who need them, including through social media platforms and home delivery. In remote communities in the Republic of Moldova, for instance, non-governmental organizations have been delivering antiretroviral medicines to the homes of about 800 people living with HIV and 100 people who are using PrEP. Multimonth dispensing of antiretroviral medicines is reducing the strain on health facilities and putting people living with HIV in greater charge of their treatment. Early adopters of multimonth dispensing have been better placed to avoid serious disruptions to their HIV treatment services

during the COVID-19 pandemic. In Zimbabwe, for example, 80% of people on HIV treatment were already receiving three-month supplies of antiretroviral medicines in early 2020, and an eight-month national supply of first-line antiretroviral medicines stands as a solid buffer against stock-outs. Other countries have accelerated multimonth dispensing during the COVID-19 crisis or temporarily adopted more liberal dispensing policies (26). For instance, South Africa's Department of Health's Central Chronic Medicines Dispensing and Distribution program decided in late May 2020 to provide automatic six and 12-month extensions of antiretroviral medicine prescriptions.

Stigma discourages people from seeking health services

As the COVID-19 pandemic unfolds, old fears and prejudices are resurfacing. Some countries have taken the short-sighted step of using criminal law to sanction COVID-19 exposure and transmission, including the extreme case of a South African businessman arrested for attempted murder after allegedly testing positive for COVID-19 and then returning to work. Such state actions could discourage people from seeking testing and undergoing contact tracing. This has been the reality for millions of people living with HIV for decades.

Among 151 reporting countries, 92 continue to criminalize HIV exposure, transmission and nondisclosure— all grave violations of the rights of people living with HIV that also frustrate efforts to control HIV epidemics. These laws reinforce stigma and discrimination against people living with HIV and those more vulnerable to HIV infection, they disregard up-to-date knowledge on the science of HIV-related risks and harms, and they have adverse impacts on public health. The most recent data from population-based surveys show that while discriminatory attitudes towards people living with HIV are declining consistently in some regions, they are rebounding in others. In eastern and southern Africa, for instance, discriminatory attitudes have been reduced to historically low levels in some countries. Elsewhere, however, disconcertingly large proportions of adults continue to hold discriminatory attitudes towards people living with HIV. In 25 of 36 countries with recent data on a composite indicator that includes two types of discriminatory attitudes, more than 50% of people aged 15 to 49 years reported having discriminatory attitudes towards people living with HIV.

Fear of prosecution can deter people living with HIV, or those at higher risk of HIV infection, from talking openly to their physicians or counselors, disclosing their

HIV-positive status or using available HIV testing and treatment services. Surveys of people living with HIV confirm that stigma and discrimination at health-care facilities—in the shape of denial of care, dismissive attitudes, coerced procedures or breaches of confidentiality—remain disturbingly common.

Across 13 countries with available data, the percentage of people living with HIV who reported being denied health services at least once in the previous 12 months because of their HIV status ranged from 1.7% in Malawi to as high as 21% in Peru and Tajikistan. Coerced medical or health procedures remain common, as do breaches of confidentiality by health-care professionals (reported by at least 15% of people in eight of 13 countries with available data). Significant proportions of people living with HIV also reported that their ability to obtain antiretroviral therapy was conditional on them using certain forms of contraception.

Gender inequality and HIV risks

Incremental gains towards gender equality in recent decades leave women and girls short of educational and economic opportunities, and they remain disproportionately affected by poverty, violence and injustice. Unequal gender norms deny women and girls the ability to make their own choices about health care, assign them with higher levels of domestic work and caregiving responsibilities, curtail their freedom to enter and remain in the labour force on terms that suit their needs, and ultimately impact women's economic independence, security and control. In much of the world, women continue to have insufficient access to high-quality sexual and reproductive health information, education and services—including family planning.

Violence impacts the lives of hundreds of millions of women and girls: nearly one in three women worldwide have experienced physical or sexual violence by an intimate partner, non-partner sexual violence or both in their lifetime. Across 46 countries, the percentage of women aged 15 to 49 years who reported having experienced physical and/or sexual violence by an intimate partner in the past 12 months ranged from 3.5% in Armenia to 47.6% in Papua New Guinea. Women belonging to ethnic and other minorities, transgender women and women with disabilities face a higher risk of different forms of violence. Adolescent girls and young women face particular challenges that can leave them at elevated risk of unintended pregnancy, violence and HIV. Many are unable to access the sexual and reproductive health services they need: of the 38 million sexually active adolescent girls aged 15 to 19 years globally, more than half are not using contraceptives.

At least 10 million unintended pregnancies occur each year among adolescent girls aged 15 to 19 years in low- and middle-income countries, and complications during pregnancy and childbirth are the leading cause of death globally for girls aged 15 to 19 years.

Knowledge about sexual and reproductive health and the prevention of HIV and sexually transmitted infections (STIs) among adolescent girls and young women is also low: only about one third of women aged 15 to 24 years in sub-Saharan Africa have comprehensive knowledge about HIV. This high level of vulnerability is fueled by a complex interplay of social, economic and structural drivers, including poverty, gender inequality, unequal power and relationship dynamics, gender-based violence, social isolation and limited access to schooling.

Women living with HIV face particular challenges, as HIV stigma and gender inequality intersect and negatively impact their health. While health-care settings should be safe spaces, as many as one in three women living with HIV across 19 countries report experiencing at least one form of discrimination related to their sexual and reproductive health in a health-care setting within the past 12 months. Women living with HIV are also about five times more likely to develop cervical cancer than their HIV-negative counterparts. This risk is linked to the human papillomavirus (HPV), a common but preventable infection that women with compromised immune systems struggle to clear. High HPV vaccination coverage among girls—combined with dramatically scaled up cervical cancer screening and treatment—could virtually eliminate cervical cancer. Despite the clear benefits of such programs, of the 118 million women who have received the HPV vaccine to date, only 1.4 million (1%) live in low- and middle-income countries (48). In nearly all regions, women living with HIV are more likely to access HIV testing and antiretroviral therapy than men, in part due to better health seeking behavior among women and the existence of HIV-related services designed specifically to reach women (such as services to prevent mother-to-child HIV transmission that are provided during antenatal care). In 2019, treatment coverage globally was 12 percentage points higher among women living with HIV than among men living with HIV, and viral suppression was 10 percentage points higher. This treatment gap among men living with HIV contributes to the higher number of new HIV infections among women in sub-Saharan Africa. Recent longitudinal studies have shown how closing these gaps accelerates declines in the incidence of HIV among women, especially young women.

People-centred approaches to pandemics

The COVID-19 pandemic has laid bare the need for systems to be more resilient, flexible and adaptable, and to provide everyone with the services they need in a more effective way. Accelerated movement towards universal health coverage can help health systems achieve the highest possible standards of health and well being for all people.

The guiding principle of universal health coverage is equity: everyone—irrespective of race, ethnicity, age, gender or social status—should receive the health services they need without suffering financial hardship due to the costs of paying for those services. A similar set of principles has guided the global HIV response for decades. Strategies that have successfully controlled HIV epidemics have generally followed the principle that no one should be left behind. They uphold people's rights, work with and take the lead from communities, and marshal strong political commitment and reliable financial support. They foster enabling legal, social and institutional environments, and they provide services that are tailored by and for the people in greatest need.

Comprehensive approaches for women and girls

Calls for gender equality are growing louder as women leaders and community mobilizers mark the 25th anniversary of the Beijing Declaration and Platform for Action. A rights-based and gender-responsive approach is needed to overcome the many barriers faced by women and girls, and action is required on multiple fronts. All women require access to a comprehensive package of quality sexual and reproductive health and rights services that are: (a) accessible and gender-responsive; (b) free from coercion and stigma and discrimination; (c) grounded in a human-rights based approach; and (d) linked to other relevant services.
Studies in multiple settings have demonstrated the advantages of integrating HIV and sexual and reproductive health care:

- The Girl Power project in Malawi used a youth friendly model that offered HIV testing, family planning and STI services in combination. Adolescent girls using the integrated services were 23% more likely to take an HIV test, 57% more likely to receive condoms, 39% more likely to access hormonal contraception and 16% more likely to use services for STIs.
- In Viet Nam, the addition of peer education outreach to integrated sexual and reproductive health and HIV services led to a nearly fivefold increase in adolescents seeking HIV testing. A systematic review of studies from

Eswatini, Kenya, Uganda and the United States also found a potential for increased uptake of HIV testing.

- ✴ Providing PrEP through routine family planning services is also a promising strategy to reach women in settings with a high burden of HIV, as shown in a study in South Africa where very high PrEP retention rates (92%) were achieved.

An important contributor to sexual and reproductive health and rights is comprehensive sexuality education for adolescents and young people of all genders. Comprehensive sexuality education is cost-effective and improves sexual and reproductive health outcomes, including delayed initiation of sexual intercourse, decreased number of sexual partners, reduced sexual risk-taking and increased use of condoms and contraception, all of which result in reduced rates of STIs, HIV infections and unintended pregnancies.

Staying in school longer has a protective benefit in reducing the risk of HIV infection. Higher levels of educational attainment among women are also associated with increased control over sexual and reproductive health and rights. Cash transfers can keep young people, particularly girls, in school, improve their academic outcomes, increase their use of health services, delay their sexual debut, reduce early marriage and teen pregnancy, and promote safer sexual behaviors. One of the largest efforts to provide adolescent girls and young women with a comprehensive, multisectoral package of services that addresses the multiple social, economic and structural drivers that fuel HIV risk is the DREAMS partnership, which is funded by the United States President's Emergency Plan for AIDS Relief (PEFPAR). Safe spaces are established for the provision of a tailored package of services that include evidence informed HIV and violence prevention education, HIV prevention, testing and treatment services, educational and economic interventions, and contextual services for parents, male partners and community members to build a supportive environment.
This approach is having a positive effect on different HIV-related outcomes. In urban Zambia, for example, layering educational and economic interventions on top of safe spaces or social asset building activities resulted in a reduced likelihood of HIV risk behaviors among adolescent girls, including reduced transactional sex and increased consistent condom use and HIV testing.

Eliminating child infections and treating children living with HIV

Alongside adolescent girls and young women, children living with HIV are often left without the support and services they need to stay healthy and

build sustainable and enjoyable lives. The number of new child infections resulting from the mother-to-child transmission of HIV has more than halved in less than two decades, progress that in large part reflects the increased provision of antiretroviral therapy to pregnant women living with HIV. Despite this vastly improved treatment coverage, progress towards the elimination of child HIV infections has largely stalled, and the 2018 and 2020 targets for reducing new HIV infections among children were missed. Analyses of epidemiological and program data are guiding efforts to address the remaining challenges, including treatment coverage gaps among pregnant women living with HIV, interruptions in antiretroviral therapy during pregnancy and breastfeeding, and women acquiring HIV during pregnancy and breastfeeding. Mentor mother and peer-to-peer models are effective at enabling women and children to access testing, adhere to treatment and remain in care, even in difficult circumstances. These models involve training HIV-positive women to provide front-line health services, advice and support to women and their families. In Uganda, the mothers2mothers (M2M) program significantly increased retention of mother–baby pairs: 82% were retained at six months after cessation of breastfeeding (compared with 42% in the control group), and 71% were retained at 18 months after birth (21% in the control group).

Neglected rights of migrants and sex workers leave them exposed to COVID-19 and HIV

There were an estimated 272 million international migrants in 2019, equal to about 3.5% of the global population. Migration is increasingly forced by conflict and violence, natural disasters and the effects of climate change. Living in crowded camps, emergency shelters and informal settlements with limited access to health care, displaced people often are highly vulnerable to health threats, including COVID-19. An extensive review of refugee and migrant health in Europe has found that any increased risk that refugees may have for specific diseases can largely be attributed to poor living conditions during

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and after migration, including in refugee camps. Indeed, large proportions of migrants living with HIV were infected after migration. User fees, discrimination, social isolation, language and cultural barriers, unsafe working conditions, fear of deportation and a lack of health insurance are among the factors hindering their access to health care. Regional cooperation can ameliorate the difficulties faced by people displaced by crises. For example, Latin American and Caribbean countries have agreed on a road map for the integration of refugees and migrants from the crisis-hit Bolivarian Republic of Venezuela. Within this "Quito Process", several countries are working to provide migrants living with HIV with high-quality antiretroviral medicines, regardless of their immigration status.

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Many migrants and sex workers share the common challenge of exploitative working conditions. Standard labor protections are denied to those who are forced to work outside the bounds of local labor laws, denying them health and safety benefits while they are working and unemployment benefits when they are not. Where any aspect of sex work is criminalized, sex workers lack legal protections against violence, discrimination and abuse. Denying sex workers the protections provided to other workers is an exclusion that is particularly harmful during economic downturns and COVID-19 lockdowns.

Transgender people

Transgender women have some of the highest rates of HIV reported for any population, with HIV prevalence of up to 40% reported in some studies. The stigma and discrimination endured by transgender people (including from health-care providers) is frequently associated with poor mental health, substance abuse, lack of familial and social support, homelessness and unemployment—all of which also compromise their access to HIV and other health services.

Gay men and other men who have sex with men

Impressive successes have been achieved in reducing HIV infections and AIDS-related deaths among gay men and other men who have sex with men in several cities within Australia, North America and western Europe. High levels of condom use, adherence to PrEP and viral suppression have been shown to enable gay men and other men who have sex with men to protect their own health and that of their sexual partners. In other parts of the world, many communities of gay men and other men who have sex with men are treated as criminals and denied access to the health and HIV services they need. At least 69 countries have laws that criminalize same-sex sexual relations. These laws undermine the basic human rights of lesbians, bisexuals, transgender persons, and gay men and other men who have sex with men, exposing them to hate speech, violence, forced anal examinations and forced heterosexual marriages.

People who use drugs

The positive public health impact of harm reduction programs that bring together needle–syringe programs, opioid substitution therapy, overdose treatment, services for HIV and hepatitis C viral infection, and other services is well established. Only a minority of countries provide harm reduction services, however, mostly on a very small scale, and often in legal contexts that criminalize drug use and discourage people from accessing services.

The UN system has made a common commitment to supporting UN Member States to develop and implement responses to the world drug problem that are balanced, comprehensive, integrated, evidence-informed, human rights-based, development-oriented and sustainable. The global community of people who use drugs has called for harm reduction services to be included in the benefits package of universal health coverage systems, arguing that the principles of universal health coverage demand that the needs of the poorest and most vulnerable people—including people who inject drugs—be addressed first. Integration of HIV and hepatitis C treatment (including the prevention of further transmission) can produce dramatic results for people who inject drugs. In a recent cluster randomized trial in India, people who inject drugs received hepatitis C testing and information at integrated care centers that provided HIV testing and treatment and harm reduction services. Those who did were four times more likely to test for hepatitis C and seven times more likely to know their hepatitis C status and initiate treatment than peers using standard care centers.

People in prisons and other closed settings

International guidelines recommend a comprehensive package of health interventions for prisons, including for HIV and tuberculosis. The risk of sexual violence among prisoners—and their insufficient access to condoms, lubricants, PrEP and harm reduction services—heighten their chances of acquiring HIV, hepatitis C and STIs. Crowded, poorly ventilated and unsanitary conditions increase the risk of tuberculosis and other communicable respiratory diseases, including COVID-19. HIV testing and antiretroviral therapy coverage in prisons is improving, but gaps remain in several countries, including countries with a high prevalence of HIV within the general population. Challenges around confidentiality, discrimination and treatment interruptions upon release also remain. The COVID-19 pandemic has highlighted the obligation of all states under international human rights law to protect the health of people in prisons and detention facilities. The United Nations Standard Minimum Rules for the Treatment of Prisoners (the Nelson Mandela Rules) make clear that health care for people in prison should be of the same standard as that available in the rest of the community. Several countries are considering or applying practical reforms, including using detention as a last resort, avoiding pretrial detention, and allowing early release or home detention of persons convicted of nonviolent crimes. There are growing calls—including from the UN Inter-Agency Standing Committee—to end the incarceration of people for minor offenses or for offenses not consistent with international law.

Integrating tuberculosis and HIV services

Scale-up of antiretroviral therapy and improvements in the integrated delivery of HIV and tuberculosis services has reduced tuberculosis-related deaths among people living with HIV by 58% globally. Preventive treatment for tuberculosis among people living with HIV in 65 high-burden countries has improved dramatically in recent years. Despite this progress, large gaps in tuberculosis detection and preventive treatment exist in several high-burden countries. In 66 countries with available data, coverage of tuberculosis preventive treatment among people living with HIV who were newly enrolled in care was just 49%. Among the 11 countries with a high TB/HIV burden that reported these data, coverage ranged from 10% in Indonesia to 97% in the Russian Federation. About 0.8 million of the 10 million new tuberculosis cases globally are among people living with HIV. Tuberculosis remains the most common cause of premature death among people living with HIV, claiming the lives of 251 000 [223 000–281 000] people living with HIV.

Noncommunicable diseases and mental health

Noncommunicable diseases are common comorbidities among people living with HIV, especially those of advanced age. A recent systematic review and meta-analysis of studies calculated pooled estimates for the prevalence of noncommunicable diseases among people living with HIV in low- and middle-income countries: hypertension prevalence was 21.2%, hypercholesterolemia prevalence was 22.2%, obesity prevalence was 7.8%, depression prevalence was 24.4%, and diabetes prevalence was 1.3–18%. Integration of noncommunicable disease services for people living with HIV is critically important to addressing their needs. When the SEARCH (Sustainable East Africa Research in Community Health) study applied a community health approach and integrated HIV into multidisease service delivery, it led to a range of improvements: HIV-associated tuberculosis incidence was reduced and hypertension control was improved alongside dramatic increases in HIV service coverage and reductions in HIV incidence and AIDS-related mortality.

Mental health conditions are a leading cause of morbidity worldwide, and rates of mental health conditions are higher among people living with HIV than they are among the general population. Mental health conditions also affect HIV treatment and care outcomes, with one large meta-analysis estimating that the likelihood of strong adherence to antiretroviral therapy was 42% lower in people experiencing depression. Integrating screening and care for mental health conditions in HIV service settings can both strengthen HIV prevention and care outcomes and improve access to mental health care and support.

Seizing the moment

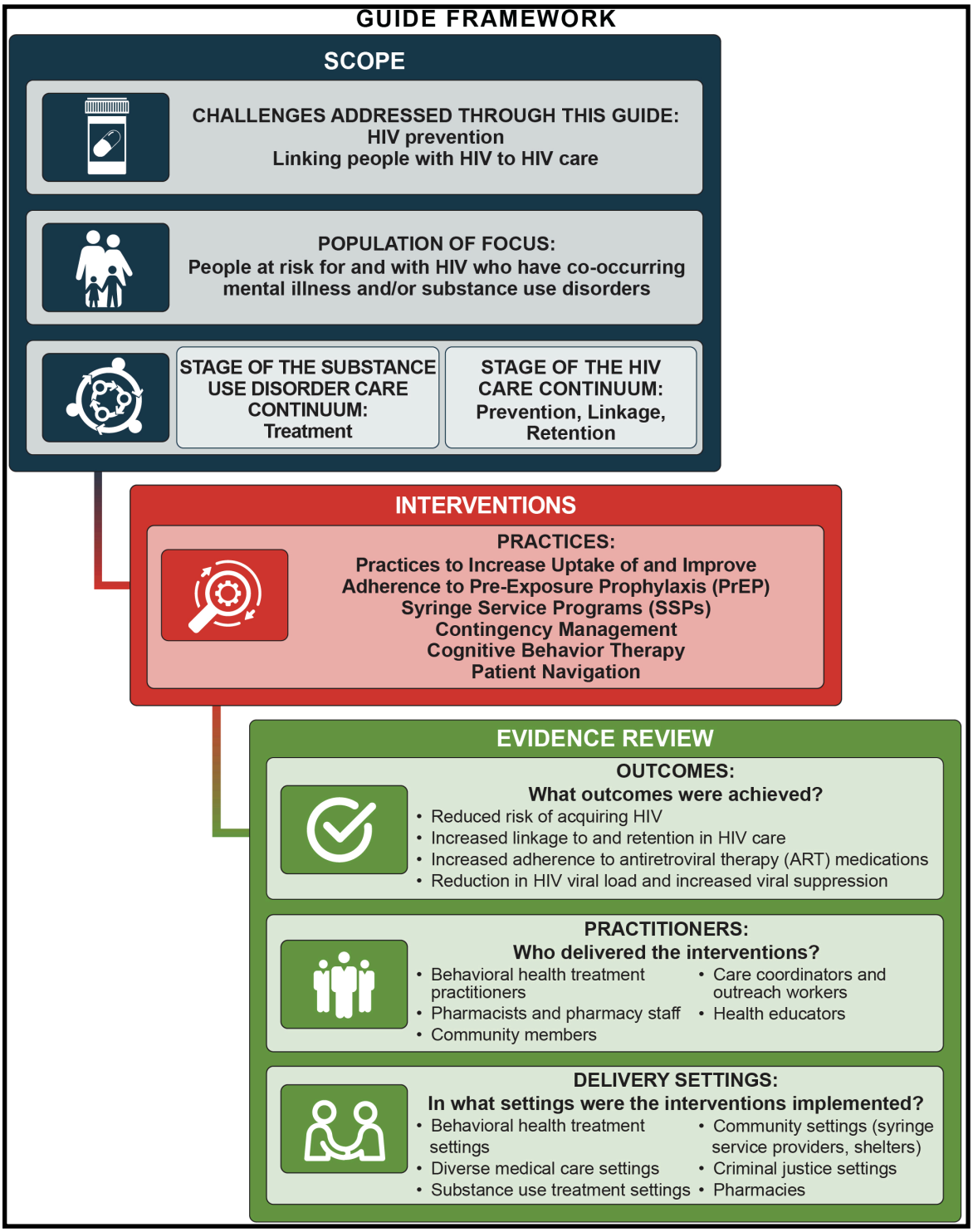
As the world grapples with a new deadly global pandemic, the leadership, resources and infrastructure of the response to the HIV pandemic have been mobilized. Veterans of national HIV responses have emerged as COVID-19 response coordinators in dozens of countries. International HIV partnerships are helping to convene the world's best epidemiologists, scientists and medical professionals to collect data, develop treatments and vaccines, and provide financing and supplies to the countries and communities that need them most. The expertise, analytical capacity, and surveillance and monitoring systems developed through HIV funding are also bolstering COVID-19 responses. For instance, laboratory systems that have been vastly expanded and improved as a result of HIV and tuberculosis investments are being mobilized for COVID-19 testing.

Activists and community organizations that are central features of the HIV response are leading efforts to ensure that COVID-19 responses are rights-based and gender-sensitive, and that they do not prejudice marginalized communities, such as LGBTI people. Communities are also stepping forward to lead local COVID-19 responses, challenging misinformation and stigmatization, delivering essential supplies to the vulnerable and organizing local support systems. Efforts to maintain health services during COVID-19 lockdowns have underscored the value of community-led services that are grounded in lived realities and responsive to the needs, priorities and rights of most-affected populations. While the successes of the HIV response are vital contributions to the COVID-19 response, our collective failure to achieve the 2020 targets has exposed systemic weaknesses and entrenched inequalities, raising questions about what might have been. What if the UNAIDS Fast-Track Strategy had been fully implemented? What if global pandemic response capacities had been stronger? We cannot re-write the past. But as more and more people refuse to accept the inequalities of that past, the international community can seize this moment, imagine a better future and re-energize efforts to achieve global health, sustainable development and the end of the AIDS epidemic.

3. Prevention and Treatment of HIV Among People Living with Substance Use and/or Mental Disorders

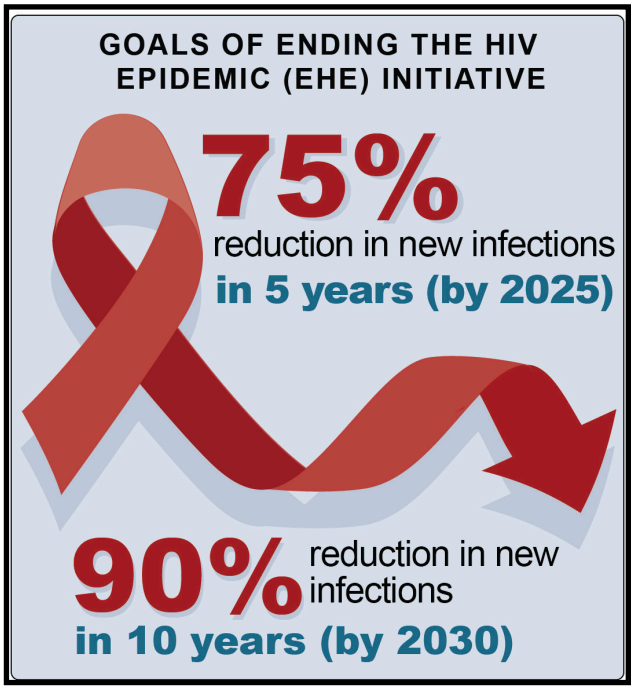
The framework below provides an overview of this section. The guide addresses the prevention and treatment of HIV among people with mental illness and/or SUD, and focuses on prevention and treatment practices that have been evaluated

with adults. The review of these programs and practices includes specific outcomes, practitioner types, and delivery settings.



First detected in 1981,1 human immunodeficiency virus (HIV) is a retrovirus that infects a type of white blood cells called CD4+ T-cells and puts people at increased risk for other infections. If left untreated, HIV can lead to acquired immunodeficiency syndrome (AIDS), which was once a fatal infection.

While there is no cure for HIV, it can be effectively managed as a chronic illness with antiretroviral therapy (ART), and prevented through harm reduction strategies (e.g., condoms and syringe services programs) and medical interventions (e.g., pre-exposure prophylaxis [PrEP] and post-exposure prophylaxis [PEP]).



Substantial progress has been made in preventing HIV and supporting people with HIV, however, there is still room for improvement in addressing linkage to treatment, ART initiation and adherence, and viral suppression, as well as engagement and retention along the HIV care continuum.

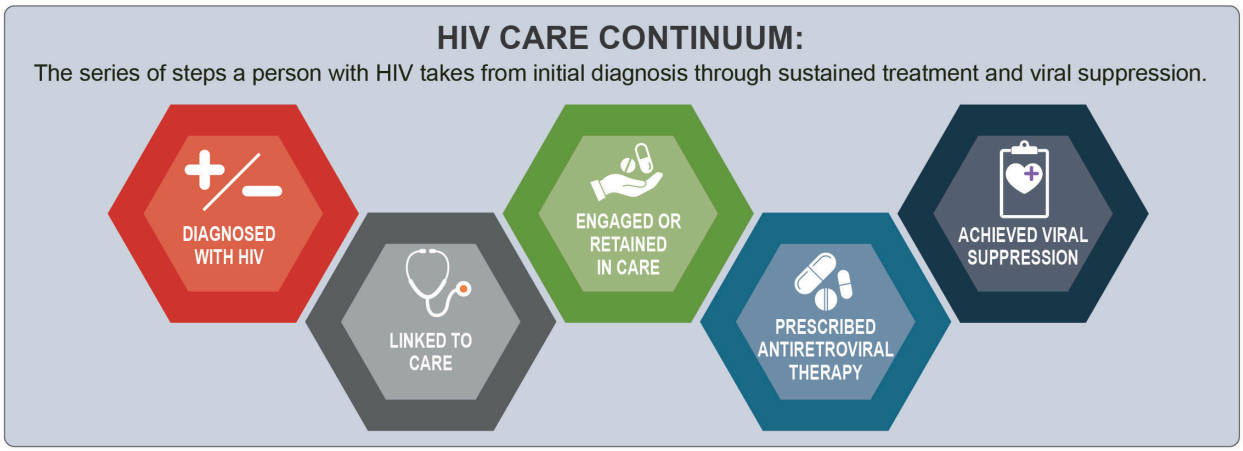
Challenges with client engagement across the HIV care continuum hinder the effectiveness of prevention and treatment efforts. These challenges increase the likelihood of HIV transmission and negative health outcomes for people with HIV.

Established in 2019, the federal initiative “Ending the HIV Epidemic: A Plan for America” (EHE)4 capitalizes on scientific discoveries and increased public awareness to prevent and treat HIV. As of 2020, there are 1 million people with HIV in the United States, and an estimated 38,000 new infections occur each year.5 The goal of the EHE initiative is to reduce new infections by 75 percent by 2025 and by 90 percent by 2030.

The success of the EHE initiative relies on identifying pathways to increase access to HIV prevention and treatment for those with complex needs.

HIV Testing

In the United States, about 1 in 7 (14 percent) of the estimated 1 million people with HIV do not know they have the disease. Testing identifies a person's HIV status and helps to link those who are newly diagnosed with HIV to care. Testing also helps to prevent HIV transmission and new infections. Individuals who are undiagnosed or unaware of their HIV infection account for an estimated 30 to 40 percent of ongoing HIV transmissions. The U.S. Preventive Services Task Force recommends that clinicians conduct screening for HIV infection among individuals aged 15 to 65, younger adolescents and older adults at increased risk, and all pregnant women, giving the recommendation an "A" rating, requiring HIV testing be provided free by health insurance companies.



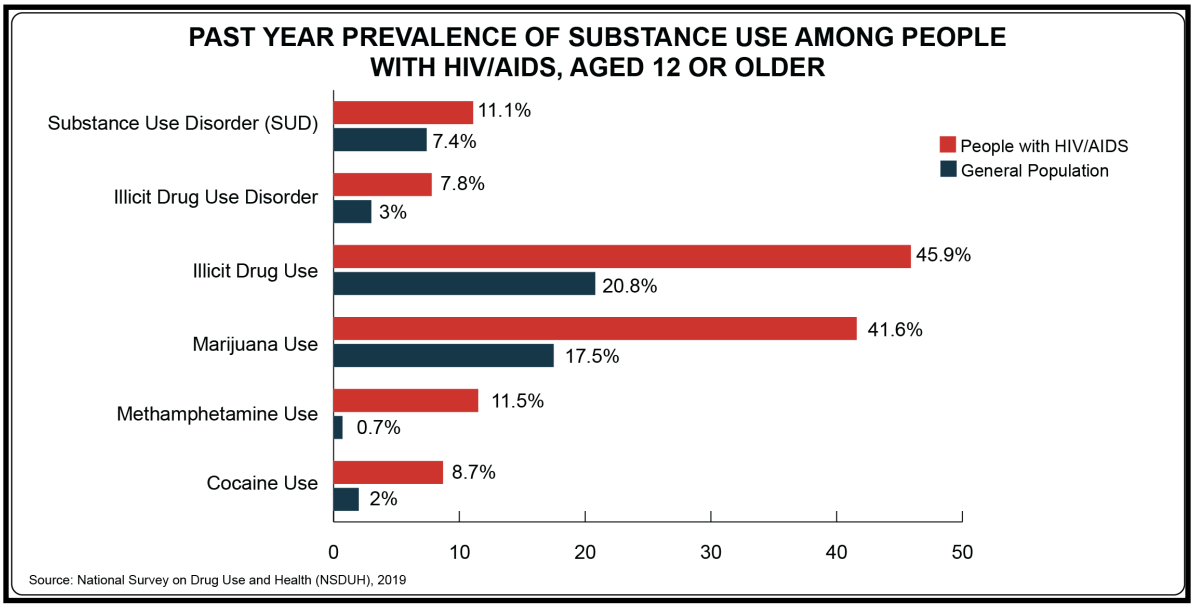
The EHE initiative recommends the following steps to increase the number of undiagnosed people with HIV who receive an HIV test, are diagnosed, and receive treatment: 1) make HIV testing simple, accessible, and routine in healthcare and non-healthcare settings using innovative technology, systems, and programs; and 2) conduct focused work to increase annual testing among people who are at substantial risk for HIV. HIV testing can be conducted in a range of clinical settings or at home (through rapid or mail-in self-tests).

Behavioral health providers play an essential role in providing integrated HIV, viral hepatitis, mental health, and substance use screenings within the clinic setting. In a 2019 "Dear Colleague Letter," SAMHSA called on mental health and substance use providers to increase on-site, same-day oral fluid HIV testing efforts and include HIV testing as part of the standard of care. Oral fluid testing can be self-administered and provides results within 20 minutes. Settings that provide screening for many common co-occurring illnesses often include testing for viral hepatitis to address both hepatitis prevention and potentially serious co-occurring HIV and viral hepatitis infections.

People with any mental illness diagnoses or symptoms were more likely to report being tested for HIV than those without mental illness diagnoses or symptoms.

Substance Use and HIV

SUD can increase the risk of getting HIV and negatively impact HIV care, treatment, and related health outcomes. The prevalence of substance use among people with HIV is also higher than among the general population (as shown in the chart below). People who inject drugs (PWID) are at increased risk for blood borne pathogens, such as HIV and hepatitis B and C. In 2017, 9 percent (or 3,641) of the 38,739 new HIV diagnoses in the United States and its territories were among PWID. Of that population, 2,625 were male and 1,016 were female. Six percent (or 2,389) of new HIV diagnoses in the United States were directly attributed to PWID. New HIV diagnoses are most prevalent among Whites, Blacks/African Americans, and individuals between the ages of 25 and 44.

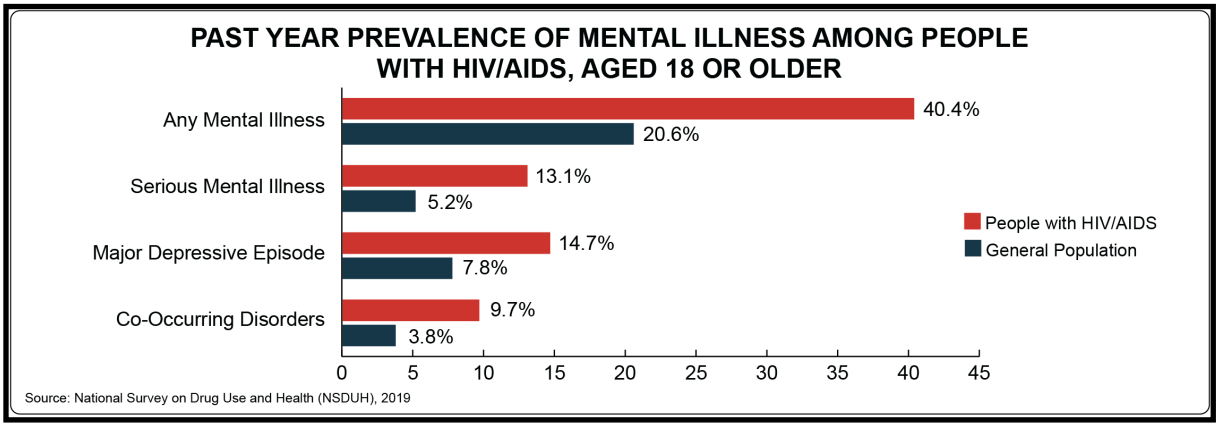


In addition, research suggests that substance use, including alcohol, methamphetamine, cocaine, opioids, and inhalants, increases sexual behaviors that are associated with increased likelihood of getting HIV (e.g., condomless sex).

Mental Health and HIV

Mental illness can interfere with HIV prevention and adherence to treatment and is linked to behaviors that increase likelihood of getting HIV. The prevalence of mental illness among people with HIV is also higher than among the general

population (as shown in the chart below). People with HIV may experience high rates of depression, mood disorders, and generalized anxiety disorder. An estimated 10 to 28 percent of people with HIV have co-occurring mental illness and/or SUD. People with HIV who also experience depression report higher rates of other co-occurring mental health concerns such as anxiety disorders (78 percent) and SUD (61 percent), as well as increased viral loads. Depression in people with HIV can also negatively affect HIV treatment, as it is associated with discontinuation of and non-adherence to ART.



In addition to depression and anxiety, trauma and post-traumatic stress disorder (PTSD) are strongly associated with HIV. Experiences of trauma among people with HIV can lead to behavior that increases likelihood of transmitting HIV, lower adherence to HIV care and ART, and higher likelihood of AIDS-related mortality. Among women in the United States with HIV, 30 percent have PTSD (five times the national rate for women). Furthermore, women from low-income, high-HIV prevalence communities experience stressors that lead to the development of PTSD, such as high rates of child maltreatment and physical, emotional, and sexual abuse.

Interrelated Factors that Impact HIV Prevention and Treatment Efforts

Understanding the complex relationship between social determinants of health, unmet needs, and HIV-related risk factors is key to addressing HIV and mental illness and/ or SUD. For example, it is difficult to engage people in HIV prevention or treatment programs when their basic ancillary needs (e.g., housing, child care, transportation, food, employment, health insurance) are not met. In urban, high-poverty areas, higher HIV prevalence tends to be associated with socioeconomic status, including educational attainment, household income, employment status, structural racism, and housing status. There are six key interrelated factors (identified below) that impact HIV prevention and treatment efforts addressed through the practices highlighted in this section.

Stigma, social marginalization, and discrimination
Stigma is a "perennial problem," contributing to poor ART adherence, higher rates of depression, and challenges related to HIV prevention (e.g., fear of disclosure impacting negotiation of condom use). Stigmatizing beliefs (e.g., that HIV can be transmitted through coughing or sneezing) contribute to a culture of social discomfort, prejudice, violence, and discriminatory actions (e.g., avoiding interactions with a person they know has HIV). Stigma and mistrust of medical systems may deter individuals from seeking care and from sharing with their healthcare providers details about behaviors that increase risk of getting HIV (e.g., injection drug use, condomless sex) and existing medical conditions (e.g., mental illness, SUD, HIV status, testing, and medication adherence).

Access to appropriate, tailored, and skilled care
Mental illness and SUD are conditions that present barriers to accessing and linking to HIV care, as well as initiating and adhering to medication (ART, PrEP, and PEP). Access to treatment is key to reaching viral suppression. Individuals may experience challenges in finding providers that have expertise in HIV, mental health, and SUD. Mental illness and SUD treatment providers are well positioned to address some of the social determinants of health and unmet needs, but they may need additional training to address co-occurring HIV.

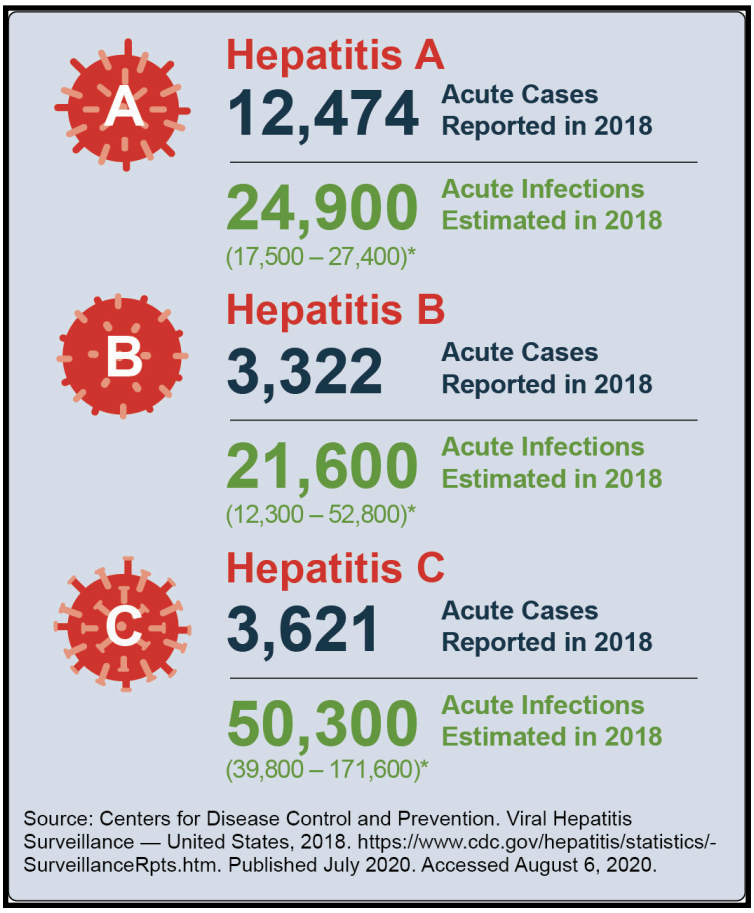
Care coordination
Untreated or undertreated mental illness and/or SUD can create obstacles to initiating and continuing PrEP and ART, increasing the potential for HIV transmission. Integrated testing (as previously described) and service delivery (e.g., multi-disciplinary teams and one-stop-shop models that provide co-located or coordinated substance use, mental health, medical, and social services are successful strategies for engaging and retaining in care people with or at risk for HIV who may have multiple co-occurring health and ancillary service needs. Coordinated care, linkage to HIV care, and patient follow-up and monitoring within behavioral health settings are also key to facilitating HIV prevention and treatment.

Medical co-morbidities
People with HIV have been shown to be at higher risk for cardiovascular disease, hepatic and renal disease, osteoporosis and fractures, metabolic disorders, skin and soft-tissue disorders, pulmonary disorders, central nervous system disorders, and various forms of cancer. Cognitive difficulties can be caused by the impact of HIV on the brain (i.e., HIV-associated neurocognitive disorder). Possible side effects

and interactions from pharmacological therapy, including ART and medication for opioid use disorder, may further complicate health outcomes.

Viral hepatitis

People with HIV are disproportionately affected by viral hepatitis (hepatitis A virus [HAV], hepatitis B virus [HBV], and hepatitis C virus [HCV]). Of those with co-occurring HIV and viral hepatitis, about one third have both HBV and HCV. HBV and HCV are bloodborne pathogens, which can be spread through needle sharing associated with injection-drug use. Nearly 75 percent of people with HIV who inject drugs also are infected with HCV. Both HBV and HCV are also associated with sexual behaviors that increase risk of HIV (e.g., condomless sex). About half of people who have HCV do not display symptoms, so it is important that regular testing is done. Co-occurring HIV and viral hepatitis present challenges in managing and treating HIV infection. Hepatitis A, B, and C are all associated with liver inflammation and liver damage. When the liver is inflamed, it is less able to process medications including anti-retroviral medications, which can cause worsened side effects of HIV medicine. People with HIV who contract viral hepatitis are more likely to experience a faster progression of liver-related injury than people who do not have HIV. Medications to treat hepatitis are similar to HIV in that they are anti-retroviral. However, some medications that treat HIV and HCV are not safe to use together, so it is important that people with HIV and HCV regularly consult with a doctor.



Incarceration

While the extent of HIV transmission within jails and prisons is not fully understood, the risk of HIV is heightened for incarcerated populations compared to non-incarcerated populations, namely due to high rates of HIV in prisons, inconsistent screening for HIV upon entry and release, condomless sex, injection drug use equipment sharing, and the labeling of condoms as contraband within prisons. Release from incarceration is widely considered an especially vulnerable period for both opioid overdose and discontinuation of HIV care and ART treatment provided during incarceration. The interruption in care can lead to reductions in treatment adherence and increases in viral loads.

HIV among people living with mental illness and SUDs

This section presents five practices that healthcare practitioners can use to prevent and treat human immunodeficiency virus (HIV) among people living with mental illness and/or substance use disorders (SUD) including:

- ✳ Practices to increase uptake of and improve adherence to Pre-Exposure Prophylaxis (PrEP)
- ✳ Syringe Services Programs (SSPs)
- ✳ Contingency Management (CM)
- ✳ Cognitive Behavioral Therapy (CBT)
- ✳ Patient Navigation

Although selected practices are non-pharmacological, some are focused on improving uptake and adherence to medications. Each practice is described and given a rating to assist practitioners, clinic administrators, and policy makers in identifying ones that might serve their population of focus. This chapter also provides an overview of each practice, including a discussion of the typical implementation settings, populations that benefit from the practices, intensity of services, and practice outcomes.

Practice Selection

To be considered for inclusion in this guide, eligible practices had to meet the following criteria:

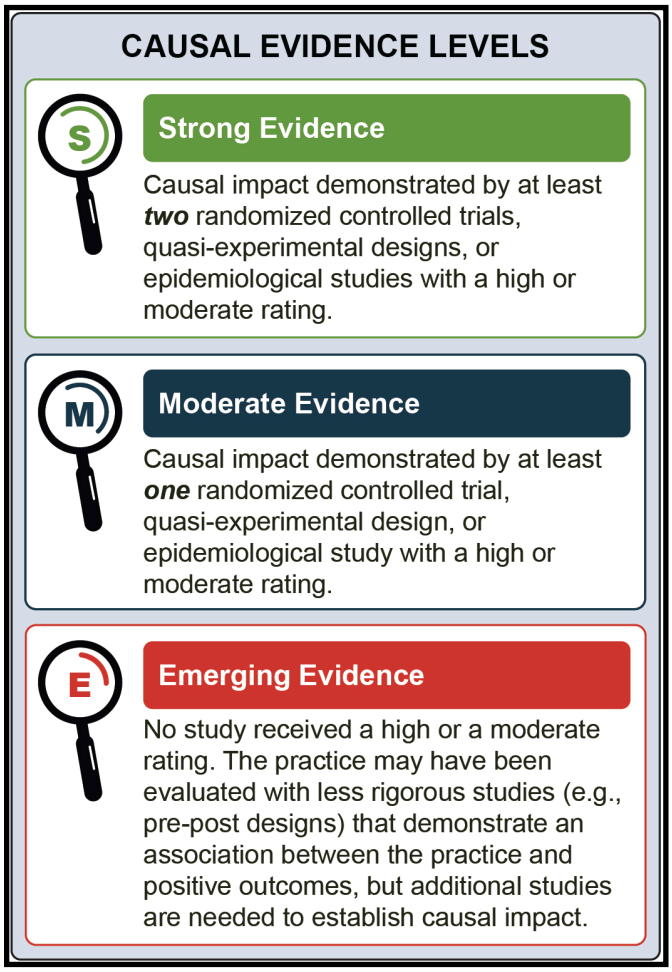
- ✓ Must be clearly defined and replicable
- ✓ Impact HIV prevention and treatment–related health outcomes among people with mental illness and/or SUD
- ✓ Are currently in use
- ✓ Have accessible technical assistance and support for implementation

Evidence Review and Rating

Authors completed a comprehensive review of published research for each selected practice to determine its strength as an evidence–based practice. Eligible research studies had to be published after the year 2000 and:

- ✓ Employ a randomized or quasi-experimental design, or
- ✓ Be a single sample pre-post design or an epidemiological study with a strong counterfactual (i.e., a study that analyzes what would have happened in the absence of the intervention).

Descriptive and implementation studies and meta-analyses were not included in the review, but were documented to provide context and identify implementation supports for the practices. Authors included systematic reviews when assessing SSPs, as an evidence base for SSPs was established pre-2000.*



Each eligible study was reviewed for evidence of measurable change in HIV and mental illness and/ or SUD-related health outcomes. In addition, trained reviewers checked each study to ensure rigorous methodology, asking questions such as:

1) Are experimental and comparison groups demographically equivalent, with the only difference being that participants in the experimental group received the intervention and those in the comparison group received treatment as usual or no/minimal intervention?
2) Was baseline equivalence established between the treatment and comparison groups on outcome measures?
3) Were missing data addressed appropriately?
4) Were outcome measures reliable, valid, and collected consistently from all participants?

Using these criteria, each study's causal impact was assessed and given a rating of low, moderate, or high. Only randomized controlled trials, quasi-experimental designs, and epidemiological studies with a strong comparison were eligible to receive a high or moderate rating.

After all studies for a practice were assessed and rated, each practice was placed into one of three categories based on its causal evidence:

- ✓ SSPs, CM, CBT, and Patient Navigation have strong evidence.
- ✓ Practices to Increase Uptake and Improve Adherence to PrEP have an emerging evidence base.

Identification of Practices Associated with HIV Prevention and Treatment

Practices to Increase Uptake of and Improve Adherence to PrEP

Goal

PrEP is a biomedical intervention in which people at risk of getting HIV adhere to a regimen of daily oral antiretroviral medications. The Food and Drug Administration has approved two forms of PrEP medication that prevent HIV from multiplying within the body. Long-acting injectable forms of PrEP are currently being tested. Efficacy of PrEP as a biomedical intervention is established. However, evidence for interventions that aim to increase PrEP uptake and adherence among people at risk of HIV who have mental illness and/ or SUD is emerging.

The U.S. Preventive Services Task Force gave PrEP a Grade A recommendation.8 It is an effective tool for reducing HIV transmission, including among populations behaviorally vulnerable to HIV, such as people who inject drugs (PWID) and people who may be exposed to HIV through sexual contact. PrEP is approximately 99 percent effective at preventing HIV when taken consistently and adhering to prescription guidelines. PrEP is recommended for people who have had an increased risk of getting HIV in the past 6 months, and the risks/benefits of uptake and continuing should be an ongoing discussion between the client and provider.

While the efficacy of PrEP as a biomedical intervention is clear, people may face significant barriers to starting and adhering to PrEP, posing obstacles to reaching

the goals of the Ending the HIV Epidemic (EHE) initiative. Barriers include, but are not limited to, the following:

- ➡ Stigma (both of HIV and of taking PrEP)
- ➡ Low awareness of the existence of PrEP among eligible PrEP users
- ➡ Low perception of risk of getting HIV
- ➡ Concern about possible side effects
- ➡ Lack of social support
- ➡ Perceived and actual cost
- ➡ Difficulty following the daily regimen
- ➡ Health insurance coverage, or health insurance that does not cover laboratory and clinical visits
- ➡ Limited access to care (e.g., transportation, hours of services)
- ➡ Mental illness and/or SUD may compound these barriers.

Since the effectiveness of PrEP as a biomedical intervention has been established, this evidence review examines psychosocial supports to increase uptake and adherence to PrEP. These psychosocial interventions include the following:

- ➡ *PrEP Mate:* A bidirectional text-messaging program, grounded in the information, motivation, and behavioral (IMB) theory of behavior change, involving daily text reminders to take PrEP and weekly text check-ins.
- ➡ *Bio-Behavioral Community Health Recovery Program (CHRP-BB):* A weekly group therapy and text-message reminder intervention encouraging PrEP adherence and teaching health management skills for people who are vulnerable to HIV (through injection drug use or condomless sex).
- ➡ *Pharmacy-led PrEP (P-PrEP):* An integrated care intervention in which an in-clinic pharmacist consults with the client and prescribes PrEP the same day that the client tests negative for HIV.

Outcomes Associated with Practices to Increase Uptake and Improve Adherence to PrEP

- ➡ Increased PrEP uptake, sustained for up to 9 months.
- ➡ Increased PrEP adherence, sustained for up to 12 months.

Typical Settings

Practitioners can implement practices designed to increase PrEP uptake and adherence in diverse mental illness, SUD, and HIV treatment settings, including the following:

- ✓ Safety net health clinics focused on HIV prevention and treatment
- ✓ Mobile application that extends the reach of PrEP support
- ✓ Methadone maintenance clinics

- ✓ Non-clinical testing centers; pharmacies; community health centers

Demographic Groups

Several categories of people can benefit from practices designed to increase PrEP uptake and adherence, including:

- ✓ Young men (mean age of 24) who have sex with men (MSM)
- ✓ Individuals who reported recreational drug use
- ✓ Individuals who reported binge drinking over the past 3 months
- ✓ PWID19
- ✓ People who test negative for HIV
- ✓ PrEP should not be prescribed to people with HIV (as it is an inappropriate medical intervention for HIV) and/or people with severe renal insufficiency.

Practitioner Types

A diverse range of behavioral health practitioners and clinical providers can implement practices to increase PrEP uptake and adherence, including:

- ✳ Clinic and research staff
- ✳ Graduate-level trained facilitators
- ✳ Pharmacists

Intensity and Duration

While PrEP can be taken indefinitely, intensity and duration of individual practices to support PrEP uptake and adherence vary depending on the intervention.

- PrEPMate includes daily text reminders to take PrEP and weekly check-in texts about PrEP adherence, side effects, and attitudes around PrEP sent from clinicians
- CHRP-BB includes four 50-minute weekly group meetings that address behaviors related to increased risk of getting HIV and increased PrEP adherence and daily text reminders to take PrEP
- P-PrEP includes same-day PrEP referral by a pharmacist and follow-up appointment with a clinician within 6 weeks

Contingency Management (CM)

Goal

CM is a behavioral therapy that uses motivational incentives and tangible reinforcers to increase desirable behavior. People in CM programs are given reinforcers—often vouchers that can be exchanged for money or goods, or chances to win prizes—when they consistently demonstrate positive behavior (e.g., negative urine drug screens, showing up for an appointment).

Many state Medicaid, Medicare, and private insurance entities may not reimburse for CM reinforcers. Additionally, the Department of Health and Human Services' (HHS) Office of the Inspector General (OIG) has ruled that the Centers for Medicare and Medicaid Services (CMS) may not provide more than $75 annually (or $15 per individual appointment) in goods to beneficiaries, limiting CM enforcers to that amount. Medicaid, Medicare, and private insurance agencies may reimburse for CM as a service, but any value of payment for the reinforcers is prohibited. Therefore, CM implementation requires careful coordination with HHS, the state health department, and other insurance providers. Providers wishing to implement CM may identify other funding for reinforcers (up to $75 per beneficiary annually), including federal, state, and private grants, as well as contributions from or opportunities to share costs with community partners.

Practitioners can implement CM along with individual or group counseling or in conjunction with scheduled medical visits, including urine drug screens, daily methadone dosing, or HIV-related appointments.

Outcomes Associated with CM

CM is an effective psychosocial intervention for reducing substance use and maintaining substance use abstinence for periods of up to 1 year. In 2006, researchers began testing CM principles in the prevention and treatment of HIV. Behavior change takes time, and while CM has been shown to be effective for periods up to one year, it is important to note that these may be temporary changes for life-long disorders. HIV prevention and treatment outcomes attributed to CM are outlined below:

✓ Reduction in self-reported sexual behaviors that increase risk for HIV over the previous month (i.e., number of sexual partners, condomless sex, sex for money or nonmonetary items, and anal sex) sustained for up to 12 months.

- ✓ Reduction in self-reported drug-use behaviors that increase likelihood for getting HIV over the previous month, (i.e., injection drug use, receptive syringe sharing, syringe lending, and using injection drug use equipment that has not been cleaned or sterilized) sustained for up to 12 months
- ✓ Reduction in viral load, sustained for up to 6 months.
- ✓ Increase in adherence to antiretroviral therapy (ART), sustained for up to 4 months

Typical Settings

Practitioners can use CM across a variety of outpatient and inpatient settings and across urban, suburban, and rural settings, including:

- ✓ Outpatient treatment clinics
- ✓ SUD treatment settings (e.g., methadone clinics)
- ✓ Counseling centers
- ✓ HIV-focused drop-in centers

Practitioner Types

CM can be implemented by a variety of practitioners, including:

- ✓ Counselors
- ✓ Post-doctoral fellows in psychology (who are provided with supervision from licensed psychologists)
- ✓ Clinic staff with education levels ranging from no bachelor's degree to master's degree in social work

Formal CM-specific training is not required, but training or coursework in behavioral analysis is available to support implementation of this practice.

Intensity and Duration

CM does not require a prescribed number of sessions or specified length of individual sessions, and has demonstrated efficacy when implemented in the following settings for the following durations:

- ➡ An intensive outpatient setting with daily counseling over 6 weeks
- ➡ A methadone clinic with daily methadone dosing and weekly individual and group counseling over 12 weeks
- ➡ A counseling center with individual counseling over 16 weeks
- ➡ A counseling center with weekly group counseling sessions over 24 weeks

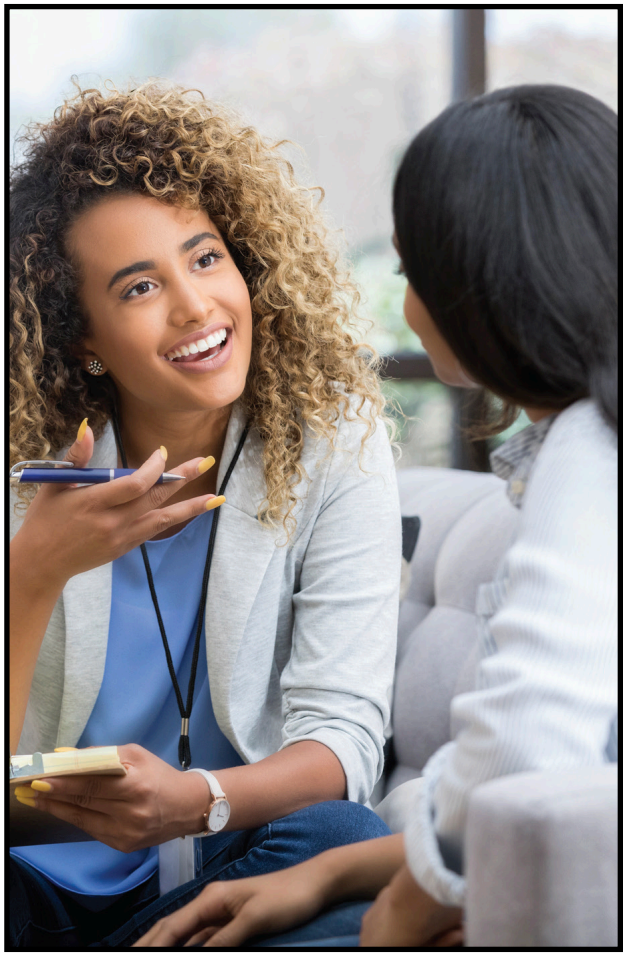
CM can also act as a "buy-in" for other behavioral interventions associated with longer-term benefits. For example, when combined with counseling, it may increase attendance at sessions, which in turn can have long-term therapeutic benefits.

Cognitive Behavioral Therapy (CBT)

Strong Evidence

Goal

Providers in mental health settings are uniquely positioned to prevent HIV and support linkage and retention in HIV care and ART adherence for people with HIV. Through individual and group counseling such as CBT, providers can build "reciprocal, robust, and trusting relationships" by having consistent and confidential interactions with clients over time.



CBT is a form of psychotherapy that seeks to modify problematic thinking, beliefs, or behavior through skill-building. CBT programs share three core principles. They are:

1) Goal-oriented
2) Time-limited
3) Structured

CBT helps individuals identify specific problems and gain the skills to manage and solve them. All studies included in this evidence review employed the core components of CBT (basing individual and group work on thoughts, feelings, emotions, and skill-building). This evidence review includes specific applications of CBT for mental health clinicians to use with clients living with mental illness and/or SUD with and at risk for HIV, detailed below:

Typical Settings

Practitioners can incorporate CBT in mental illness and/or SUD and social service settings including:

✓ Academic medical centers

- ✓ Outpatient treatment centers
- ✓ Methadone clinics
- ✓ Homeless shelters
- ✓ Community health clinics

Cognitive Behavioral Skill Building Intervention (E-CB)

E-CB facilitates HIV prevention through structured sessions on the following topics:

- HIV education, including personalizing risk of getting HIV, condom use and negotiation skills and identifying situations with increased risk of getting HIV
- developing and practicing problem solving, assertiveness, and communication training approaches.[57]

Cognitive Behavioral Therapy for Trauma and Self Care (Project Thrive)

Project Thrive addresses posttraumatic stress responses in MSM with histories of childhood sexual abuse who are at increased risk for HIV. This individual therapy model integrates counseling for sexual health with cognitive and behavioral strategies as a feasible and acceptable treatment among MSM to effectively reduce sexual risk for HIV and decrease post-traumatic stress disorder (PTSD) symptom severity.[58-59]

Behavioral Activation for Methamphetamine Dependence (Project IMPACT)

Project IMPACT is an individual therapy intervention that aims to reduce crystal methamphetamine use and condomless sex among MSM. This integrated treatment consists of behavioral activation, an evidence-based approach for depression that involves identifying and participating in pleasurable, goal-directed activities, and CBT with HIV sexual risk counseling.[60]

Cognitive Behavioral Therapy for Social Anxiety and Sexual Health (Sexual Confidence)

Sexual Confidence adapts the CBT framework for social anxiety to include substance use management in interpersonal situations and reducing sexual behaviors that increase likelihood of getting HIV through sessions on the following:

- setting goals related to reducing risk of getting HIV and reducing social anxiety
- the role of social anxiety and substance use in increasing risk of getting HIV
- discussing and practicing coping skills for anxiety reduction[61-62]

Cognitive Behavioral Therapy for HIV Medication Adherence and Depression (CBT-AD)

CBT-AD integrates continued adherence counseling with traditional CBT techniques for the treatment of depression. CBT-AD uses proactive problem solving, action planning, and motivational interviewing to:

- facilitate behavior change[63]
- address the cognitive and behavioral patterns commonly experienced by adults with co-occurring depression and HIV[64]
- improve ART adherence[63]

Outcomes Associated with CBT

- Reduced sexual behaviors that increase likelihood of getting HIV, including improved attitudes towards condom use and greater condom use skills, sustained for up to 6 months[57,62, 65-68]
- Reduced PTSD and depression symptom severity for up to 9 months[58, 60]
- Reduction in crystal methamphetamine use for up to 6 months[68]
- Increased perceived susceptibility to getting HIV, defined as perceptions of personal vulnerability to HIV disease, sustained for up to 6 months[57]

- Reduction in viral load, sustained for up to 12 months[57]
- Increase in adherence to ART, sustained for up to 15 months[63, 69-70]

Practitioner Types

CBT can be implemented effectively by a variety of professionals including:

- ✓ Clinical psychologists
- ✓ Master's level psychologists, social workers, and counselors
- ✓ Case managers
- ✓ Facilitators with an average of 10 years of experience leading group-based HIV prevention interventions with people who use drugs

Practitioners do not need to be certified to practice CBT, but certifications are available.

Intensity and Duration

CBT generally provides the tools for behavior change in 8 to 12 individual or group sessions, meeting once or twice weekly, with each session lasting between 60 and 90 minutes. The length of treatment also varies depending on the individual's symptoms, resources, and preference. As highlighted below, studies included in this evidence review varied by time and number of sessions.

Patient Navigation

Goal

Patient navigation is a client-centered approach aimed at improving care engagement by addressing client and system barriers, and helps clients access medical and support services in an often complex healthcare system. Originally developed as a strategy to improve timely access to cancer screening, diagnosis, and treatment, patient navigation has been used to improve the health outcomes of multiple medical conditions, including HIV. During individual sessions, navigators work with participants to facilitate access to care, review health information, overcome personal or logistical challenges, and provide psychosocial support by promoting self-efficacy and problem-solving behaviors. In addition to the sessions, navigators accompany participants to HIV care and SUD treatment appointments. In the context of the HIV-care continuum, patient navigation services typically focus on linkage to and retention in care, improving HIV treatment outcomes, client satisfaction, and client self-management.

Outcomes Associated with Patient Navigation

- ✓ Viral suppression, sustained up to 12 months
- ✓ Linkage to HIV care, with the greatest probability of linkage occurring within 6 months
- ✓ Retention in HIV care, sustained up to 12 months
- ✓ Adherence to ART medications, sustained up to 12 months

Typical Settings

Practitioners can provide patient navigation services in a wide range of treatment settings including:

- ➡ Correctional and criminal justice settings
- ➡ Mental illness and/or SUD treatment programs
- ➡ Primary health and HIV-specific care clinics
- ➡ Hospitals

4. Guidance for Selecting and Implementing Evidence-based Practices

This section discusses key implementation considerations to address the challenges of implementing programs for human immunodeficiency virus (HIV) prevention and treatment among people with mental illness and/ or substance use disorders (SUD). It covers steps from practice selection and program funding through engaging and retaining people in care.

Prior to implementing practices identified in the previous section, each program or clinic should conduct a needs assessment to understand the following factors:

- ➡ Client population (e.g., the population of focus, their unique HIV-related risk factors,1 cultures, challenges, and assets)
- ➡ Existing protocols and procedures that could facilitate or become barriers to implementation (e.g., intake procedures)
- ➡ Local factors that could impact service delivery (e.g., partnerships with community-based organizations and service providers, geography, transportation, and socio-political climate)
- ➡ Program or organizational strengths, resources, and areas for development (e.g., organizational leaders and program champions, budget, available health

insurance reimbursement to support planned activities, staffing and infrastructure, and information management support)
- ➡ Training opportunities (program-specific and ongoing professional development)

Based on the needs assessment, practitioners can work with their clinical teams, administrators, leaders, and community members and partners to take the following steps to identify practices that are appropriate and feasible given available resources and local characteristics:
- ➡ Identify prevention and treatment priorities
- ➡ Identify desired short- and long-term outcomes
- ➡ Map resources (e.g., housing, employment, transportation, legal services) available within the local area to effectively connect clients with needed services
- ➡ Develop a logic model (a graphic depiction of the relationship between a program's activities and their intended outcomes)

Implementation Challenges and Strategies

This chapter includes strategies to promote implementation and appropriate adaptation of practices to the population of focus, as well as specific implementation tools for the programs and practices described in Chapters 2 and 4. Key considerations described in this chapter include:
- ✓ Adapting and tailoring the practice to meet the needs of the client population
- ✓ Care coordination
- ✓ Workforce capacity and development
- ✓ Access to services
- ✓ Financing

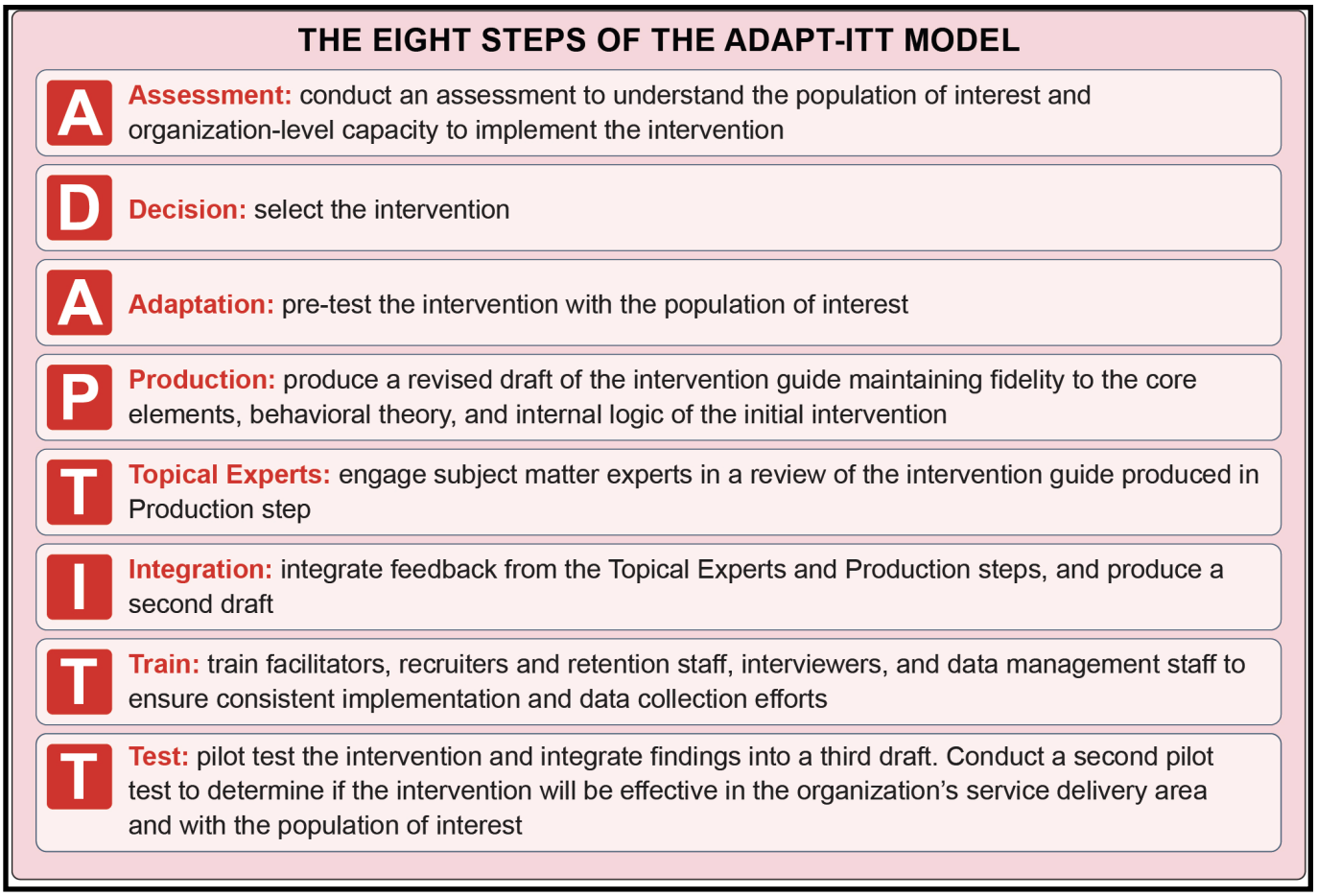
Challenge

Practices implemented without adaptation may not be relevant to or acceptable for the client population.5 Practices should be culturally relevant, available in the appropriate language, and produced at the appropriate reading level.

Strategies

Clinicians, program administrators and clinic leadership can:

- ✓ Identify and consistently implement key characteristics (or core components) of each practice to generate anticipated outcomes. Outside of the core components, organizations can use their needs assessment to identify local-level adaptations that will improve service delivery to their client population.
- ✓ When adapting a program, organizations should strive to preserve the setting (e.g., outpatient clinic, mobile health unit), maintain the prescribed dosage, and, if necessary, add rather than remove content.
- ✓ Use a systematic process, such as the ADAPT-ITT model, to balance local program adaptation needs and adherence to the instructions provided in the original model.
- ✓ Engage existing and potential clients in project planning, practice selection, and materials development. Members of the client community will have insight into ways to make programs culturally appropriate, reflecting a community's preferred language, attitudes, beliefs, values, and experiences.



- ✓ Assess and address staff and client health literacy, and ensure materials meet federal plain language and National Standards for Culturally and Linguistically Appropriate Services guidelines.
- ✓ Adapt and tailor client care plans and individualize case management approaches to meet the unique needs of the client. Effective case management is a client-driven process where the case manager and client collaborate on a care plan, including specific goals for prevention or treatment, and then continue to communicate to ensure the client is able to reach their goals

Challenge

People at risk for or with HIV who also have co-occurring mental illness and/or SUD experience complex medical comorbidities. Fragmented behavioral health and HIV primary care services make it difficult for practitioners to communicate with each other and their clients, potentially leading to poor HIV and mental illness and/or SUD outcomes.16

Moreover, fragmented care systems place a burden on the clients as they become the ones responsible for communicating sometimes complex health information among practitioners. Ancillary needs (e.g., housing, childcare, transportation, food insecurity, employment), which are critical to clients seeking or engaging in care, may also be difficult to address in a fragmented system.17-20

Strategies

Effectively addressing these interrelated conditions takes a coordinated approach21 between mental illness and/ or SUD and HIV care providers, and other agencies and stakeholders that are well-positioned to address the social determinants of health. Coordinated models may feature screening for mental illness and/or SUD using validated tools; team-based care, including both physician and non-physician staff; shared IT and electronic medical record systems to facilitate communication within care teams; and systematic measurement and review of patient outcomes.

When HIV clinics screen for mental illness and SUD and are able to provide coordinated care to address mental illness, SUD, and HIV, clients are more likely to reach viral suppression than their counterparts visiting HIV primary care services without coordinated mental health and substance use services.32

Collaborative Care involves increased collaboration between behavioral healthcare management, mental health, and primary care providers. This model includes taking a team-based, client-centered, collaborative approach to elements of client care, such as client registries, client education, screening or assessment tools, adherence monitoring, and evidence-based treatment guidelines.

Integrated Care involves merging primary health care, mental illness and/or SUD screening and treatment, additional medical services (e.g., hepatology, dermatology), and social services (e.g., housing, employment) into one treatment plan. These linkages improve client outcomes by combining efforts such as referrals, case planning, and resources.

The two terms are not interchangeable, and exist on a continuum.For example, a system can collaborate while having separate EHR, billing, and scheduling systems. A system can also have integrated care with co-located services where practitioners collaborate and case-conference to discuss client care.

Examples of coordinated care models include patient centered medical homes, primary care case management arrangements, co-located or limited capacity primary care in behavioral health organizations, SAMHSA's Primary Care and Behavioral Health Integration model, and Certified Community Behavioral Health Clinic models.

Coordinated services help practitioners streamline service delivery to address unmet needs.

Practitioners can use the following strategies to determine the level of integration feasible and appropriate within their organization:

- ✓ Identify leaders within clinical networks and health systems who can champion integration and advocate for coordination, co-location, and integration over time. Integration takes administrative, political, and financial investments, as well as cultural change and different ways of communicating among care teams and clinics.
- ✓ Modify funding structures, billing codes, and procedures to account for new coordinated models and consultation between practitioners.
- ✓ Permit data sharing across AIDS-Service Organizations, social and health service practitioners, behavioral health specialists, and the department of corrections to increase service coordination.33 When sharing data across

organizations, review updated laws, policies, and regulations on confidentiality to maintain compliance and protect client information and obtain consent from clients for data sharing during client assessment and intake.

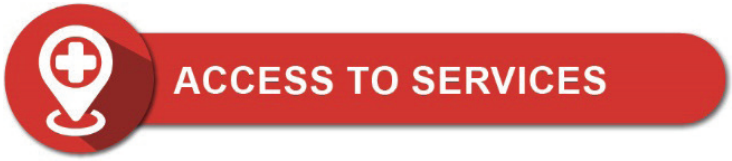
Challenge

Behavioral health treatment practitioners and their clinical teams (e.g., case managers, clinical coordinators) are well positioned to address unmet needs (e.g., transportation, housing, employment, childcare), but may need additional training to address co-occurring infectious diseases. Practitioners who deliver services aimed at preventing and treating HIV among people experiencing co-occurring mental illness and/or SUD may need training and capacity building in the following areas:

- ✓ Practice-specific training to facilitate consistent implementation
- ✓ Working with clients who have co-occurring HIV and mental illness and/or SUD
- ✓ Creating a culturally appropriate, non-judgmental, and non-stigmatizing clinical environment supportive of both clients and staff Strategies
- ✓ Provide intervention-specific training to implement the practices.
- ✓ Receiving customized, site-specific training can be resource intensive, and the provision of program-specific training and technical assistance may be dependent on grant awards. In recent years, federal funders have emphasized the need for replicable practice models that are easy to adapt, scale up, and implement in the absence of technical assistance, leading to an increase in robust training resources available online. These models include:
  - ➡ CDC's Effective Behavioral Intervention (EBIs) models
  - ➡ HRSA's Dissemination of Evidence In-formed Interventions (DEII) model
  - ➡ HRSA's Evidence-Informed Interventions (E2i) models

- ✓ Program managers and practitioners should select implementation trainings that are not overly cumbersome or time consuming.
- ✓ Provide cross-disciplinary training and institutional support to practitioners to facilitate better understanding of different disciplines and ways to promote coordinated client care.
- ✓ Promote cross-training provided by the AIDS Education and Training Centers (AETCs) on HIV-related programs, policies, and practices to both Ryan White HIV/AIDS Program (RWHAP) and behavioral health practitioners. Similarly, promote training offered by SAMHSA's Prevention, Mental Health and Addiction Technology Transfer Centers for practitioners and volunteers providing care for persons with and at risk of HIV.

- ✓ Create mechanisms for staff to work and train across HIV and behavioral health service programs.
- ✓ Identify in-house trainings (e.g., grand-rounds, in-service trainings), local trainings, online webinars, opportunities to attend conferences, and continuing education unit training opportunities to support cross-disciplinary learning.
- ✓ Prevent vicarious trauma (i.e., work-related trauma due to continuous exposure to victims of trauma and violence), burnout, and turnover by supporting manageable caseloads for staff and providing consistent clinical supervision. For example, peers and patient navigators may not have the formal clinical training their licensed mental health, substance use, and social work colleagues do, and may benefit from ongoing, structured clinical supervision.
- ✓ Provide ongoing trainings on ways to create welcoming, supportive environments for people with or at risk for HIV.
- ✓ Conduct and support staff training to enhance cultural competence and create a safe, supportive environment that improves client-staff relationships and reduces the risk of a client discontinuing treatment.
- ✓ Include sessions on non-stigmatizing language and trauma-informed practices to improve client interactions with all staff (from the front desk, to their nurse, to the billing department).



Challenge

Linkage to and retention in care requires connection between the client and the provider. However, transportation and geographic barriers can make in-person, face-to-face connections challenging. Transportation-related challenges can include having to travel long distances to clinics, inability to afford gas or fares for public transportation, and unreliable or lack of access to a personal vehicle or public transportation for travel to appointments. People with HIV in rural areas are less likely to receive HIV care or be engaged in ART as a result of limited availability of HIV-specific practitioners, provider discrimination, confidentiality concerns, and lack of financial resources. Geographic barriers can be compounded by HIV-related stigma where individuals may be reluctant to seek HIV prevention or treatment services in a small town or community for fear they may be “outed.”

Coordination of Mental Health and HIV Care in a Mental Health Setting

Each of the case examples in this chapter illustrates how organizations have implemented one or more evidence-based practices in a clinical or community setting. While none of these examples highlights a program that is primarily focused on mental health, it is critical that programs primarily serving people with mental illness assess their clients for HIV risk, conduct HIV testing, and provide appropriate and integrated HIV prevention and treatment services and mental health treatment to address their client's complex needs.3
When first working with a potential client, mental health providers can conduct an intake and/or mental health assessment using screening tools such as the brief measure for assessing generalized anxiety disorder (GAD- 7)4 or the major depressive disorder module of the Patient Health Questionnaire (PHQ-9).5 During this intake and screening, a mental health provider has an opportunity to discuss a client's overall health and wellbeing, including co-occurring medical conditions such as HIV.

If a client has not had a recent HIV test, mental health providers can supply a self-administered oral fluids test which can provide results within 20 minutes. If a client does not have HIV, a mental health provider can provide PrEP education, and support PrEP uptake and adherence (as described in Chapter 2); PrEP is highly effective in preventing HIV transmission from condomless sex and injection drug use.
If a client has HIV, a mental health provider can link a client to HIV primary care treatment, and provide the counseling necessary to support client mental health and ART uptake and adherence.

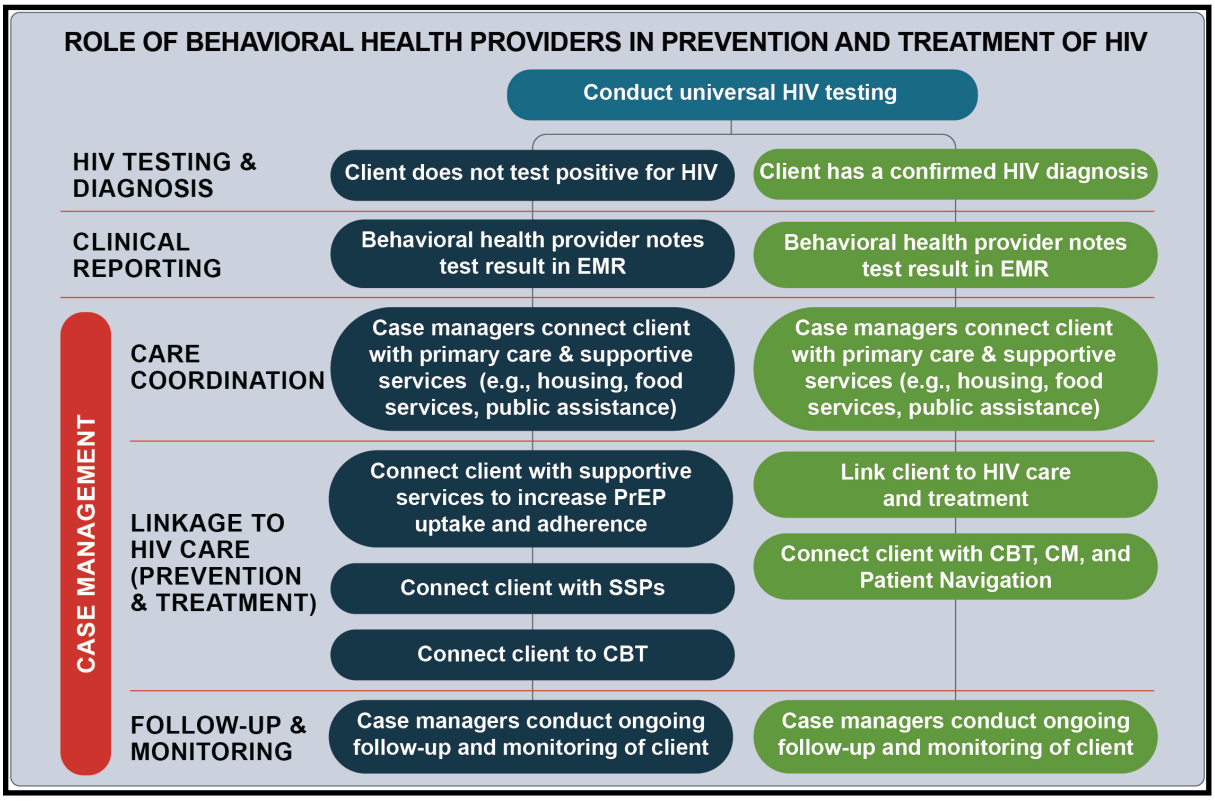
For clients at risk for or with HIV, mental health providers can also connect the client to case management to address a client's unmet ancillary needs (e.g., housing, employment, transportation), which will help reduce barriers to PrEP and ART adherence.

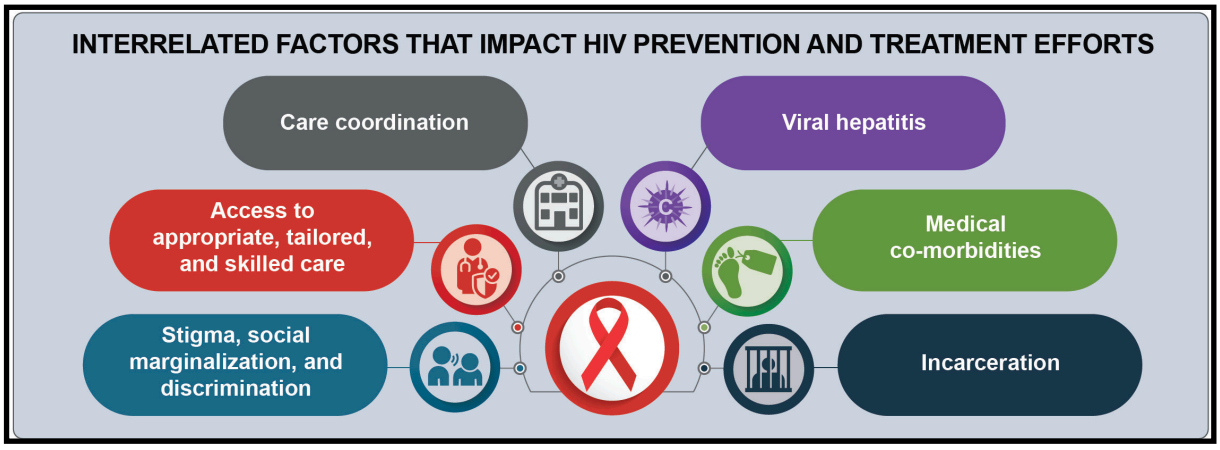
Strategies
Program administrators and practitioners can overcome these challenges by employing the following strategies:

✓ ***Telehealth*** **-** Telehealth can connect clients with specialty practitioners and provide access to services without having to travel. Telephone-based Cognitive

Behavioral Therapy (CBT), as an example, has been shown to reduce depressive symptoms and improve ART adherence among people with HIV.

- ✓ ***Transportation assistance*** - Vouchers for gas or public transportation can help eliminate worry about missing appointments due to transportation cost-related barriers. In one model, peer navigators provided transportation to appointments for the first month to give clients sufficient time to establish a long-term transportation plan. Ride share companies may also provide travel assistance. For example, Uber Health has partnered with an IT vendor, Cerner, in six states to get clients to and from their medical appointments. Lyft is also designated as a covered option for providing rides for eligible Medicaid beneficiaries.
- ✓ ***Combined healthcare visits*** - Combining HIV care and other healthcare needs (e.g., routine check-up, behavioral health services) in one visit can limit the number of times a client needs to visit their healthcare provider, especially in settings where significant travel may be needed to attend appointments. Practitioners should clarify if adequate reimbursement for these visits is available by confirming whether third party payers have the capacity to reimburse for same-day services.
- ✓ ***Mobile health programs*** - Mobile health programs have been used successfully to increase HIV screening among high-incidence populations in underserved areas. Many syringe services programs (SSPs) utilize mobile sites due to their flexibility to respond to changing client needs and ability to provide a more informal, easily accessible location for clients who are unable to travel to a fixed site.
- ✓ ***Outreach*** - Outreach activities, commonly used to link and retain people with HIV in care, can reduce barriers to accessing care. Patient navigation models specifically emphasize outreach, with navigation sessions often taking place in community settings where clients may feel more comfortable than in a clinic environment. SSPs also expand their reach through secondary or peer-delivery models. SSPs provide people who inject drugs (PWID) with sterile injection drug use equipment to distribute to their networks and to inform them of disposal options.


ROLE OF BEHAVIORAL HEALTH PROVIDERS IN PREVENTION AND TREATMENT OF HIV
Conduct universal HIV testing
HIV TESTING & DIAGNOSIS
Client does not test positive for HIV
Client has a confirmed HIV diagnosis
CLINICAL REPORTING
Behavioral health provider notes test result in EMR
Behavioral health provider notes test result in EMR
CASE MANAGEMENT
CARE COORDINATION
Case managers connect client with primary care & supportive services (e.g., housing, food services, public assistance)
Case managers connect client with primary care & supportive services (e.g., housing, food services, public assistance)
LINKAGE TO HIV CARE (PREVENTION & TREATMENT)
Connect client with supportive services to increase PrEP uptake and adherence
Connect client with SSPs
Connect client to CBT
Link client to HIV care and treatment
Connect client with CBT, CM, and Patient Navigation
FOLLOW-UP & MONITORING
Case managers conduct ongoing follow-up and monitoring of client
Case managers conduct ongoing follow-up and monitoring of client


INTERRELATED FACTORS THAT IMPACT HIV PREVENTION AND TREATMENT EFFORTS
Care coordination
Viral hepatitis
Access to appropriate, tailored, and skilled care
Medical co-morbidities
Stigma, social marginalization, and discrimination
Incarceration

Resources

Contingency Management

- Contingency Management: Using Motivational Incentives to Improve Drug Abuse Treatment provides an overview of CM principles, a case study of a program using CM, and guidance regarding how to implement and supervise CM procedures.
- The UCLA Integrated Substance Abuse Program's A Treatment Manual for Implementing Contingency Management: Using Incentives to Improve Parolee Enrollment and Attendance in Community Treatment is a guide for implementing CM for SUD treatment among parolees.
- The Behavioral Health Recovery Management project A Clinician's Guide for Implementing Contingency Management Programs provides step-by-step guidance on CM implementation.

Cognitive Behavioral Therapy

- National Association of Cognitive Behavioral Therapists CBT Onsite Training provides multiple resources for both administrators and clients, training, and certification for CBT administrators (i.e., professionals, educators, graduate students).
- Beck Academy CBT training and certification offers training and certification for CBT administrators (i.e., professionals, educators, graduate students), online and in-person training courses, newsletters, assistance with program implementation, and information on utilizing supervisors and consultants.
- The Evidence-Based Practice Institute's Intersecting Epidemics: Evidenced Based Approaches for Treating Depression and HIV/AIDS is an on-demand course (paid access), including a video recording, slides, and handouts.
- Massachusetts General Hospital offers an online CBT program led by clinical experts (through paid access) for practitioners, including live chats with faculty and interactive discussion boards.

Patient Navigation

- Texas Institute for Excellence in Mental Health Peer Specialist Training and Certification Programs: A National Overview is a compilation of information on existing peer specialist training and certification programs in the United States.
- Best Practices for Integrating Peer Navigators into HIV Models of Care is an AIDS United publication that provides findings and lessons learned from diverse peer navigation models and grantee types.

- ✴ As part of the National Minority AIDS Council's Organizational Effectiveness Series: Building Healthy Organizations, HIV Navigation Services: A Guide to Peer and Patient Navigation Programs provides information and tools to use in planning and implementing patient navigation programs.
- ✴ The Peer Assisted Treatment of HIV and Substance (PATHS) Model guide describes the development, implementation, and evaluation of a navigation program that incorporates peers into a substance use treatment program for people with HIV.
- ✴ Rural Health Information Hub's Rural HIV/ AIDS Prevention and Treatment Toolkit contains resources and information focused on developing, implementing, evaluating, and sustaining rural HIV/AIDS programs, including a patient navigation model.

5. HIV/AIDS, Mental Health, and Counseling

5.1 Stigma

After more than 30 years, HIV-related stigma continues to be a barrier that we must overcome to reach the goal of an AIDS-free generation in the United States. We all have a role to play in stopping HIV, and it starts with supporting people living with HIV and talking about HIV with our friends, families, and loved ones.

What is stigma? Stigma is shame and disgrace that result from prejudice associated with something regarded as socially unacceptable. Stigma around HIV includes certain words, beliefs, and actions that have negative meaning for those at high risk for getting HIV or those already living with HIV. Here are a few examples:

- ➡ Referring to people as HIVers or Positives
- ➡ Believing that only certain groups of people can get HIV
- ➡ Refusing casual contact with someone living with HIV
- ➡ Making moral judgments about people who take steps to prevent HIV transmission
- ➡ Socially isolating a member of a community because they are HIV positive
- ➡ Refusal by a health care professional to provide high-quality care or services to a person living with HIV

Ongoing stigma in our communities leads to perceived discrimination, fear, and anxiety. It affects the emotional well-being and mental health of people living with HIV and prevents some from getting tested and treated for HIV.

AIDS stigma has been further divided into the following three categories:

- ***Instrumental AIDS stigma***—a reflection of the fear and apprehension that are likely to be associated with any deadly and transmissible illness.
- ***Symbolic AIDS stigma***—the use of HIV/AIDS to express attitudes toward the social groups or lifestyles perceived to be associated with the disease.
- ***Courtesy AIDS stigma***—stigmatization of people connected to the issue of HIV/AIDS or HIV- positive people.

Often, AIDS stigma is expressed in conjunction with one or more other stigmas, particularly those associated with homosexuality, bisexuality, promiscuity, prostitution, and intravenous drug use.

In many developed countries, there is an association between AIDS and homosexuality or bisexuality, and this association is correlated with higher levels of sexual prejudice such as anti-homosexual attitudes. There is also a perceived association between AIDS and all male-male sexual behavior, including sex between uninfected men.

Originally, the growth of widespread stigma was revealed through patient clinical experiences. Protecting confidentiality, promoting anti-discrimination laws, and emphasizing public education campaigns has been highlighted in *The American Psychologist*. According to Valdiserri of the World Health Organization, ‘‘To underestimate the insidious power of stigma is to risk the very success of effective HIV prevention and care programs. As public health practitioners, it is our responsibility to work toward minimizing the negative health consequences of HIV/AIDS stigma’’ *(Valdiserri, R. O., HIV/AIDS stigma: an impediment to public health. American Journal of Public Health, 92, 341–342).* According to Parker, R., & Aggleton, P. who wrote *HIV and AIDS-related stigma and discrimination: a conceptual framework and implications for action,* ‘‘To move beyond the limitations of current thinking in this area, we need to reframe our understandings of stigmatization and discrimination to conceptualize them as social processes that can only be understood in relation to broader notions of power and domination. In our view, stigma plays a key role in producing and reproducing relations of power and control. It causes some groups to be devalued and others to feel that they are superior in some way. Ultimately, therefore, stigma is linked to the workings of social inequality and to properly understand issues of stigmatization and discrimination, whether in relation to HIV and AIDS or any other issue, requires us to think more broadly about how some individuals and groups come to be socially excluded, and about the forces that create and reinforce exclusion in different settings’’ *(Parker, R., & Aggleton, P, HIV and AIDS-related stigma and discrimination: a conceptual framework and implications for action. Social Science & Medicine).*

5.2 Substance Use and HIV/AIDS

The goal of HIV care is to achieve and maintain viral suppression – a very low level of HIV in the body. Yet, the health of a person living with HIV cannot be defined solely by their viral load levels. Adhering to the antiretroviral treatment (ART) that suppresses HIV and maintaining a healthy lifestyle are critical to controlling the disease and can be complicated by behavioral health conditions (mental illness and substance use disorders).

People living with HIV have much higher rates of behavioral health disorders than the general population. Consider these facts about the connections between HIV/AIDS, mental illness, substance use and trauma.

- People living with HIV have high rates of past or current history of alcohol or substance use disorders (SUDs).
- 66 percent have used illicit drugs and 16.5 percent have a history of intravenous drug use.
- 24 percent report receiving treatment for SUDs.

5.3 Mental Illness and HIV/AIDS

People living with HIV experience mental illness at significantly higher rates than the general population. The rate of co-occurring mental illnesses in people with HIV was so high that “having a single mental health diagnosis was the exception rather than the rule.”. Specifically, people living with HIV have:

- Two to five times higher rates of depression.
- Up to four times higher rates of depression among women with HIV than women who do not have HIV.
- Higher rates of anxiety.

5.4 Trauma and HIV/AIDS

People living with HIV are more likely to have a history of trauma:

- A person who has experienced trauma and has a serious mental illness has an increased likelihood of having an HIV infection.
- The prevalence of traumatic experiences among those with HIV can be as high as 42 percent for women and up to 70 percent for all people living with HIV – which means that people with HIV are as much as twenty times more likely to have experienced trauma than the general population.

5.5 Co-Occurring Disorders

An estimated 10-28 percent of people with HIV have co-occurring SUDs and mental illnesses. Many people living with HIV and with depression had several other mental health disorders, including 78 percent with anxiety disorders and 61 percent with SUDs.

Impact of Behavioral Health Conditions on HIV Care

The prevalence of mental illness among people living with HIV poses a threat to the health of the individual and has a profound effect on physical wellness. For example, people with depression and HIV are more likely to have higher viral loads, more symptoms of anxiety and are more likely to have a substance use problem.xvii People with HIV and a co-occurring behavioral health condition may increase risky behaviors, such as unprotected sex or sharing needles, or diminish self-care, such as taking medication as prescribed and getting adequate food and rest. Other interrelated social determinants of health, including poverty, low educational attainment and housing insecurity can also complicate HIV treatment and maintenance of a healthy lifestyle. Addressing behavioral health concerns can play a critical role in the public health approach to reducing transmission of HIV. These reasons are why it is important for HIV clinics to conduct behavioral health screenings.

5.6 Behavioral Health Screening Instruments

Numerous tools are available for screening both general and specific behavioral health issues, including:

- General Wellness — Healthy Living Questionnaire or Patient Stress Questionnaire
- Trauma — Life Event Checklist
- Depression — PHQ-9
- Generalized Anxiety Disorder — GAD-7
- Substance Use Prescreen — National Institute on Alcohol Abuse and Alcoholism's (NIAAA) 3 Question Screen or National Institute on Drug Abuse's (NIDA) quick screenSubstance Use In-Depth — AUDIT or ASSIST

Note: These tools are examples and do not include all screening forms available.

A truly effective model for supporting individual and population health integrates behavioral health services (including screening, assessment and treatment) with primary HIV care. Integrating depression screening helps identify those who can benefit from combined psychotherapy and pharmacotherapy interventions. The Screening, Brief Intervention and Referral to Treatment (SBIRT) model identifies risky substance use, provides brief interventions for those with lower level substance use before it becomes a problem and offers referral for those who need more intensive, specialty care. Early detection through screening can result in earlier intervention and substance abuse treatment, including medication-assisted treatment, which can make a substantial difference in the health of the individual and reduce transmission of HIV by increasing medication compliance.

Integrated primary HIV and behavioral health care improves physical health outcomes and leads to increased savings in health care costs through reduced emergency room use, increased efficiency, reimbursable use of staff time and other means of cost-savings.

SBIRT

Screening, Brief Intervention and Referral to Treatment (SBIRT) is an evidence-based practice used to identify, reduce and prevent problematic substance use, abuse and dependence on alcohol and illicit drugs. The SBIRT model responds to a recommendation
by the Institute of Medicine for community-based screening of health risk behaviors, including substance use.

The Three Steps of SBIRT:

1. ***Screening*** — A health care professional assesses a person for risky substance use behaviors through standardized screening tools.
2. ***Brief Intervention*** — A short nonjudgmental conversation between a health care professional and patient exhibiting risky substance use behaviors, including feedback and advice.
3. ***Referral to Treatment*** — For patients whose screening results indicate the need for specialty services, a health care professional provides a referral for additional treatment.

The efficacy of the SBIRT model in identifying risk of SUDs led a western state to implement it for all Ryan White programs, including clinics and AIDS service organizations. The state's public health program ensured adoption across all programs by requiring use of SBIRT in its contract. While some SBIRT programs pose one or two questions about substance use, this state asks four key questions.

Two questions focus on alcohol — the number of drinks per week and the last time four to five drinks were consumed in one day — one asked about the use of an illegal drug or a prescription drug for non-medical reasons in the past year and one focused on tobacco use. If the results indicate a possible substance use problem, health educators use additional screens or longer assessment instruments to explore the scope of the issue. Staff at many primary care programs were skeptical about the effectiveness of screening and worried about its effect on various clinic flow issues. Questions arose about the time it would require, who would perform the screening and brief intervention, where would it take place and finding appropriate places for referral. As training rolled out across the state and similar clinics reported success, primary care providers started to embrace SBIRT. Approximately 85 percent of patients at publicly funded clinics who are HIV-positive are screened with SBIRT at least once a year and 50 to 60 percent are screened annually for mental health concerns.

Focus groups revealed that patients appreciated the opportunity to talk with medical providers about substance use when asked in a respectful way and providers felt it gave them a more complete picture of patients' health. The SBIRT program helped normalize discussions about substance use in medical settings by demonstrating to primary care providers that those who screen positive for some risky behaviors are not necessarily addicted to alcohol or other drugs, but are part of a wider continuum of people who may need intervention.

Lessons learned about supporting SBIRT implementation included the importance of finding champions within each program and using them to develop staff support, define clear protocols that match clinic flow and improve referral systems to ensure that those who need more than a brief intervention receive additional treatment.

Behavioral health screening is an important step for health care provider organizations to increase access to quality behavioral health care. By following the steps and examples outlined, organizations can build effective behavioral health screening that supports a system of integrated care. These recommendations and lessons learned, when implemented, can result in a truly effective and more comprehensive model to meet the multiple needs of individuals living with HIV.

5.7 Psychological Impact (Anxiety, Depression, Suicidality, PTSD)

HIV/AIDS imposes a significant psychological burden. People with HIV often suffer from depression and anxiety as they adjust to the impact of the diagnosis of being infected and face the difficulties of living with a chronic life-threatening illness, for instance shortened life expectancy, complicated therapeutic regimens, stigmatization, and loss of social support, family or friends. HIV infection can be associated with high risk of suicide or attempted suicide. The psychological predictors of suicidal ideation in HIV-infected individuals include concurrent substance-use disorders, past history of depression and presence of hopelessness. Studies have demonstrated a high seroprevalence of HIV infection in people with serious chronic mental illnesses. Prevalence rates in mentally ill inpatients and outpatients have been reported to be between 5% and 23%, compared with a range of 0.3% to 0.4% in the general population in the United States of America over comparable time periods. Some studies have reported behavioral risk factors for transmission of HIV in between 30% and 60% of people with severe mental illnesses. These risks include high rates of sexual contact with multiple partners, injecting drug use, sexual contact with injecting drug users, sexual abuse (in which women are particularly vulnerable to HIV infection), unprotected sex between men and low use of condoms. Besides these behavioral risks, mental disorders may also interfere with the ability to acquire and/or use information about HIV/AIDS and thus to practice safer behaviors or increase the likelihood of situations occurring in which risk behaviors are more common.

Inadequate provision of integrated services for people with mental-health and substance-use disorders, HIV/AIDS and related physical, psychological and social problems creates an additional serious barrier to treatment and care for HIV/AIDS.

There is consistently strong evidence from high-income countries that adherence to highly active antiretroviral therapy is lowered by depression, cognitive impairment, alcohol use and substance-use disorders. Furthermore, such therapy, especially with efivarenz, can be associated with a range of side effects on the central nervous system, including depression, nervousness, euphoria, hallucination and psychosis. Mental disorders, including substance use disorders, are risk factors for contracting HIV, and the presence of HIV/AIDS increases the risk of development of mental disorders. The resulting comorbidity complicates help-seeking, diagnosis, quality of care provided, treatment and its outcomes, and adherence.

The diagnosis of mental health problems in HIV-infected individuals faces several barriers. Patients often do not reveal their psychological state to health-care professionals for fear of being stigmatized further. Also, health-care professionals are often not skilled in detecting psychological symptoms and, even when they do, they often fail to take the necessary action for further assessment, management and referral.

Many individuals already have pre-existing psychological issues which make it even more challenging to cope with HIV. Being a victim of sexual abuse is very common among those with HIV. Further, some people may not only be coming out to their families about being HIV+, but also coming out about being homosexual as well. If diagnosed with HIV or AIDS, it is important for the individual to gain emotional and psychological support. Unfortunately, due to the perceived stigma of the disease, many people do not seek the services that they need. However, HIV *is treatable* and with medical and psychological treatment, people can live happy and productive lives in spite of having the disease.

- The E-CB intervention consists of six 90-minute sessions over the course of 6 weeks. Weekly sessions gave participants time to practice lessons between sessions, reinforcing content discussed during the sessions.
- Project Thrive consists of approximately 10 individual therapy sessions on integrated cognitive therapy strategies, behavioral techniques, and sexual risk reduction counseling.
- Project IMPACT consists of 10 weekly, 50-minute, in-person sessions that include HIV risk reduction sessions, sessions of cognitive behavioral therapy for reducing substance use, behavioral activation sessions, and preventing re-starting substance use.
- Sexual Confidence consists of 10 weekly 1 hour sessions using an integrated CBT model focusing on conversations between the client and facilitator (instead of a didactic learning session).
- CBT-AD consists of between nine and twelve 50- to 60-minute sessions, with three “open sessions” (which allow for the individual and therapist to revisit the modules that are most relevant to the client’s specific needs)

Therapy can help clients become more proactive, re-engage in life and in relationships, learn to cope with symptoms, and take an active role in their health issues. Therapy can help those with HIV to develop greater self-awareness, especially with self-defeating behaviors, stronger coping skills, and the motivation to engage in meaningful and productive activities. Further, there are many promising studies that indicate a potential link between the HIV positive person's health, and taking care of their emotional health. If a person is diagnosed with HIV or AIDS, they should reach out to trusted friends and family members. Individuals can also seek a support group for those with HIV, contact their local AIDS Service Organization for information on available psychosocial support, and seek therapy with a competent and licensed therapist who is practiced in working with those who have HIV or AIDS.

Anxiety

Anxiety is a common symptom in HIV-infected patients. When anxiety symptoms are severe or persistent, patients may have an anxiety disorder. These disorders include panic disorder, generalized anxiety disorder, obsessive-compulsive disorder, and post-traumatic stress disorder (PTSD) Among HIV-infected patients receiving medical care, 20.3% have been found to have an anxiety disorder, with 12.3% meeting the criteria for panic disorder, 10.4% for PTSD, and 2.8% having generalized anxiety disorder. Patients with other psychiatric disorders, such as adjustment disorders, major depression, psychosis, or substance use disorders, can also present with significant anxiety. To help patients receive optimal care, clinicians need to be aware of the differences among these specific disorders. Furthermore, patients with histories of anxiety or mood disorders are susceptible to recurrence of anxiety symptoms during the course of HIV illness. Anxiety can manifest in many ways, such as shortness of breath, chest pain, racing/pounding heart, dizziness, diaphoresis, numbness or tingling, nausea, or the sensation of choking. When clients present with these somatic symptoms, for which no underlying medical etiology can be established, clinicians should consider an anxiety disorder as the cause. In addition to somatic complaints, clients with anxiety disorders often present with fear, worry, insomnia, impaired concentration and memory, diminished appetite, ruminations, compulsive rituals, and avoidance of situations that make them anxious.

Anxiety symptoms such as worry, nervousness, fear, and tension are commonly experienced by people with HIV during periods of their illness and may be a response to stressful situations. An anxiety disorder occurs when symptoms:

- ➡ Interfere with a patient's daily function (e.g., the patient is unable to work, leave home, attend to medical care)

- Interfere with personal relationships
- Cause marked subjective distress

Even brief episodes of anxiety, such as those occurring during a panic attack, may interfere markedly in a patient's life and may warrant a diagnosis of an anxiety disorder. Anxiety-like symptoms may also be caused by mental health disorders other than anxiety disorders. For example, it may be difficult to distinguish depression with agitation from an adjustment disorder with anxious mood. In general, adjustment reactions follow a stressful event, which is often not true in clinical depression, and are less likely to present with the entire vegetative symptom complex seen in depression, which is characterized by insomnia, diminished appetite, diurnal variation in mood, loss of pleasure/interest, feelings of guilt, fatigue, and attention and concentration problems *(Kranzler HR, Rounsavill BJ, eds. Dual Diagnosis and Treatment: Substance Abuse and Comorbid Medical and Psychiatric Disorders. New York: Marcel Dekker).*

Certain anxiety symptoms can be effectively managed without the use of medication. There are also patients who prefer to avoid the use of psychotropic medication. Patients with mild anxiety symptoms that do not interfere with function may respond to supportive or behavioral interventions. Clinicians may find the following strategies helpful in such situations:

- Expressing empathy
- Educating clients about anxiety
- Reassuring clients that anxiety is the cause of somatic symptoms experienced during panic attacks
- Identifying the psychological factors that contribute to anxiety
- Preparing clients for stressful situations and assisting in development of coping mechanisms
- Teaching client's simple relaxation exercises. Slow, deep breathing with focus on inspiration and expiration of air can be helpful. Such exercises can be useful when clients practice for 1 minute three times a day, increasing to 5 minutes, if possible.

Depression

Clinical depression is the most commonly observed mental health disorder among HIV-infected patients, affecting up to 20% of patients. The prevalence may be even greater among substance users. Depressive symptoms have been associated with risk behavior, non-adherence to medications, and shortened survival. Although sadness and grief are normal responses to many of the consequences of HIV infection, clinical depression is not. Failure to recognize depression may

endanger both the patient and others in the community. Patients with depression are at higher risk for co-morbid psychiatric, alcohol, and substance use-related disorders, particularly alcohol, cannabis, and cocaine use *(Kranzler HR, Rounsavill BJ, eds. Dual Diagnosis and Treatment: Substance Abuse and Comorbid Medical and Psychiatric Disorders. New York: Marcel Dekker).*

Although many of the somatic symptoms of depression may be attributed to HIV infection, opportunistic or other infections, or side effects of medications, the primary care clinician should recognize that the following symptoms can be caused by depression:

- Depressed mood
- Loss of interest or pleasure
- Feelings of guilt
- Suicidal thoughts
- Sleep disturbance
- Appetite/weight changes
- Attention/concentration problems
- Energy level changes/fatigue
- Psychomotor disturbance

Many HIV-infected patients may not recognize or report symptoms. They may present instead with behavioral changes that may indicate the presence of an underlying depressive disorder. Clinicians should recognize the following behavioral changes as possible indications of an underlying depressive disorder:

➡ A change in treatment adherence

➡ An inability to make life choices, including those related to medical care and adjustment to HIV disease

➡ A preoccupation with a particular problem, usually one that presents as minor

➡ A change in functioning, including an inability to perform activities of daily living, a return to substance use, or a self-imposed isolation

➡ Unexplained medical complaints, particularly pain or fatigue

➡ Interpersonal problems

➡ Presenting with difficult behaviors in the medical setting

HIV-infected patients do not become depressed simply because their disease progresses; however, it is particularly important to screen for depression during the crisis points noted in Table 1. Medically ill patients may experience normal

sadness, grief, and discouragement or demoralization. However, the presence of hopelessness, anaerobia (the absence of pleasure from usually pleasurable activities), ruminative guilt, and suicidal ideation may indicate accompanying clinical depression requiring psychiatric intervention *(Kranzler HR, Rounsavill BJ, eds. Dual Diagnosis and Treatment: Substance Abuse and Comorbid Medical and Psychiatric Disorders. New York: Marcel Dekker).*

Crisis Points for HIV-Infected Persons

- Learning of HIV-positive status
- Disclosure of HIV status to family and friends
- Introduction of medication
- Occurrence of any physical illness
- Recognition of new symptoms/progression of disease (e.g., major decrease in CD4 cells, increase in viral load)
- Necessity of hospitalization (particularly the first hospitalization)
- Death of a significant other
- Diagnosis of AIDS
- A return to a higher level of functioning (e.g., re-entry into job market/school, giving up entitlements)
- Major life changes (e.g., childbirth, pregnancy, loss of job, end of relationship, relocation)
- Necessity of making end-of-life and permanency planning decisions

Data are from Duffy V. The 14 crisis points of AIDS. AIDS Patient Care STDs

The following psychiatric disorders, which require a different treatment approach, may present with symptoms of depression and should be excluded as possible causes:

- Bipolar Disorder
- Post-Traumatic Stress Disorder
- HIV-associated dementia
- Alcohol and substance use

Suicidality

HIV-infected patients may be at higher risk for suicidal behavior, particularly after a diagnosis of HIV disease or during progression to AIDS, as patients' health and quality of life decline. Other patients, such as those with certain personality

disorders, may be at increased risk for violent behavior. Although only a small number of HIV-infected patients attempt or commit suicide or violence, routine mental health assessment and procedures in the clinic setting for responding to mental health emergencies can ensure that the potential for such behavior is identified and appropriately addressed *(Coté TR, Biggar RJ, Dannenberg AL. Risk of suicide among persons with AIDS: A national assessment, JAMA)*.

Rates of suicidal behavior have been more widely studied in gay men than in other populations, although some studies have shown that HIV-infected women have higher rates of suicide attempts than HIV-infected men. Studies conducted before the introduction of HAART indicated an increased risk of completed suicide in patients with HIV/AIDS that was 7 to 36 times greater than in the non-HIV-infected population. Since the introduction of HAART, more recent evidence suggests that suicide among HIV-infected patients may be mediated more often by factors other than HIV, including depression, alcohol, or other substance-related disorders. Because patients with suicidal behavior often present with co-morbid depression, screening for and timely treatment of depression may reduce a patient's risk for suicide. Suicide risk in HIV-infected patients may be higher than in populations with other chronic medical illnesses, such as cancer. Evidence suggests that risk for suicidal behavior increases during the initial weeks following a diagnosis of HIV disease and then declines as patients adjust to their HIV status. However, as patients' health and quality of life decline, risk of suicide may again increase, particularly among middle-aged and older patients, who frequently experience poorer health-related quality of life when progressing to AIDS. A comprehensive mental health assessment is essential for any patient who directly expresses suicidal or violent behavior or whose behavior and risk factors suggest potential for suicide or violence *(Source: Bellini M, Bruschi C. HIV infection and suicidality, Affect Disord)*.

PTSD

Exposure to a traumatic event is normally accompanied by distress. For most individuals such distress resolves spontaneously without the onset of any psychiatric illness. Among a subset of people, the type, severity, and duration of symptoms that develop following trauma will meet criteria for either acute stress disorder (ASD) or post-traumatic stress disorder (PTSD).

Trauma can affect both psychological and physical functioning. Some research has suggested that the physical effects of trauma have been related to significant health problems, such as diminished functioning of the immune system and increased

susceptibility to infections. The psychological effects of PTSD may manifest in increased risk-taking behavior, such as substance use, poor eating habits, or unsafe sexual activity. In addition, patients with PTSD may suffer from depression, social isolation, impairments in trust and attachments, and feelings of anger. Patients with HIV/AIDS may be affected by past trauma to the point that it manifests in problems with disease management, such as disrupted or negative interactions with medical personnel and/or medication non-adherence.

A history of previous traumatic experiences increases a person's vulnerability to developing PTSD upon exposure to subsequent trauma. Previous traumatic experiences may impair his/her ability to handle future stressors. The more severe the trauma is, the greater the likelihood will be that the patient will develop PTSD *(Cooper J, Carty J, Creamer M. Pharmacotherapy for post-traumatic stress disorder: Empirical review and clinical recommendations).*

The rate of PTSD following exposure to a particular trauma ranges from 12% to 70%, with the higher rates occurring in populations exposed to traumas that involve interpersonal violence (e.g., rape, sexual abuse, torture). Women have higher rates of PTSD than men. Among women, sexual assault is the most common precipitating trauma, whereas among men, the most common trauma is combat exposure. Although PTSD has a lifetime prevalence rate of approximately 1.3% to 7.8% in the general population, the rates of PTSD in the HIV-infected population are higher. The prevalence of PTSD in HIV-infected individuals may be as high as 42%. Although onset of a severe, life-threatening illness (such as HIV/AIDS) can sometimes in itself be a traumatic experience leading to PTSD, more often a history of physical or psychological trauma (and diagnosis of PTSD) co-occurs with an individual's HIV status. Among people with the most severe mental illnesses, specifically schizophrenia, schizoaffective disorder, and bipolar disorder, comorbid PTSD is an important predictor of HIV infection *(Cooper J, Carty J, Creamer M. Pharmacotherapy for posttraumatic stress disorder: Empirical review and clinical recommendations).*

Many of the symptoms of ASD overlap with those of PTSD. ASD defines a severe stress response that follows shortly after a traumatic event, whereas PTSD cannot be diagnosed until symptoms have persisted for 30 days or longer. The presence of full or partial ASD is associated with an increased risk of developing PTSD. In various studies, the presence of numbing, depersonalization, a sense of reliving the trauma, motor restlessness, and peri-traumatic dissociation were found to predict progression to PTSD. These associations raise the possibility that effective early treatment of trauma symptoms can be a useful strategy in the prevention of PTSD.

However, it should be noted that many trauma survivors who develop PTSD do not have initial ASD symptoms, and many individuals with ASD will not develop PTSD *(Cooper J, Carty J, Creamer M. Pharmacotherapy for posttraumatic stress disorder: Empirical review and clinical recommendations).*

5.8 Screening and Counseling Clients with HIV And Substance Use Disorders (SUDs)

The pandemics of substance abuse and HIV/AIDS are clearly moving along similar paths, and each continues to present unique, yet interrelated, challenges. First, both disorders are considered to be chronic--that is, lifelong diseases. Second, substance abuse is a primary risk behavior for HIV infection. Third, a diagnosis of HIV infection or related conditions can be a stressor for an individual already in recovery from a substance abuse disorder. However, the diagnosis of HIV infection may motivate a client to enter substance abuse treatment. Injection drug users who test positive for HIV are more likely to enter treatment than those who test negative (Bux et al; McCusker et al.,). Also, studies have noted a reduction in risk-taking behaviors among injection drug users who test positive for HIV (Colon et al; MacGowan et al.). The diagnoses of a substance abuse disorder and HIV/AIDS require extensive physical and mental health care and counseling in conjunction with extensive social services. To deal with the myriad issues surrounding substance abusers who are HIV positive, substance abuse treatment professionals must continually update their skills and knowledge as well as reexamine their own attitudes and biases.

Training, Attitudes, and Issues

Before conducting any screening, assessment, or treatment planning, clinicians should reassess their personal attitudes and experiences in working with persons who are HIV-infected and have a substance use disorder. This section discusses several ways in which clinicians can accomplish this, including formal training, examining personal attitudes (e.g., counter-transference and homophobia), examining fears of infection, and avoiding burnout. It is important to reassess comfort levels with each client because each client will vary in demographic and cultural background. For instance, a service provider may feel comfortable working with a young Asian American male with a history of alcohol use, yet the same provider may not be at all comfortable with a pregnant Hispanic woman who is an active injection drug user and wishes to have her baby.

Training

Clinicians must have the proper training to screen, assess, and counsel clients. Achieving staff competency is an ongoing process. The complexities related to people with HIV/AIDS and substance abuse disorders are constantly changing and do not allow staff members to defer learning or training or even to maintain a "status quo" attitude about their competency.

Examples of methods to help staff grow in the areas of assessment, screening, and treatment planning include the following:

- ***Model skills and competencies.*** Less experienced staff can observe supervisors or more tenured staff who demonstrate desired qualities.
- ***Peer training and feedback***. Peer teams can provide feedback through direct observation of staff members' interactions with clients, as well as review of staff members' client charts.
- ***Case presentations***. Weekly or monthly group case presentations conducted by a different staff member each time can be effective for building skills and monitoring quality. Case simulation, in which each staff member has an opportunity to ask the "client" a question, is a highly useful training tool. At the end of the presentation, everyone attending can provide feedback about the activity.
- ***Experiential skills-building exercises***. Many activities can be used to sensitize staff to the client's experiences. Activities can include encouraging staff members to go to a confidential and anonymous HIV/AIDS test site, or anonymously sit in the waiting room of the local food stamp office, HIV/AIDS clinic, or county jail. Staff must use different avenues to maintain a keen sensitivity to and awareness of the client's issues.
- ***Assessment instruments.*** Use specific assessment tools, such as substance abuse and sexual history questionnaires (e.g., the Addiction Severity Index [ASI]).
- ***Formal conferences, training, consultations with clinicians.*** Often agency budgets are tight, and the first expense to be cut is staff development. This is a major problem for many programs. Programs must establish that improvement and excellence are serious goals and that attending treatment-oriented conferences is a part of building staff competency and moving toward these goals.

Attitudes

It is important that counselors be aware of any of their own attitudes that might interfere with helping a client. By learning to put aside personal judgments and focus on client needs, staff members can build trust and rapport with the client.

When a counselor can deal with a client in a sensitive, empathic manner, there is a much greater chance that both will have a positive and successful encounter.

Counter-transference is a set of thoughts, feelings, and beliefs experienced by a service provider that occurs in response to the client. Although sometimes these beliefs and feelings are conscious, generally they are not. It is thus unrealistic to expect counselors, usually untrained in addressing unconscious mental processing, to be aware of counter-transference. Regular clinical supervision, which should be integrated into the staffing of the program, can help raise their awareness. If such resources exist, counselors may, with caution, address this issue.

In order to deal with counter-transference issues, counselors must be willing to examine their skills and attitudes. Working with clients who have HIV/AIDS and substance abuse disorders brings up issues for treatment staff that can be both physically and emotionally demanding. Counselors see a broad range of diverse clients from all walks of life. To work in both these fields, providers must learn to be comfortable in discussing topics they may never have talked about openly--sex, drug use, death, grief, and so on. To effect positive change, counselors also must be willing to seek additional specialized training and support.

Examining attitudes and skills

Counter-transference can manifest itself in many different ways. The key to seeing counter-transference issues is awareness and consciousness-raising. The commitment to "do no harm" to clients and their families, along with a desire to provide quality services, should be the driving forces for willingly examining these issues.

Following are some common counter-transference issues for providers working with substance abusers who are HIV positive (*adapted from National Association of Social Workers*):

- Fear of contagion
- Fear of the unknown
- Fear of death, dying, grief, and loss
- Stigmatization (e.g., of people with mental health problems, "addicts," people who are HIV positive)
- Powerlessness, helplessness, and loss of control
- Shame and guilt
- Homophobia
- Anger, rage, and hostility
- Frustration
- Over-identification

- Denial
- Differences in culture, race, class, and lifestyle
- Fantasies of professional omnipotence
  - Burnout
  - Measures of success and personal reward

Homophobia

To be aware of homophobic responses among treatment professionals and of their own counter-transference issues, it is important that counselors understand how the client is handling his homosexuality. The counselor should understand the possible link between substance abuse and gay or lesbian identity formation. Substance abuse can be an easy relief, can provide acceptance, and, more important, can mirror the "comforting" dissociation developed in childhood. The "symptom-relieving" aspects of substance abuse help fight the effects of homophobia; substance abuse can allow "forbidden" behavior, allow social comfort in bars or other unfamiliar social settings and provide comfort just from the dissociative state itself. For example, some men have their first homosexual sexual experience while drinking or being drunk. This connection is a very powerful behavioral link--the pleasure and release of substance abuse with the pleasure and release of sex--and is very difficult to change or "unlink" later in life.

Homophobia Questionnaire for Clinicians

In regard to the issue of homophobia, it is also critical to understand how stereotypes affect the treatment options offered. The professional should take an inventory of these stereotypes to assess her homophobia potential and should be aware of the roles counter-transference can play. The short assessment tool can be used to examine where providers and clients alike might rank on a continuum of homophobic reactions. This tool is also useful in group supervision sessions or discussions with both gay/lesbian and heterosexual colleagues.

It is important that clinicians have a working knowledge of some of the terminology and definitions pertaining to homophobia. Following is a brief list of terms and definitions.

- ***Overt homophobia*** includes violence, verbal abuse, and name-calling.
- ***Institutional homophobia*** describes the way in which governments, businesses, schools, churches, and other institutions and organizations treat people differently and less favorably based on their sexual orientation.
- ***Cultural homophobia*** includes social standards and norms requiring heterosexuality.

- ***Internalized homophobia*** is acceptance and integration by lesbians and gays of the negative attitudes expressed by society toward them.
- ***Heterosexism*** is the system of advantages bestowed on heterosexuals. It is the institutional form of homophobia that assumes all people are or should be heterosexual and therefore excludes the needs, concerns, and life experiences of lesbians, gays, and bisexuals.
- ***Coming out*** may possibly be the most important part of gay and lesbian development. This is the process, often lifelong, in which a person acknowledges, accepts, and in many cases appreciates his or her own lesbian, gay, bisexual, or transgender identity. This often involves sharing this information with others. Family members of gay and lesbian individuals go through a similar process.
- ***Oppression*** is the systematic subjugation of a particular social group by another group with access to social and political power, by withholding access to that power.
- ***Lesbian/gay baiting*** involves actions or words that imply or state that the presence of a gay man or lesbian hurts or discredits a social system. The purpose is to hurt, demean, intimidate, or control, and to stop social change or acceptance of lesbians and gays within the social system.

These definitions can help the counselor become aware of the added layer of discrimination felt by gay men and lesbians in treatment for HIV/AIDS and a substance abuse disorder. Following is a list of some "Do's" to keep in mind when working with homosexual clients *(adapted from Storms,)*.

- Identify the lesbian/gay client's strengths and accept them as you find them.
- Listen empathically and refrain from making judgments about the client's lifestyle.
- Remain aware of the client's sexual orientation and the possible effects of this orientation on the client's experience and world-view.
- Explore the client's sexual practices with an eye toward internalized homophobia.
- Be aware of your own preference and mindful of possible homophobia or confusion in your own sexual identity.
- Be knowledgeable about compulsive sexual behavior and sexual practices in the lesbian/gay community.
- Ask your lesbian/gay clients what terms they prefer when discussing their sexual orientation and those of others.
- Encourage self-empowerment, consciousness-raising, and participation in the lesbian and gay community.
- Encourage your program to hire openly lesbian and gay counselors/therapists.

- Educate others about internalized homophobia and heterosexism. Be gay- and lesbian-affirming rather than just gay- and lesbian-tolerant.
- Stay abreast of current information on resources and display this information in your office. Attend seminars and professional workshops about working with lesbian and gay clients.

Fear of infection

Fear of infection is one of the most challenging issues for counselors. It is essential that providers examine this issue without blaming or judging themselves and others. Most professionals who work with substance abusers and HIV-positive individuals have thought about becoming infected with HIV, hepatitis, or tuberculosis (TB) through their jobs *(Sherman and Ouellette)*. Some fear that scientists are not aware of modes of infection or transmission that might put service providers and their families at greater risk of infection *(Montgomery and Lewis)*. The key to dealing with this fear is to discuss it and vent the feelings with someone who is safe, trusted, and informed, *and* to practice universal precautions at all times.

Beyond this, it is essential for providers to have regular and frequent in-service training with updates on the latest research and data about transmission and treatment of HIV/AIDS, hepatitis, and TB.

Special considerations for clinicians who treat HIV-infected clients

The challenges and stresses related to working with people with HIV/AIDS are in some ways unique. The fact that providers often deal with multiple and serial losses and see clients suffering on a daily basis clearly affects the providers' psychological health. In recent years, therapists have begun to examine and assess these service providers for symptoms of post-traumatic stress disorder (PTSD).

Burnout often is referred to as "bereavement overload." One definition characterizes burnout as lowered energy, enthusiasm, and idealism for doing one's job, that is, as a loss of concern for the people served and for the work *(Hayter)*. Unlike fatigue, burnout does not resolve after a given amount of rest and recreation.

Burnout prevention and stress management techniques should be used both in the work setting and in counselors' personal lives. Working with HIV-infected substance abusers requires agencies and individuals to be more creative and flexible in finding new and different ways to support and nurture counselors to prevent burnout. Agencies that have taken on this challenge with integrity and

commitment have seen highly effective staff function at optimal levels for many years.

Suggestions for ways in which agencies can take care of clinicians at work include

- Assigning clearly specific duties
- Having clear boundaries on professional obligations
- Enlisting volunteer help from community organizations
- Allowing for "time out" activities
- Varying tasks and responsibilities
- Building in "mental health days"
- Providing for continuing education
- Holding staff retreats (with enjoyable activities planned)
- Holding discussion, process, and support groups
- Convening regular staff/team supervision meetings

In addition, it is important that agencies allocate time to discuss the deaths and losses faced by staff. This may mean supporting special memorial events at which those who have been lost to HIV/AIDS disease can be remembered. Agencies also can support staff through contracts with employee assistance program therapists and by providing an onsite therapeutic support group for staff members to attend as they wish.

Screening

Client-Specific Needs

A positive screen for HIV infection typically leads to a referral for formal assessment, usually to an HIV/AIDS case management service. Frequently, substance abuse treatment programs provide referrals to HIV/AIDS care services. Providers will want to identify substance abuse treatment programs and agencies with these networks. At a minimum, services should include the following client needs in priority order:

- Substance abuse treatment
- Medical care
- Housing
- Mental health care
- Nutritional care
- Dental care
- Ancillary services
- Support systems

Interim substance abuse treatment for clients on waiting lists
Because of an insufficient number of substance abuse treatment slots, clients often must wait for treatment. Risk-reduction efforts can be made, however, while the client is waiting for substance abuse treatment.

If substance abuse treatment slots remain unavailable, alcohol and drug counselors should refer clients who need medical care to primary medical care services. Clients who display more acute symptoms or conditions should probably be referred to an emergency department. However, emergency department care typically is limited to wound care and provision of nutritional supplements. Clients who do not have acute symptoms or conditions but need medical care should be referred for primary medical care, either to their own physicians or to primary medical care clinics or services.

Mental health care
A diagnosis of mental illness may reflect the client's affective and mood responses to this medical judgment, may be a consequence of self-medication, or may reflect neurological complications of HIV/AIDS, as well as an underlying mental health disorder. Mental health care should consist of both a neuropsychiatric workup and full mental health status examinations. Service providers should be alert to and notify clients and psychiatrists that complications may arise from the use of prescription medication for mental health problems and interactions between drug residue in the body and medications for HIV/AIDS and opportunistic infections.

Nutritional care
Substance-abusing clients living with HIV/AIDS are typically mal- or undernourished because of street lifestyles, the effects of HIV disease, and the physical effects of substance abuse. This combination typically results in diminished appetite, weight loss (especially of lean muscle mass), poor hygiene, immune suppression, protein deficiencies, vitamin and mineral exhaustion, and anemia. In addition, providers should be aware that apparent lack of nutrition is not associated with digestive disease or parasites.

Good nutrition is a fundamental part of overall medical care. It improves strength, energy, longevity, and quality of life; increases muscle mass and body weight; decreases likelihood of hospitalization and length of stay; and slows progression of HIV to AIDS. Without adequate nutrition, HIV/AIDS clients can easily develop malnutrition. Various causes of malnutrition and weight loss include:

- Inadequate intake of food
- Anorexia
- Malabsorption of food
- Altered metabolism
- Food and drug interactions
- Androgen deficiency
- No cooking facilities
- Limited income
- Reliance on community food programs

With the onset of malnutrition, the client loses weight and experiences several body composition changes. *Starvation* results in loss of body fat and muscle. *Wasting syndrome* produces a loss of a serious percentage of body weight, with accompanying diarrhea and fever, and has been considered a defining symptom of AIDS since 1987. The degree of loss of lean body mass can indicate the length of time that the client has left to live.

Lipodystrophy syndrome

Lipodystrophy syndrome occurs in early end-stage AIDS and produces altered body composition and various hormonal and physiological changes. The cause of the syndrome and its relationship with HIV and protease inhibitors are unknown. Because of the disfiguring nature of some symptoms, lipodystrophy can be particularly distressing for women. Symptoms include:

- Redistribution of body fat
- Increase in waist size
- Thinning of the arms and legs
- Increased facial wrinkling
- Weakness and muscle wasting
- Gastrointestinal symptoms
- Increased triglycerides and cholesterol
- Decreased testosterone levels
- Hypertension
- Diabetes

Ancillary services

The steady increase in the number of women living with HIV/AIDS is creating a great demand for ancillary services such as child care, housing, and transportation. Families needing housing may face long waiting lists for Section 8 housing or may receive Section 8 certificates only to find few landlords willing to accept Section 8 housing payments. Another concern for substance abusers, whether currently using

or in recovery, is the fact that most low-cost housing tends to be in areas known for high drug traffic and crime.

Disclosure Issues

Disclosure issues are difficult for all HIV-infected clients. For substance-abusing clients, these issues take on additional challenges. For example, disclosure of positive HIV status may lead to personal threats or harm to both client and family. A client's family may refuse to associate with him upon learning of his HIV/AIDS status. Particularly for clients whose culture reflects definition of self within a community or self in relation to a clan (as opposed to individual definition), separation from community can serve as a trigger for lapse or relapse into risky substance use and sex-related behaviors. Therefore, providers must use caution when notifying clients of test results and should comply with regulations to ensure that a client's confidentiality is preserved.

Also, during group therapy clients often feel an obligation to reveal their HIV status to the rest of the group. Counselors should caution clients about the impact of such disclosure and consider discouraging them from making it. Clients who wish to disclose their HIV status generally do so in response to treatment themes of honesty and openness and are not completely aware of the consequences. Of course, in treatment settings where all patients are HIV positive, there is no need for this concern.

HIV/AIDS-Specific Substance Abuse Counseling Issues

There are many counseling issues specific to HIV/AIDS that providers should be familiar with when treating HIV-infected, substance-abusing clients.

Cultural Competency Issues

Culture is the integrated pattern of human behavior that includes thoughts, speech, actions, and artifacts. Culture depends on the capacity of humans for learning and transmitting knowledge to succeeding generations. It takes into account the customs, beliefs, social norms, and material traits of a racial, religious, or social group. With this type of definition, it is easy to see that there is indeed a culture of addiction, a culture of poverty, a gay culture, and even a recovery culture.

Cross and colleagues present a comprehensive discussion of culturally competent systems of care. Five essential elements contribute to cultural competence *(Cross et al.)*, which can briefly be described as follows:

1. **Valuing diversity.** Counselors value diversity when they accept that the people they serve come from very different backgrounds and may make different

choices based on culture. Although all people share common basic needs, there are vast differences in how people go about meeting those needs. Accepting the fact that each culture finds some behaviors, actions, or values more important or desirable than others helps workers interact more successfully with different people.

2. **Cultural self-assessment.** When counselors understand how systems of care are shaped by dominant cultures, it may be easier for them to assess how these systems interface with other cultures. Care providers can then choose actions that minimize cross-cultural barriers.
3. **Dynamics of difference.** When cultural systems interact, both representatives (e.g., care provider and client) may misjudge the other's actions based on history and learned expectations. Both will bring dynamics of difference--culturally prescribed patterns of communication, etiquette, and problem solving, as well as underlying feelings about serving or being served by someone who is different. Incorporating an understanding of these dynamics and their origins into the system enhances chances for productive cross-cultural interventions.
4. **Institutionalization of cultural knowledge.** Workers must have accurate cultural knowledge and information or access to such information. They also must have available to them community contacts and consultants to answer culturally related questions.
5. **Adaptations to diversity.** The previous four elements build a context for a cross-culturally competent system of care and service. Both workers' and systems' approaches can be adapted to create a better fit between needs of people and services available. For instance, members of certain ethnic groups repeatedly receive negative messages from the media about their culture. Programs can be developed that incorporate alternative culturally enhancing experiences, develop problem solving skills, and teach about the origins of stereotypes and prejudice. By creating and implementing such programs, workers can begin to institutionalize cultural interventions as a legitimate helping approach.

Finally, becoming culturally competent is a developmental process for individual counselors. It is not something that happens because one reads a book, or attends a workshop, or happens to be a member of a minority group. It is a process born of a commitment to provide quality services to all and willingness to risk. (*Cross et al.*)

Making culturally competent decisions

Treatment providers and counselors must examine two essential factors when working with culturally, racially, or ethnically different populations: the socioeconomic status of the client or group and the client's degree of acculturation.

A distinction should be made when discussing a population as a whole and a particular segment of that population. For example, when treating an HIV-infected substance-abusing Hispanic woman, the counselor should focus on the woman as an individual and on the particular circumstances of this individual's life, rather than seeing her as an abstract representative of her culture or race. More often, poverty is the relevant issue to be discussed, rather than specific ethnic or racial factors.

The second factor, degree of acculturation, is important and should be part of the assessment process. How acculturated or assimilated are the family and client? What generation is this client? Assessing for this and knowing that several generations with different values and levels of acculturation may all live in one household, can test the communication skills and counseling skills of the best service providers. When discussing acculturation/ assimilation and values, counselors should keep in mind that, in general, the more years a family has lived in the United States, the less traditional their values tend to be. Thus a fourth-generation Chinese-American client may not speak Chinese or hold traditional Chinese values. Knowing the values and beliefs of a client is crucial if treatment is to be effective.

Providers must also help develop culturally competent systems of care. A part of this is making services accessible to and often used by the target risk populations. Culturally competent systems also recognize the importance of culture, cross-cultural relationships, cultural differences, and the ability to meet culturally unique needs.

Guidelines to Minimize Cultural Clashes

Aside from assessing cultural competence using the five elements discussed previously, it also is helpful to examine some ways in which providers can minimize cultural clashes and blocks that may exist when working with clients. The guidelines given are adapted from a project conducted by the University of Hawaii AIDS Education Project.

One concern in providing culturally competent care is how to discuss values and differences around sex and sexuality. In many cultures, people avoid discussing sex because they find such discussions disrespectful. This is one reason why so many cultures avoid discussing homosexuality. A counselor should consider using a less direct approach when initiating discussion about issues related to sex and sexual orientation. Many providers believe that some of the public health problems faced in communities of color and the gay community are related to their inability to

speak often and directly enough about safer sex practices, risky behaviors, and homosexuality. Even in the recovery culture and in many treatment settings, sex and sexuality are blatantly avoided. Service providers must acknowledge that they, too, in addition to their clients, are often uncomfortable talking about sexuality, sexual identity, and sexual orientation.

Providers also should be aware of the messages often given to communities of color and particularly women. The message, "stop having sex," often advocated by providers has been mixed with historical issues and fears of racial/ethnic genocide, thus making it difficult for most groups to give any credence to those expounding this method of reducing HIV/AIDS. The value of sex and procreation in many cultures makes it difficult for someone from outside the client's culture, especially someone of a different gender, to tell people to not have sex or to have sex only with a condom.

Finally, it is important that the counselor recognize that much of what is asked of clients and their families is personal and private. Questions related to sex, dying, and substance abuse are not usual topics of conversation, and when asking these questions, the counselor crosses many boundaries. It often is considered disrespectful (and offensive to certain cultural values) to ask questions about these specific areas. One wise way to broach these subjects with clients, especially clients who are significantly older than the provider or from a more traditional culture, is to simply apologize. The most practical advice is for providers to:

1) Maintain an open mind
2) Use cultural consultants for training and support
3) When in doubt, defer to the concepts of health and stability over pathology and dysfunction.

5.9 Special Populations

Gay, lesbian, bisexual, and transgender populations

Providers wishing to serve the needs of particular ethnic or cultural groups have learned that communities must be understood, respected, and consulted in order to make effective interventions; this also holds true when working with gay men, lesbians, and bisexual men and women. This population is defined not by traditionally understood cultural and ethnic minority criteria, but by having a sexual orientation that differs from that of the majority. Transgender people also form a unique population, often linked to gay men, lesbians, and bisexuals, although they differ from the majority by gender identification rather than sexual orientation.

A sudden increase in the use of methamphetamine, known as "speed," "crystal," "ice," or "crank," by gay and bisexual men has become a matter of grave concern. A primary route of administration for this drug is injection. Combined with its disinhibiting and sexually stimulating effects, gay male injectors of methamphetamine are at extremely high risk for HIV exposure: The drug causes the abuser to suspend all judgment and leaves him often impotent but extremely sexually aroused and often an anal-receptive partner in sex (*Gorman et al.*).

Men who have sex with men (or MSMs--the CDC category used to report its data) may self-identify as gay (men with homosexual sexual orientations), bisexual (men who feel sexually drawn to both men and women), or heterosexual (men having sex with men as a purely physical act and not a reflection of innate sexual orientation). No matter what their sexual orientation, unprotected sexual contact puts MSMs at risk for HIV. In most reviews of gay men and safer sex practices, most men who were knowledgeable about safer sex failed to practice it while under the influence of some substance. Many men from minority backgrounds who have sex with other men do not self-identify as gay or bisexual, so interventions should be based not on sexual orientation, but on sexual behavior.

Some women who have sex with women continue to have sex with men. A number of these women may be injection drug users and share syringes; consequently, they are prone to HIV infection. Although it is unlikely that female-to-female transmission of the virus will occur, lesbians have been urged to use safer sex precautions, such as using dental dams during oral sex.

Lesbians present some specific issues that must be highlighted. Compared with gay men, they are more likely to have lower incomes (as do women in general when compared with men); are more likely to be parents (about one-third of lesbians are biological parents); face prejudice as women as well as for being gay, including the stronger reaction against and willingness to ignore females with substance abuse disorders; are more likely to come out later in life (about 28 years of age versus 18 years of age in men); and are more likely to have bisexual feelings or experiences, so that they are still at sexual risk for HIV infection as well as possible IDU risk.

Gay youth also present treatment challenges. Special sensitivity and understanding are needed to work with youth of any background, especially youth who are gay or lesbian or from an ethnic minority background. Young gay males in particular may be subjected to harassment at home or school, and they are prone to alcohol use, dropping out of school, running away, and getting involved in sex for drugs or

money. Many young gay male street workers abuse amphetamines, "tweaking" to have a sexual experience, and may exchange sex for drugs.

In general, gay men, lesbians, bisexuals, and transgender people are wary of the medical establishment and may resist seeking health care, distrust the advice given, or question the treatment plan suggested if the provider displays evidence of homophobia or heterosexism.

Transgender individuals

Some substance abuse treatment clients are transgender. The following definitions have been provided to clarify the confusion some providers may feel when working with transgender clients (CSAT, in press [b]).

Transgender people are a diverse group of individuals who cross or transcend culturally defined categories of gender. They can include the following:

- **Male-to-female (MTF) and female-to-male (FTM)** ***transsexuals***--those who desire or have had hormone therapy or sex reassignment surgery
- ***Cross-dressers*** **or** ***transvestites***--those who desire to wear clothing associated with another sex
- ***Transgenderists***--those who live in the gender role associated with another sex without desiring sex reassignment surgery
- ***Bigender persons***--those who identify as both man and woman
- ***Drag queens*** **and** ***kings***--usually gay men and lesbian women who "do drag" and dress up in, respectively, women's and men's clothing
- ***Female*** **and** ***male impersonators***--males who impersonate women and females who impersonate men, usually for entertainment

Gender identification is different from sexual orientation. *Gender identity* refers to a person's basic conviction of being male, female, or transgender. *Sexual orientation* refers to sexual attraction to others (men, women, or transgender persons). For example, many cross-dressers are heterosexual men who have active sexual relationships with women. Many homosexual men, although historically considered effeminate, identify strongly as men and appear very masculine.

Substance use plays a significant role in the high HIV prevalence in MTF transgender individuals. One study that investigated 519 transgender individuals in San Francisco found high rates of substance abuse among both MTF and FTM individuals. The study reported that 55 percent of the MTF sample indicated they had been in substance abuse treatment at some time during their lifetime. The study also found that HIV prevalence was significantly higher among MTF individuals

(35 percent) than FTM individuals (2 percent), and among the MTF individuals, HIV prevalence for African Americans was 61 percent. Although the HIV prevalence rate was low in the FTM individuals, they commonly reported engaging in many of the same HIV risk behaviors as the MTF individuals *(Clements et al.)*.

Counseling transgender individuals who are HIV positive and in substance abuse treatment can involve many different issues. Some of these issues are obvious: lack of family and social supports, isolation, low self-esteem, and internalized transphobia, to name a few. Some issues are not so obvious; for example, transgender clients currently undergoing hormone therapy often experience emotional and physical changes that can make treatment for substance abuse more difficult and relapse more likely. Although medically managed hormone treatment should not be interrupted, both the clinician and client must be aware that estrogen and testosterone therapies are mind- and mood-altering substances, particularly when incorrectly taken. Improper administration of estrogen mimics the premenstrual symptoms of non-transsexual women, which can have a deleterious effect on recovery (CSAT, in press [b]). These premenstrual symptoms can trigger or exacerbate Post Acute Withdrawal Syndrome, which is believed to be the leading cause of relapse.

Additional relapse triggers or clinical issues may include the following:

1) Inability to find, engage in, or maintain gainful employment due to employer prejudice against transgender individuals;
2) Lack of formal education or training because the client was forced to leave school or home before completing his or her education;
3) The fact that HIV-positive transgender clients may be denied sex reassignment surgery due to their HIV status, even if they are asymptomatic and healthy; and
4) The general lack of substance-free role models and widespread social support for transgender individuals.

Women

The needs of women have always represented a unique challenge to health care and substance abuse treatment systems. Traditionally, these challenges have not been well met and are being exacerbated by the growing number of substance-abusing women infected with HIV. The diseases of substance abuse and HIV/AIDS present differently in women than in men and progress at different rates for a variety of reasons, including the fact that women usually present later in the HIV/AIDS disease process than men.

Gender-specific services for women should include the following:

- Medical and substance abuse treatment that is accessible, available, and incorporates
  - ➞General health (including reproductive health) and wellness across the life span
  - ➞Mental health counseling (particularly for PTSD)
  - ➞Parenting skills and support
  - ➞Family-focused support
  - ➞Relationship issues
  - ➞Trauma/abuse support
  - ➞Educational/vocational services
  - ➞Legal services
  - ➞Sexuality and sexual orientation issues
  - ➞Eating disorder support
  - ➞Women-only support groups
    - Empowerment--that is, holistic programming that emphasizes the development of a partnership with a female service provider, one in which there are mutual respect and many opportunities for positive role modeling
    - Transportation services
    - Child care, both onsite and supervised
    - Woman-sensitive women working with women
    - Long-term case management services that extend to the client and her family

A woman's identity as caregiver/caretaker must be recognized as an extremely powerful factor in how she accesses care and treatment and how successful she is in her recovery and health maintenance. There is no question that this identity/role can explain why a woman seeks treatment ("for the kids") or why she leaves treatment ("to get home to my husband/partner/kids"). This is also a factor in a woman's sense of guilt and shame from becoming HIV infected--a societal stigma that only "bad girls" get HIV or are addicts or alcoholics, and the stigma of being an unfit mother if she has lost custody of her children.

Providers must be open and prepared to discuss safer sex and drug and alcohol abuse from a risk-reduction perspective. They must be well informed about and comfortable in discussing sexuality. Risk reduction is an ongoing type of intervention that goes beyond assertiveness training and teaching women how to put condoms on men. It recognizes the need to "start where the client is" and use appropriate interventions, which may help a woman reduce her risk of getting re-infected or of infecting a partner. This includes instructing female injection drug

users about how to use bleach to "clean their works," how to use a female condom, or how to use a vaginal spermicide foam (not the safest risk-reduction method, however) to lower their risk of HIV infection when having intercourse. It also involves making referrals to substance abuse treatment and instruction for male partners on how to use a condom correctly.

Hispanic Populations

The Hispanic population in the United States is diverse, composed of a wide range of racial, indigenous, and ethnic groups. The following are important statistics related to the U.S. Hispanic population that affect how outreach, prevention, and treatment planning should be conducted:

- Hispanics have the highest labor force participation rate of all groups.
- Hispanic men have the highest fertility rate of all groups across all ages.
- Hispanic men have the lowest divorce rate of all groups.
- Hispanic men are on average younger than other men in the United States (with median age of 26.2 years).
- Hispanic women seek detoxification and treatment for substance abuse disorders in lower numbers than women from any other ethnic/cultural group.
- 90 percent of Hispanics are Catholic.
- 36 percent of Hispanic children live below the poverty level.
- There is a clear increase in substance abuse as Hispanics become more acculturated (i.e., in second and third generations, and so on).
- Hispanics are overrepresented among HIV/AIDS cases for men, women, and children.
- Hispanics as a group may include aliens who are undocumented or carry immigrant visas (green cards) and who avoid contact with the health care system because they fear possible deportation.

Within the context of acculturation and socioeconomic status, providers should be aware of specific cultural issues that can support interventions and improve a provider's ability to engage Hispanic clients, such as the role of the family, the values of interdependence, respect, and "personalismo" (i.e., importance of personal contact). Understanding these concepts will help establish rapport and trust.

The Hispanic family is generally extended and has many members. A Hispanic client's support system may be composed of siblings, godparents, aunts, and uncles who are all very involved with the client. The family as a whole is of great importance, and often what is best for the family will override what is best for one of its members. Because the family is so important to most Hispanics, children are

highly valued. This makes it easier to see how some Hispanic women who are HIV positive grieve deeply about the decision not to have children and may feel unfulfilled and inadequate as a result. This also sheds some light on the challenges of involving Hispanics in substance abuse treatment. Leaving their children behind while in treatment or turning guardianship over to a State agency may be unacceptable and create more conflict.

Case Study: Heterosexual Minority Men

Often, families are aware of homosexual family members, but usually this is not discussed openly. The reality is that many Hispanic men who prefer sex with other men do marry and have children. This partly explains why Hispanics are at such high risk for HIV/AIDS. If the man has married and fathered a child, he has been congruent with the values relating to family; if he then goes out with men, or even with other women, this behavior may be tolerated as long as he continues to provide for his family.

African Americans

As is the case with members of other minority groups, the health and social repercussions of substance abuse problems are magnified in the lives of African Americans. In terms of past-year prevalence rates of illicit drug use, NHSDA found that the rate for African Americans (8.2 percent) was somewhat higher than for whites (6.1 percent) and Hispanics (6.1 percent). In addition, HIV/AIDS disproportionately affects African Americans, and from July 1998 through June 1999, injection drug use accounted for 26 percent of AIDS cases among African American males and 26 percent of cases among African American females.

African American women in particular have special needs. Minority women represent the fastest-growing segment of the U.S. HIV/AIDS pandemic. One study examined the psychological and social factors related to HIV risk among 153 African American inner-city women. The women completed measures of HIV risk history, sexual and substance use behaviors, perceived risk for HIV infection, self-efficacy to reduce risk (i.e., the belief that one can effectively perform specific behaviors), and perceived social norms supporting risk reduction. Fifty-five percent of the women reported at least one factor that had placed them at known risk for HIV infection.

Many African Americans have a deep-seated mistrust of the health system. This dates back to the pre-Civil War period when, because they were considered property and had no legal right to refuse, slaves were sometimes used in medical. A collective memory thus exists among the African American community of their

exploitation by the medical establishment. More recently, the syphilis study performed at Tuskegee University from 1932 to 1972, during which 400 African American men infected with syphilis were deliberately denied life-saving treatment, has fostered in some African Americans the belief that contact with health care institutions will automatically expose them to racist administrators and policies. Several articles point to the Tuskegee study as a significant factor in the low participation of African Americans in clinical trials and organ donation efforts and in the reluctance of many African Americans to seek routine preventive care.

A study that compared the use and perceptions of substance abuse treatment services among African American, Hispanic, and white substance-abusing arrestees confirmed that African American substance abusers were more likely than white substance abusers to hold unfavorable views of treatment. Another study examined the attitudes of African Americans in a northeastern city toward mental health treatment and found that only 34 percent of the sample felt positively toward community mental health centers. The study also revealed that women and married persons demonstrated more positive attitudes than did men and unmarried persons and that participants with a high tolerance of substance abuse possessed more negative attitudes than did others.

Counselors should be aware that the issues of slavery and institutional racism are constant and prevalent facts in the lives of many African Americans and should be addressed early in treatment so they are acknowledged, validated, and brought into the treatment process.

Many African Americans have strong social networks. They may have friends or a pastor with whom they might share information they would not share with a substance abuse counselor. These confidants might act as "co-therapists" for the client. It can be helpful for clients if counselors can identify and integrate clients' co-therapists into their substance abuse treatment plans. Along these lines, for African Americans with substance use disorders and HIV/AIDS, support groups of friends may be more likely to be helpful and less undermining than support groups of families. This is perhaps due to the lingering stigma of the ways in which HIV/AIDS is acquired--both intravenous drug use and homosexual activity are still highly stigmatized acts within many African American communities. Thus, activating family supports may be difficult, and providers should encourage clients to participate in support groups composed of their peers.

Asian Americans

Asians and Pacific Islanders are a culturally and linguistically diverse people from the Asian continent and the Pacific Islands. In the United States, they include nearly 40 different nationalities, 50 different ethnic groups, and more than 100 languages and dialects.

If we look at HIV diagnoses by race and ethnicity, we see that African Americans are most affected by HIV. In 2015, African Americans made up only 12%* of the US population but had 45% of all new HIV diagnoses. Additionally, Hispanic/ Latinos** are also strongly affected. They made up 18% of the US population but had 24% of all new HIV diagnoses.

The increasing size and diversity of the Asian and Pacific Islander population make it difficult to discuss group norms regarding substance abuse. Norms for alcohol and tobacco use vary by culture and there appear to be no norms governing the consumption of narcotics or other substances.

Service providers also should shed the notion of the "model minority," which often typecasts Asians and Pacific Islanders and limits treatment access. Often, Asians and Pacific Islanders believe the model minority myth and feel isolated when they test positive or report substance abuse disorders. They may also feel they have let down their families and communities.

Despite differences in cultural norms and mores among Asians and Pacific Islanders, cross-cultural beliefs in the importance of group and collective identity, service, and responsibility suggest the use of treatment strategies that incorporate biological or constructed families and communities rather than a focus on individual behavior change. Moreover, treatments that emphasize nonverbal or indirect communication skills, not confrontation, may be more culturally appropriate and more effective. Most American treatment modalities rely heavily on verbal therapies that require direct verbal emotional expression and a high level of personal disclosure. Many substance abuse treatment programs favor a confrontational approach, and many HIV/AIDS programs favor support groups and psychotherapy. These treatment approaches, unless modified for Asian and Pacific Islander clients, are often unsuccessful because they violate Asian and Pacific Islander cultural norms. By American standards, Asians and Pacific Islanders tend to communicate more indirectly, often by telling stories and discussing what happened to themselves and others. Their feelings and opinions are implied rather than directly stated. Asians and Pacific Islanders are also less likely to provide

direct verbal expression of their feelings by using "I" statements than are members of other groups. Providers should expect to reveal personal information about themselves if they want clients to disclose their own problems. Asians and Pacific Islanders may prefer to keep strong feelings under control so that they will not become disruptive. Caring is often demonstrated by physical support such as by giving money, cooking favorite foods, or giving advice rather than by verbal expression or physical affection.

A problem solving approach rather than an intra-psychic one is more effective with Asian and Pacific Islander clients. Problem solving enables a counselor to provide information, educational materials, and referrals without probing for more personal information and pushing a client to express feelings. For Asian and Pacific Islander clients with somatic complaints, suggest relaxation and breathing techniques, meditation, qigong, yoga, massage, acupuncture, tai chi, or biofeedback. It is generally not helpful to discuss underlying feelings because it is not only culturally unacceptable, but many Asian and Pacific Islander clients do not see the emotional-physical connection. In problem solving, providers should actively give suggestions and if necessary, be directive rather than let Asian and Pacific Islander clients struggle to figure out what options are available to them.

Asking personal questions about substance abuse and sexual risk factors, especially early in the helping relationship, could be viewed as intrusive and disrespectful. Asian and Pacific Islander clients may not answer truthfully, if at all, and may not return. It is best to start with the least intrusive or nonthreatening questions during the intake and explain why the information is needed. If clients seem uncomfortable with certain questions, ask them at a later date.

Asian and Pacific Islander clients may not initiate contact when they have a problem because of cultural tendencies to minimize problems to reduce stigma and because they do not want to be intrusive and bothersome. In all interactions, it is helpful to minimize the stigma Asian and Pacific Islander clients attach to their HIV/AIDS status and substance abuse disorders. Counselors should not refer to themselves as HIV/AIDS, mental health, or alcohol and drug counselors unless they know the client is comfortable with this. These titles imply the client has an unacceptable condition and can increase stigma. Clients may be more receptive to treatment for HIV/AIDS and substance abuse issues if they are combined with other, less stigmatized health issues.

Group interventions can be effective if everyone speaks the same language well enough and if the group is centered around an unstigmatized activity, social

gathering, or education session. Providing refreshments also facilitates bonding. Asian and Pacific Islander participants will look to a facilitator to provide direction and guidance. Rather than be assertive in talking, Asian and Pacific Islander clients will more likely wait for a space to open up for them to speak and consequently will rarely have the opportunity to do so when in a group with predominately non-Asians and Pacific Islanders. Should this happen, the group leader needs to facilitate opportunities for Asian and Pacific Islander clients to participate.

Native Americans

The CDC found that Native Americans have high rates of STDs and substance abuse, which in turn raise their risk of HIV/AIDS. They also lack access to diagnosis and treatment. Gay men and substance abusers run the highest risk of HIV/AIDS among Native Americans and Alaskan Natives, just as they do among white Americans.

The combination of high rates of cofactors for HIV/AIDS, limited access to health care, lack of information and education about HIV/AIDS issues, substantial numbers of Native Americans who are already infected with HIV, and the flow of Native Americans between urban centers and reservations all lead to an HIV/AIDS crisis for Native American communities.

Limited treatment services for HIV-infected substance abusers exist on and outside tribal lands. In 1991, the American Indian Community House, which ministers to the health, social service, and cultural needs of Native Americans in the New York City area, created the HIV/AIDS Project, the first Native American program east of the Mississippi River to provide culturally sensitive legal services, HIV/AIDS treatment information, emergency assistance, and prevention education. The Friendship House Association of American Indians in San Francisco provides another example of treatment (drop-in centers). This program provides comprehensive treatment to Native Americans living with HIV/AIDS as well as treatment for substance dependency. Services target the gay, lesbian, and bisexual communities. HIV/AIDS is presently underreported for Native Americans and is based on the high incidence of sexually transmitted diseases (STDs) in general, and thus substance abuse treatment centers will be faced with more and more HIV-infected Native Americans.

Clients involved with the criminal justice system

Many persons with substance abuse disorders receive treatment only after arrest and are offered treatment as a diversionary service or receive treatment while they are in jail or prison. The racial and class patterns characterizing arrest,

adjudication, and sentencing in the United States skew more white Americans (regardless of social class or income) to treatment trajectories and more persons of color to jail or prison trajectories. Access to treatment within the criminal justice system is thus highly associated with ethnicity and social class. Only a handful of correctional facilities in the United States have instituted some type of therapeutic community treatment program in prison with a parallel transitional program for new parolees. Unfortunately, many HIV-infected individuals who are in treatment for HIV find it impossible to remain on their medication schedules after being arrested because their medications are often confiscated for days at a time.

Risky behaviors that lead to HIV infection are not eliminated when a person is imprisoned but may actually increase in frequency and availability. This occurs for several reasons. First, drug offenses count for the single largest number of Federal and State crimes for which people are arrested and incarcerated. Injection drug users face particular risk in prison settings as clean syringes are all but impossible to secure. Although syringes are not officially available, they can be acquired through illicit prison markets at exorbitant prices ($34 in one Canadian facility) or through risky exchange of syringes for unprotected sex. Syringes are typically not new or sterile. As a result, injection drug users have as their only recourse used or shared syringes, which increases their chances of HIV infection. Tattooing is also common practice among prisoners and is another source of HIV infection. To date, there have been at least two documented cases of HIV/AIDS related to tattooing with unsterile needles in a correctional facility.

Only six prison systems in the United States distribute condoms: Mississippi, New York City, Philadelphia, San Francisco, Vermont, and the District of Columbia. Distribution strategies range from receipt of a single condom per medical visit to receipt of multiple condoms during HIV/AIDS education workshops. Furthermore, condom distribution programs send mixed messages because sexual activity in some facilities is illegal and a punishable offense. In other facilities, correctional medical and social service staff may advocate condom availability while administration and security officers oppose it. Sixteen prison systems mandate HIV testing, and although 77 percent make testing available to inmates on request, few inmates request it for several reasons. First, confidentiality of results is not guaranteed. Second, mandatory testing may result in the segregation of those who test positive from those who test negative or who do not test. Third, prisoners do not wish to acknowledge activities that could subject them to further sanctions. Fourth, confidentiality on discharge is eliminated because the Federal Bureau of Prisons requires HIV testing for all inmates on their release. HIV-positive inmates are asked to directly notify sex partners and significant others of the results.

However, the Bureau of Prisons handles only a small percentage of inmates, and its policy is not the norm.

Treatment for HIV-positive inmates is often inadequate when available. Primary medical care may be limited to *Pneumocystis carinii* pneumonia prophylaxis and HIV monotherapy. Combination therapy may not be available or accessible to inmates, given the cost of medications, limited storage, refrigeration requirements for some medicines, and the strict adherence regimen required by combination therapy, which would require round-the-clock monitoring and assistance by typically unwilling and suspicious security staff.

Although there are large numbers of substance abusers within correctional facilities, less than 15 percent participate in treatment programs. This is partly because of lack of program availability and the common type of program offered (i.e., 12-Step, abstinence-based.). When persons with substance abuse disorders in treatment relapse, as is often the case, they may also engage in risky sexual behaviors. They are most likely to engage in risky sexual behaviors with sexual partners from similar treatment networks. These partners may include people who have used syringes, traded sex for money or drugs, or been victims of trauma. All of these populations are likely to have higher rates of HIV infection, making transmission likely.

Inmates who do complete or participate in treatment programs often rapidly relapse on discharge. For inmates who do complete treatment, there are often no aftercare programs to help them remain substance free.

Adolescents

Adolescents are another group that is experiencing an increase in incidence and prevalence of HIV. Since 1994, findings from the Monitoring the Future surveys have revealed a dramatic and sustained increase in consumption of licit and illicit drugs among adolescents--this after nearly two decades of sustained decrease in drug consumption. Studies also note that teens are having sex earlier than ever before, often with multiple partners and inconsistent use of condoms, putting them at greater risk for HIV/AIDS. Beyond this, young people find themselves marginalized in U.S. society; this is especially true for young gay and bisexual youth, sexually active young women, and young people of color.

According to the CDC, AIDS is the fifth leading cause of death for Americans between the ages of 25 and 44. At greatest risk are young, disadvantaged females, particularly African American females, who are being infected with HIV at

younger ages and higher rates than their male counterparts. Because of the long and variable time between HIV infection and AIDS, surveillance of HIV infection provides a clearer picture of the pandemic in young people than surveillance of AIDS cases. From the States for which HIV is a reportable condition, young people ages 13 to 24 accounted for a much greater proportion of HIV than AIDS cases *(Source: CDC)*.

Adolescents may benefit from treatment that is developmentally appropriate and peer oriented. Addressing educational needs may be particularly important as well as involving family members in the planning of treatment and therapy. Substance abuse among adolescents is frequently associated with depression, eating disorders, and sexual abuse history. Histories of familial sexual and substance abuse are predictive of serious adolescent substance involvement and subsequent treatment needs.

Older adults

The last few years have witnessed greater increases in the number of HIV/AIDS cases among middle-aged and older individuals than in those under 40 years of age. Women comprise a greater percentage of all AIDS cases as age increases, ranging from 13 percent of AIDS cases among people aged 50-59, 15 percent of AIDS cases among those aged 60-69, and 21 percent of those 65 and over. For women with HIV, 22 percent of this group is in the 50-59 age bracket; 24 percent is aged 60-64; and 31 percent aged 65 and older. The rate of HIV infection in older women reflects the greater incidence of surgeries (such as hysterectomy) that require blood transfusions.

Although many of these AIDS cases are the result of HIV infection at a younger age, many people become infected after age 50. Rates of HIV infection among older adults are difficult to ascertain because very few people over 50 years of age routinely test for HIV. Because older adults are diagnosed with HIV/AIDS at advanced stages, older adults are less amenable to treatment, become sicker, and die faster than their under-50 counterparts. In addition, retroviral treatments and opportunistic infection prophylaxis may interact with medications the older person is taking to treat other preexisting chronic illnesses and conditions. Also, the vast majority of medication studies are done on much younger subjects. There is little research on the metabolism of anti-HIV drugs in older adults.

There is, as well, little research on the substance-abusing behavior of older adults, and very few substance abuse treatment programs address the needs of older adult substance abusers. Unfortunately, many medical professionals do not consider

older patients to be at risk for either substance abuse (with the exception of alcohol use) or HIV infection. A study in Texas found that most doctors never asked patients older than 50 years questions about substance abuse or HIV/AIDS or discussed risk factor reduction. Doctors were much more likely to rarely or never ask patients over 50 about HIV/AIDS risk factors (40 percent) than to rarely or never ask patients under 30 (7 percent). Older persons may not be comfortable disclosing their sexual behaviors or substance abuse to others, since their generation or culture may not encourage such disclosures. This can make finding treatment programs and support programs especially difficult. Certainly, there is a need to educate service providers about the sex- and substance-related behaviors of older persons. At the very least, service providers should conduct thorough sex and substance abuse risk assessments with their patients over 50, and challenge all assumptions that older people do not engage in these activities or will not discuss them.

Sex industry workers

Among sex workers, street prostitutes are the most vulnerable to HIV infection, given the coexisting features of poverty, homelessness, history of childhood sexual abuse, and alcohol and drug dependence. Comparatively, male and female sex workers who work in massage parlors, escort services, their own apartments, or brothels rather than on the street are far less likely to be at risk for infection, less likely to depend on substances, and more likely to control sexual transactions and insist on condom use. Seroprevalence rates among sex workers vary dramatically. A 1990 study of nearly 1,400 sex workers in six U.S. cities yielded a seroprevalence rate of 12 percent, ranging from 0 to 47 percent as a function of the city and the level of injection substance abuse. Most alarming was the high association of injection substance abuse and HIV infection rate.

Among female sex workers, IDU continues to be the major cause of HIV infection. Female injection drug users who trade sex for money or drugs are more likely to share syringes than injection drug users who do not exchange sex for money or drugs. Drug use also increases the likelihood of sex work and risky sex. Studies of crack cocaine abusers in three urban neighborhoods found that 68 percent of the women who were regular crack smokers exchanged sex for drugs or money. Of those, 30 percent had not used a condom in 30 days. Recent research has also demonstrated an association between HIV infection, heavy crack use, and unprotected fellatio. This is likely due to the combination of poor dental hygiene, damage to the mouth from hot crack stems or pipes, high frequency of fellatio, and inconsistent or marginal condom use. Street-based sex workers may agree to

unprotected sex if clients offer more money, if workers themselves are desperate for money to buy drugs, or if activity has been slow.

HIV treatment challenges may occur given the sex workers' more immediate needs for drugs, food, and housing. These needs overshadow future concerns about living with HIV/AIDS. Beyond this, sex workers with HIV/AIDS may continue to work routinely for the purpose of exchanging sex for drugs or money. Sex workers thus run risks of spreading HIV/AIDS as well as reinfection of HIV and the acquisition and transmission of other diseases such as hepatitis and STDs.

There are many examples of effective treatment programs for sex workers with substance abuse disorders, including the California Prostitutes Education Project (CAL-PEP); Sisters Helping Each Other in Chicago, Illinois; Second Chance in Toledo, Ohio; the Threshold Project in Seattle, Washington; Alternatives for Girls in Detroit, Michigan; and the On the Streets Mobile Unit-Options Program in New York City. Most of these programs use former sex workers as outreach staff, use a risk-reduction model of care, and establish linkages with organizations in the treatment continuum.

Homeless people

Homeless people suffer higher rates of many diseases, including HIV/AIDS and substance abuse disorders, than the general population. No national statistics exist, but studies within major U.S. cities are illustrative.

5.10 Individual Therapy Strategies

Clients may raise several issues in therapy that then become clinical issues. Following are common issues that clients raise during the inpatient treatment process along with suggested responses from the counselor during individual therapy:

- Feeling the problem (of HIV infection or living with AIDS) has not "hit them" yet. The counselor can provide the client with education about risky behaviors, living with AIDS, and so on. Presenting the client with future scenarios and life trajectories if behaviors remain unchanged may be helpful. Sharing success stories about positive changes in peers may also be a helpful strategy.
- Expressing the need to make their own decisions and choices regarding care, treatment, and their lives. Counselors should underscore the fact that clients must decide what is in their best interests, taking care to define "their best interests" within the client's definition of self as either an individual, a provider, a parent or caregiver, a member of a family or community, or a combination

thereof. Counselors should balance this by letting clients know that no one has all the answers to their problems, and reassure clients that their feelings are valid, not unusual, and realistic. Changing one's life is hard work.

- ➡ Knowing how to change behavior, yet not making these changes. The counselor should support client efforts to reduce risk behaviors but educate the client as to why risk remains. Exploring what the client is willing to consider changing provides an outline of possible actions. Working together with the client on strategies to resolve barriers to change in small steps may be a useful tactic as well.
- ➡ Giving up hope for change or feeling overwhelmed by problems. Workers should reassure clients that their feelings are typical and that change is hard. Telling clients about positive role models who have successfully changed after facing many difficulties along the way is another useful approach.

Service providers should know that this initial phase of client change is the longest and most difficult for many clients. It is not uncommon for clients to spend a lot of time in inpatient treatment weighing the pros and cons of their behavior. Clients may have invested much energy in intentionally not thinking about the problem. Thinking about the problem may release painful issues (real or perceived) for clients that they have not allowed themselves to reflect on. Service providers should be acutely aware of the power of denial for many substance-abusing clients living with HIV/AIDS.

It is often difficult for the client to anticipate potential problems, interactions, and pitfalls, particularly those that will be faced in the external community. The counselor must help the client examine the barriers that may arise and develop strong responsive coping skills and activities. A weak plan of action can lead to quick lapses and relapses. This level of client activity (preparing for action) is characterized by switches in both personal external cues for behaviors and the ways in which clients perceive and cope with internal situations. This is a time for counselors to develop specific plans and identify individuals in a person's social environment who may provide support or information to the client upon discharge.

The idea of self-liberation can be used to influence a client to choose to act in a specific manner or believe in his ability to change. Clients can benefit from thinking about what may change once the new behavior(s) have begun so they can be prepared for those changes. Questions similar to the following can be used to facilitate self-liberation:

- ➡ Is this what you want to do? Are you prepared for the risks involved?
- ➡ What are your reasons for changing your behavior?

- ➡ When do you want to make your change?
- ➡ What problems do you think you may face in the future?
- ➡ Whom have you discussed this with?
- ➡ How do you feel the environment is going to affect your change?
- ➡ Are there any support groups you could join in the area? Would you like to join any?

5.11 Group Therapy Strategies

The gains made in individual treatment can be consolidated in well-designed and well-facilitated group therapy. Consciousness-raising techniques may help when talking with a client who seems to lack basic information about behaviors or topics, such as HIV transmission. Questions such as the following can determine how much consciousness raising is needed:

- ❖ What are your concerns about HIV/AIDS?
- ❖ What do you think about "cleaning your works" in order to protect yourself?

Dramatic relief strategies can be used when talking with a client who knows something about topics like HIV/AIDS but still engages in unsafe behavior. Questions such as the following are helpful in determining the level of dramatic relief strategies:

- ❖ Do you feel you are at risk for HIV/AIDS?
- ❖ Do you worry about getting an STD?

Group therapy also can be used to present role models (peers) who have successfully addressed many of the issues clients in inpatient treatment may face. Peer programs can provide support for substance recovery and other psychosocial services. There are many resources in the community for these interventions; all a program must provide is a meeting place. It is helpful if the peer group facilitator has some training, even if this consists solely of the orientation that all substance abuse treatment program volunteers receive. Because they are not led by professionals, peer groups may be limited in what they can achieve. However, the absence of professional involvement may give peer groups greater credibility with hard-to-reach clients.

Self-reevaluation (or self-reflection) and environmental reevaluation are good activities to use in group settings during inpatient treatment when clients might be motivated to change behavior. Self-reevaluation occurs when clients think about their behavior, and environmental reevaluation occurs when they think about the

impact of their behavior on others. A clinician can initiate self-reevaluation by asking questions such as the following:

- Are there times you are willing to take risks by not using a condom? Why or why not?
- How often do you think about HIV/AIDS?
- Do you ever worry about getting something from your partner? What do you worry about? Why do you worry?
- Do you ever worry about giving something to your partner? What do you worry about? Why do you worry?

Environmental reevaluation can be facilitated with questions such as the following:

- How does your partner (partners) feel about using condoms?
- How would your partner (partners) feel if condoms were used?
- Do people close to you ever talk about your addiction? What do they say?
- Do people close to you ever talk about HIV/AIDS? What do they say?
- How does your addiction affect people who are close to you?

Group therapy in inpatient settings can be very helpful in setting the stage for actual behavior change. It is challenging for clients who have started to change behavior within a structured setting to continue the change when they return to the less structured environment from which they came. This environment may not necessarily support newly acquired lifestyle changes.

Stage of HIV Infection

Segregating groups by stage of HIV infection presents difficulties, but not doing so can also be problematic. Clients who are HIV positive but asymptomatic and attending a support group for the first time may be uncomfortable when encountering clients in the late stages of AIDS. Such a meeting may force them to confront fears about their own mortality before they are ready to do so.

Because treatment programs have limited resources, separating groups by stage of HIV infection may be impractical. Programs able to support separate groups may wish to use the three-group model, with groups consisting of

- Clients newly aware of their positive HIV status
- Those who are asymptomatic or mildly symptomatic
- Those with more advanced disease

The interplay between substance abuse disorders and HIV infection in groups can be complicated. As clients move further into substance abuse recovery, they may

be getting progressively more ill from HIV disease. In a mixed group, healthier clients may provide support to sicker ones.

In a group consisting solely of clients symptomatic with AIDS, members are vulnerable to becoming involved in a process of continual grieving. Sometimes groups have to discontinue for a period of time when too many members become sick or die. For this reason, it may be helpful to establish support groups for time-limited periods.

5.12 Outpatient Treatment

Outpatient treatment consolidates the gains made in the detoxification and inpatient and residential treatment levels of care. Typically, clients may still need to think about change or begin to plan for change on their discharge from inpatient or residential treatment. On entering outpatient treatment, clients may have actually begun some behavior change, but the novelty of the change can lead to relapse as the client moves away from the controlled and structured environment.

Clients in outpatient treatment usually need support from at least one other person who cares about them. This can be a time when clients are vulnerable because as they change, others around them may change in response. Friends and significant others may feel threatened, abandoned, jealous, or angry and may try to sabotage the client's efforts. This puts tremendous pressure on clients because they are experiencing new feelings and new, difficult ways of life. Although many of these life changes may be positive, they are also unfamiliar for many clients.

During outpatient treatment, group therapy could focus on the use of successful peers in modeling helpful but difficult strategies such as stimulus control and counter conditioning. Individual therapy will involve helping the client balance and coordinate recovery with other issues, such as assessing client responses and concerns with case management, care coordination, and child and family issues when relevant.

Stimulus control and counter conditioning are two strategies clients may find helpful. Stimulus control helps clients restructure their environment so they can avoid circumstances that elicit problem behaviors. There are three methods for managing tempting stimuli:

✓ Develop a plan for managing the situation.

- ✓ Manage the situation so the temptation does not occur. For instance, a person who knows alcohol puts her at risk for unsafe sex will not drink when sex may occur.
- ✓ Restructure the environment so that stimuli for more positive events occur and so clients remain aware of people, places, and things that cause relapse.

In developing stimulus control strategies, consider developing questions such as the following:

- ➡ What are the situations where you may be at risk of not using a condom?
- ➡ How can you avoid them?
- ➡ How do you stay safe when you have sex?
- ➡ Where do you keep your condoms?
- ➡ What are the situations in which you find yourself using substances?

Counter conditioning involves exchanging risky behaviors with less risky alternatives in situations that are not amenable to stimulus control. To develop counter conditioning strategies, questions such as the following can be used:

- ➡ If you found yourself in a situation where you were tempted to have sex without a condom, how could you deal with it so that you could have safer sex?
- ➡ How would you deal with a situation where you insisted on having safer sex and your partner got angry?

A major risk during outpatient treatment is the involvement of the client in sexual networks and sexual mixing. Many clients in treatment may select sexual partners from similar networks (recovery programs, 12-Step meetings, and so on). These partners might include persons who have used syringes, traded sex for drugs or money, been victims of trauma, or been incarcerated. All of these populations may have higher rates of HIV infection, making transmission more likely, and clients should be counseled about these risks.

Drop-in Centers

Drop-in centers are an excellent way to engage homeless people in treatment. These centers offer a needed service for substance-abusing individuals who are homeless. As individuals start dropping in, they begin to interact with staff and form trusting relationships, which builds a necessary foundation for beginning treatment. The use of maintenance strategies characterizes treatment in drop-in centers. At this phase, service providers must work to prevent relapse and bring together the gains achieved during inpatient and outpatient treatment. During this

time, clients may have learned to adjust their new behavior to the environment in which they live, and the behavior has perhaps become habitual.

Also during this time, many clients relapse and may return to earlier treatment levels and milestones. As discussed elsewhere, there are many factors leading to client relapse. Situations such as breaking off relationships, starting new ones, severe temptation, or lack of environmental support may contribute to relapse. In addition, the client can easily choose not to try again due to the negative feelings associated with relapse such as shame, embarrassment, guilt, failure, regret, anger, or denial.

Service providers may work with clients so that they can realize that their past successes indicate better chances of success in the future. They should underscore the fact that clients have learned new ways of coping with old behaviors and have developed supportive relationships. Service providers may find the use of reinforcement management a helpful strategy that can be facilitated in either individual or group level modes. Reinforcement management helps clients develop internal and external reinforcers and rewards that increase the chance of new behaviors continuing.

Workers can also reassure clients that relapse encounters are part of an ongoing process. Helping clients determine what caused the slip can be useful in helping them develop strategies to avoid lapses in the future. Workers can also work with clients to help them learn more about themselves, their environment, and their addiction and risky behaviors. Questions similar to the following can help determine if clients need better or more reinforcement management:

- Do you feel good about your new behavior?
  - What kind of things do you tell yourself, knowing you are practicing safer sex?
  - What kind of things do you tell yourself, knowing you are controlling your substance abuse?

5.13 Counseling Terminally Ill Clients

The counseling of ill and dying clients should be supportive and non-confrontational, addressing issues relevant to the client's illness at a pace determined by the client. However, clients are not the only ones to be affected by the approach of death; counselors too may need assistance in dealing with clients' deaths. This section addresses the issues of denial, planning for death, pain management, unfinished business, and bereavement. A five-stage bereavement and

loss model, based on Elisabeth Kubler-Ross' book *On Death and Dying*, also is presented.

Denial

Denial about a client's HIV/AIDS diagnosis can be experienced by both clients and counselors. Denial is a natural response and should be confronted only if it causes harm; for example, when a client in denial about his illness delays in making arrangements for medical and nursing care or procuring assistance with daily living activities. Counseling can play an important role in helping clients accept their illness and the eventual need for home health or hospice care.

Denial can also affect counselors. For example, because of the advances being made in the medical treatment of HIV/AIDS, a counselor may be in denial that a client will die of AIDS. Counselors must recognize and confront their own denial issues so that they are able to discuss death and dying and realistically explore these issues with their clients. Programs need to have in-service education and proper supervision for counselors who work with terminally ill clients. Proper supervision will help the counselor confront her denial and help lessen her stress.

Planning for death

It is often difficult for a counselor to know how or when to talk to a client about planning for death. It is optimal, if possible, to begin a discussion of the client's future, including death, before the client is extremely ill. Questions that often lead the counselor into a discussion of death and dying, and also are centered on contingency planning, include, "if you were to become too ill to care for yourself any longer, what would you do, who would help, where would you go?" The counselor and client should also consider where the client would like to die because different arrangements may be required.

Clinicians who will be working with clients at the end stages of AIDS should examine their own beliefs about death and dying. In addition to this, counselors may need to learn about the physical and biological process of dying so that it can be explained to clients. It is also important to keep in mind that clients' perspectives on death and dying are deeply rooted in their personal histories, religious practices, ethnic customs, family traditions, and community standards.

Many clients fear dying alone or in pain, or of losing control of their bodily functions, and thus having to rely on others for care. If clients want to talk about this personal and often frightening experience, the counselor should listen and help the client locate answers to any questions concerning the process of dying.

Clinicians should ask their clients how much they want to know and make sure that clients know what to expect physically. Understanding the process and planning the details within their power can give clients a sense of control.

In addition, clients may ask counselors to share their own beliefs about death and dying. Minimal sharing can be reassuring, but counselors should focus on the clients' perspectives, beliefs, and needs. As counselors listen, valuable information and insight into possible resources and support needed by clients will come to light.

Pain management

Pain management is often a difficult struggle with those who are in the end stages of AIDS. The issue of pain is complex because many medical conditions related to a client's HIV/AIDS can cause her pain. Clinicians may be concerned that pain medications may reinforce an addiction. Also, clients who have achieved abstinence from drugs may not wish to use medications for pain relief. Another concern of clients is the appropriateness of pain management when it might hasten death. If a client raises this issue, the counselor should be prepared to discuss it, however, the counselor does not initiate discussion on this topic. If the topic arises, clients should be encouraged to discuss pain management issues with their physicians and, if appropriate, their significant others.

Unfinished business

One important area that counselors should explore with their clients is "unfinished business." For example, a counselor might suggest that a client make a will. But there may remain other issues to be addressed. Should a client consider making an advance directive or a living will? Will the client want to appoint a health care proxy? Should he consider granting power of attorney to a significant other? Should he appoint a guardian for his children? Are there family issues that he wants to address?

Some clinicians express a desire to be there at the time of a client's death, or a client may request that someone be there until death. Counselors and health care providers may also spend more time counseling the client's significant others or support people during this time than they spend counseling the client. Here again, a little information can go a long way to reduce fear and anxiety in clients and their significant others.

Bereavement

Bereavement is a particular problem for programs with large numbers of HIV-infected clients. Bereavement can affect clients (who may grieve at the deaths of other clients, friends, or loved ones from HIV/AIDS); clients' significant others; and counselors who work with dying clients. The following strategies may be helpful in supporting those clients who are dealing with bereavement.

- Acknowledge the reality of the bereavement in supportive individual counseling.
- Encourage the expression of grief both verbally and nonverbally (e.g., art therapy, expressive movement, psychodrama).
- Provide group support for clients and their significant others who are experiencing grief and bereavement.
- Acknowledge deaths with memorial services, flowers, photographs, and participation in commemorative projects such as The NAMES Project Foundation's AIDS Memorial Quilt, which attempts to include the names of everyone who has died of AIDS.

Kubler-Ross bereavement and loss model

One of the best and most often referred to models of bereavement and loss comes from physician and psychiatrist Elisabeth Kubler-Ross. In her book, *On Death and Dying*, she provides a five-stage theory that has become common language when dealing with death and dying. Her model of bereavement is essentially a series of defense mechanisms, or coping strategies, that are used by an individual confronted by death. These stages can also be observed as individuals are confronted with other traumatic circumstances or information, such as a positive HIV test, an HIV/AIDS diagnosis, or the death of a friend or peer. The five stages are denial, anger, bargaining, depression, and acceptance.

Individual interpretations of and responses to death and dying vary greatly, not only between people, but between cultures and religions. Yet, as this model eloquently describes, adjusting to death is a process, not an event that occurs seamlessly and in a logical sequential order. The coping strategies and stages described below are not a recipe for health. Acceptance may not be the goal for everyone. Emotional processing is made more challenging when survival needs such as shelter, food, and medical care are not being met. Many clients are used to surviving with "street smarts" and not by psychoanalytical parameters and discussions about childhood. This model is included merely to help providers understand and relate to their experiences and their clients' experiences.

- **Denial:** An effort to psychologically buy some time while adjusting to the information or situation. It is here that people can feel the most isolated and the most suspicious and doubtful of the information that they are receiving. Denial is a natural and healthy response. It is not necessarily something that counselors must feel compelled to confront and rid clients of at the earliest possible moment. Allowing clients to have denial can be challenging, and for the caregivers and support staff it can be anxiety producing, but it is important to remember that above all else, this is the client's experience. Denial is not always negative. The times that denial must be confronted are when it causes a danger to self or others.

- **Anger:** This stage emerges as the person accepts the diagnosis and begins to strike out. The most common targets for this anger are the people closest and safest to him, especially caregivers and service providers. Anger can also be a test. The person facing death may want to know who can be counted on as the end nears. This can sometimes be indirectly demonstrated by the client who may test the counselor's tolerance of anger; if the anger can be tolerated, perhaps the counselor can be trusted to tolerate the client's death and feelings of fear.

- **Bargaining:** Bargaining is the stage at which the individual commits to an uncommonly generous or humanitarian act with the belief that she will be spared or miraculously cured if deemed "good enough." The goal is a miraculous correction of the wrongs she has done, or possibly to buy some valuable time for treatment or dealing with end-of-life issues. The obvious danger is that most are not "cured" in that sense of the word, so what can happen is a loss of belief or faith.

- **Depression:** Depression represents a loss of denial, and an acknowledgment that the information is accurate and the situation and its consequences are unavoidable. As with clinical depression, the depth and severity depends on the specifics of the situation, mitigating factors, available resources, and the individual. This stage is marked by surrender to sadness; it is appropriate and adaptive. It is a time to collect resources and energies so that more processing can occur at a later time.

- **Acceptance:** This is the stage in which some come to terms with their situation and feel a welcomed release from struggle and strife. Option formation and reality-based planning, given the circumstances, become the focus. Acceptance

occurs when there is agreement between the physical body, the emotional heart, and the cognitive mind, that death will eventually be the outcome.

No code or do-not-resuscitate orders

The responsibilities for determining when, how, and under what circumstances to evoke or effect no code or do-not-resuscitate (DNR) orders are properly the role of the family, or those with power of attorney, and the physician. The order itself comes from the physician or from the client through the physician. Although alcohol and drug counselors do not initiate discussion of this topic, they should be aware of these terms and what they mean so that they can help prepare and inform the client and his family of these options.

No code and DNR are terms used while a client is receiving care at an inpatient facility to identify a client who does not wish to receive medical intervention to save his life. For example, if a client has a DNR order and his heart stopped, he would not receive electric shock or cardiopulmonary resuscitation. It is the framing of these decisions and the terms used to help clients understand them that make all the difference. A counselor can help clients and their families talk about these concerns by first normalizing the process. That is, to present issues as no codes or DNRs, wills, and guardianship of minor children as decisions each person or family must come to grips with--whether they are ill or not, HIV positive or not. Counselors can approach and begin to discuss these issues within a context of "hoping for the best and planning for the worst." The discussion, then, is not related to being terminally ill, but rather to choosing, taking control, and making difficult, responsible decisions.

It also is helpful for the client or the family to discuss with the physician changing the goal of medical treatment. For example, at some point in the treatment process, when death is imminent and further aggressive medical intervention will be futile, the goal of treatment could be changed to "comfort care" from "no code."

Some States also permit a person who has been discharged from a hospital to home to have a DNR, which can be tacked to the door. The drawback of home DNRs is when a client dies and emergency medical personnel arrive, in most places they are required to try to revive the client. A counselor should be familiar with State laws about home DNRs so that a client who wants to die at home can be given the best information about this option.

Health care providers and counselors must maintain a sense of how their communication efforts are affecting the people they are trying to help. A specific

and practical example of this is in discussions around no code or DNR orders. As health care providers discuss treatment options with clients and their significant others and the possibility of changing the goal of treatment to comfort care, one distinction that can be helpful for some people is the difference between "life support" and "death prolonging."

The current standard of care as defined by the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) states that providers should develop a framework for decision-making in situations that may require the withholding of resuscitative services or the foregoing or withdrawing of life-sustaining treatment. Decision-making in such cases should reflect the following priorities*:*

- Enhancing the client's comfort and dignity by addressing treatment of primary and secondary symptoms
- Effectively managing pain
- Responding to the client's and his family's psychosocial, spiritual, and cultural needs

Many believe that decisions about medical treatment should not be based on "heroic" or "extraordinary" measures, or on medical complexity. They should be based on the potential outcomes and the benefits and burdens to clients and their support systems. An open and honest dialogue with the client, followed by a similar meeting with the entire care team, can facilitate decisions and move people to a place of comfort and resolution. Many States allow an individual to designate someone to serve as their "Durable Power of Attorney" for health care. Staff and clients should know what the State's regulations are.

Assisting Clients in Preparing Their Children for the Loss of a Parent

It is estimated that the number of children orphaned by HIV/AIDS will increase by 200 percent in the next 20 years. Parents living with HIV/AIDS face a multitude of issues in preparing both seropositive and seronegative children for the loss of their parents. Fortunately, the child care system is developing credible guidelines on working with children with parents living with HIV/AIDS. In addition, placing a focus on providing for the future care and maintenance of the children can serve as a cause for personal motivation and empowerment. Pragmatically, clients should be assisted in preparing their children for the loss of parents in the following areas:

- **Legal guardianship**. Workers should help clients identify significant others or friends within the client system who could serve as legal guardians for their children. By stressing that children without legal guardianship become wards of the State, clients sometimes find the motivation to search for and secure guardians for their children. Workers should understand that the search for

guardians for children of clients with substance abuse and HIV/AIDS-related issues can be difficult because clients often have exhausted their support system of family and friends well before involvement in formal treatment systems or programs.

- **Standby guardianship**. A standby guardian is someone who agrees to stand ready to assume guardianship (legal responsibility) for a minor when the parent of that child dies or becomes incapacitated. A parent will use the procedure when there is significant risk that he will die or become incapacitated within a certain period of time (e.g., in New York, this period is 2 years). The parent must usually petition a court for the appointment of a specific individual to be the standby guardian. The standby guardian can assume responsibility when the parent becomes incapacitated and then relinquish it when and if the parent recovers. The standby guardian's authority is effective when she receives notification of the parent's incapacity or death.
- **Leaving a legacy of living memories**. An approach often used in agencies is working with parents to create living legacies for their children. For instance, families may be encouraged to make videotapes or audiotapes of themselves for their children. The National Hospice Organization has an excellent library of grief and bereavement materials, including some very good age-appropriate materials for children.
- **Dealing with survivor guilt.** The issue of survivor guilt is relevant for all family members but particularly so for the infected parent whose infant dies first. The problem of guilt must be brought forth, discussed, and processed so that clients can take a more proactive approach to their other problems.

HIV and Risk of Relapse

Declining health as a result of HIV disease is a recognized risk factor for relapse into substance abuse. Physical and psychological stresses associated with HIV disease include pain, decreased functional ability, fatigue, and weakness, as well as fear, anxiety, grief, and possibly increased isolation and separation from loved ones, all of which increase individuals' risk of resuming substance abuse.

HIV/AIDS milestones are significant for the client, her significant others, and her support network. Counselors often can anticipate crisis, upset, or a readiness for change when a client reaches an HIV/AIDS milestone. Counselors who know and understand these milestones have an opportunity to prepare clients through the development of coping skills and strategies. It is a time of great opportunity for change (becoming clean and sober) or for relapsing. Milestones can create the impetus for a new way and learning new behaviors, or they can serve as an impetus for clients to act in self-destructive or harmful ways.

Following are some of the milestones of HIV infection that clinicians should learn to recognize.

- Taking an HIV test
- Receiving positive or negative HIV test results
- Experiencing the first symptoms
- Experiencing the first opportunistic infection
- Experiencing the first AIDS-related hospitalization
- Being diagnosed with AIDS
- Losing a friend, or significant other who dies from AIDS
- Beginning the medication regimen
- Experiencing little or no response to various medication regimens
- Decreasing CD4+ T cell count or increasing viral load

Clinicians as well as Alcohol and drug counselors may wish to suggest the following strategies to clients who are at risk of relapse because of HIV-related stress:

- Individual counseling
- Participation in a peer support group
- Medical attention to relieve physical discomfort and alleviate anxiety
- Relaxation and stress management techniques
- Recreational activities

Dealing with client relapse

The most successful relapse counseling is nonjudgmental. However, clients should understand that preventing relapse is their responsibility. If a client relapses into a risk behavior for substance abuse or HIV, the counselor's role is to help the client to understand the conditions that caused the behavior to occur and to identify alternative behaviors that could have been substituted to prevent the relapse. Relapse should be viewed as a learning experience and part of the recovery process. Clients should not be dismissed from substance abuse treatment or HIV/AIDS support groups because of a relapse. Rather, peer pressure may be constructively used to help clients acknowledge the reasons for and the consequences of their actions. However, if the client's relapse includes the risk of non-adherence to HIV medications, these medications should be stopped entirely to prevent the emergence of resistance. Once the client is recommitted to therapy, the regimen should be reevaluated.

5.14 Issues for the Clinician

Case Study: Frankie

Frankie is a 21-year-old, self-admitted gay man. He has been injecting "crystal meth" off and on for 3 years. He has also been a chronic marijuana and alcohol abuser since he was 12 years old. He uses these substances particularly when he can't afford the "rig" and other drugs. He has sold his body for drugs but claims that he only has sex with "nice businessmen types." Frankie is new to the area and has been in town for about 9 months. He says his family does not approve of his lifestyle, so they made him leave home. He is in phone contact with his sister occasionally but only to let her know that he is "alive." Frankie lives in shelters and on the streets with other homeless adults and youth.

Frankie decides to enroll in an outpatient program because he has been hassled by the police lately and he went on a bad run using something called "fry" (marijuana soaked in formaldehyde, then smoked). He ended up in the emergency psychiatric unit at the county hospital and the staff there suggested that he seek some help. In addition, Frankie does know about HIV/AIDS and STDs and is concerned about his sexual behavior.

Referral and linkages

Frankie will need referrals for counseling and possibly testing for HIV and STDs if the facility does not provide these services. Referrals and linkages can be obtained by getting Frankie's written consent if the facility is communicating with another organization about services for its clients. However, if an outside agency is providing services to the facility, then a Qualified Service Organizational Agreement (QSOA) or Release of Information form will be required in order for the substance abuse treatment facility to be compliant with confidentiality laws. Frankie will also need a risk assessment to help him determine just what his risks are and risk-reduction counseling regardless of his decision about any medical testing.

Special population/cultural competency
The fact that Frankie is gay could be a concern if the treatment facility has not dealt with members of the gay population or has difficulty in dealing with this population. It will be important that Frankie is assigned to a counselor who is nonjudgmental and has had some experience with young gay men.

Relapse
With Frankie, it may not be an issue of relapse as much as getting Frankie to discontinue or cut down his use. He is currently motivated for treatment but this "scare" may not last. A risk reduction model may work best with Frankie as this appears to be his first attempt at treatment and total abstinence may be unrealistic. This should be explored further with Frankie.

Denial/anger
Although Frankie may not have shown any of these emotions yet, they probably should be explored with him (as well as others, such as depression, grief, loss) specifically as it relates to his family and their treatment of him, as well as his having to survive on the streets.

Medical complications
The medical complications to the heart, kidneys, lungs, and brain would be worse if he has HIV/AIDS or any other STDs. Because he has been on the streets, he probably has not seen a doctor for anything until he ended up in the emergency room.

Case Study: Tina

Tina is a 29-year-old African American female. She has been using marijuana and alcohol since she was a teenager and progressed to using cocaine by her early 20s. Tina reports snorting cocaine for a couple of years when working as a dancer. She then discovered crack, which has been her drug of choice for the last 6 years.

Tina has been in and out of jail several times over the past few years, usually on prostitution charges. While in jail, she always tests for STDs and HIV/AIDS. She has repeatedly tested positive for Chlamydia and has received treatment numerous times. Despite the treatments for the STD, she continues to test positive. During her most recent incarceration she was diagnosed with pelvic inflammatory disease, had an abnormal Pap smear, and tested positive for HIV. Other than being a little underweight she looks good and states that she feels fine with the exception of some abdominal pain.

Tina is very excited about her "new life" with her boyfriend, by whom she has been trying to become pregnant. Having HIV/AIDS does not seem to be a major concern for Tina because she knows that there is medication out there for the disease. She reports that she was already getting off drugs before the bust because she wants to get married and have a baby now that she's found the right man. She reports her main support to be her boyfriend of 2 months. She does have a couple of female friends but does not consider them close.

She has been court ordered to go to substance abuse treatment. She has made several treatment attempts before and states she doesn't understand why she has to go to treatment now when she was already planning to stop her drug use voluntarily. She is now being admitted to a 30-day inpatient treatment program; otherwise, she faces going to jail for a minimum of 1 year.

Relapse

This is the main area of concern. Tina has a long history of substance abuse. She reports little to no social support for her recovery. The nature of crack addiction suggests that a 30-day inpatient setting will "only be the beginning" of the treatment episode. The connection and consequences of high-risk activities need to be discussed and risk-reduction practices demonstrated and rehearsed. It appears

that Tina is clearly in denial about her addiction and diseases and does not understand treatment and recovery. This may be exhibited through her either becoming a "compliant client" just to get along or a defiant, angry client because she doesn't think she needs treatment.

Medical

Tina has a number of medical issues that must be addressed and further explored. Tests and treatment for recurrent STDs, pelvic inflammatory disease, abnormal Pap smear, and HIV/AIDS are needed. With further exploration cervical cancer may be revealed, which could, in turn, give her an AIDS diagnosis. A pregnancy test may also be needed. The counselor needs to remember that it is Tina's decision about the issue of pregnancy. A counselor should watch for the issues relating to HIV/AIDS and pregnancy that can arise.

Referrals and linkages

Tina will need medical referrals. She has so many issues in this area she would benefit by having an HIV/AIDS case manager to assist her in linking with and coordinating appointments, medication, and so on. She may also need all the "standard" services such as housing, transportation, and clothing.

Compliance

There could be some compliance issues with this client. This is indicated by the good possibility that she was not taking her STD medication as directed and her statement that she doesn't understand why she has to go to treatment. This belief should be explored further because it could be a lack of information/education and not a compliance issue at all.

Integrating Treatment Services

Substance abuse treatment is moving away from more intensive treatment programming toward less intensive, shorter term treatment; HIV/AIDS treatment also has shifted from intensive inpatient care to focus more on primary, clinic-based care. Providers are under pressure to perform with less money, less time, and more challenges. As a result, substance abuse treatment and HIV/AIDS treatment should reflect their interconnected relationship by coordinating as much as possible to maximize care for persons having both HIV/AIDS and substance abuse disorders. Substance abuse treatment programs and their personnel must stretch their dwindling resources by integrating the care they provide with that of other service providers.

HIV/AIDS Services in Substance Abuse Treatment

HIV prevention is an essential part of substance abuse treatment and relevant to any treatment setting. Addressing HIV/AIDS issues beyond prevention, however, is much more complicated. For the person who abuses substances and has HIV/AIDS, the complicated physical and mental health problems--such as tuberculosis (TB); hepatitis A, B, and C; sexually transmitted diseases (STDs) other than HIV/AIDS; dental problems; diabetes; poor nutrition; dementia; and depression--require that each substance abuse treatment setting incorporate a holistic, integrated model of treatment. Treatment for the client with HIV/AIDS must be carefully reviewed. Important areas to examine are issues of confidentiality, quality of services to clients, complex treatments, staff training, client readiness, and use and allocation of limited resources.

Persons with HIV/AIDS and substance abuse disorders require more than the typical physical examination and TB test. The addition of nontraditional treatment components--such as nutritional counseling, exercise regimens, education about testicular self-examination (for men), breast exams (for women), and ways to lower cholesterol--will greatly enhance the mental and physical health of persons with HIV/AIDS. For persons with a long history of substance abuse, the possibility of mental health issues and psychiatric disorders should be explored. Many inpatient treatment and detoxification settings use a nurse to assist with physical withdrawal symptoms, medications, and occasional medical concerns. This type of care can be augmented by (1) incorporating some of the treatment components listed above, (2) using health educators and nutritionists, and (3) cross-training the treatment staff.

People with HIV/AIDS are in need of all levels of treatment for substance abuse disorders. In the early days of the HIV pandemic, individuals with HIV/AIDS did not have access to a full range of substance abuse treatment services; even today, some providers still do not offer all levels of care. Often, clients with HIV/AIDS present only their substance abuse for treatment. Their fear of disclosing HIV/AIDS status, their denial of having a substance abuse disorder, the lack of training of staff and clients, and homophobia make treatment of the "whole" person very difficult. Furthermore, the fact that HIV/AIDS case managers and health care providers are not adequately trained to screen and assess for either substance abuse disorders or psychiatric disorders and refer to appropriate treatment has limited the range of services for clients with HIV/AIDS who have substance abuse disorders.

Treatment of HIV/AIDS continues to become more complex and specialized. The resources and time needed to provide ongoing HIV/AIDS medical care are great. For the most part, it is unrealistic to expect these services to be provided within substance abuse treatment settings, but it is imperative that every substance abuse treatment program maintain a close relationship with HIV/AIDS medical care providers within its community and surrounding area. Drug and alcohol counselors and HIV/AIDS service providers must continue to develop their skills in assessing and establishing appropriate treatment plans that support the "whole" person. Medical providers and counselors can work together closely to support medical and substance abuse treatment and adherence to treatment goals. This includes establishing agency agreements and creating formal referral mechanisms.

Issues of Integrated Care

Early Intervention Settings

Early intervention often can be the first step in addressing HIV/AIDS issues in substance abuse treatment, or vice versa. The practice in early intervention for persons with substance abuse disorders has been to provide HIV pre- and posttest counseling to stop the spread of AIDS. Today the emphasis is on testing, treatment, and follow-up. The latest medical research indicates that beginning combination therapy early in the pathogenesis of HIV/AIDS may enhance the health of the client over a long period (*Hodgson)*. This will result in fewer opportunistic infections and, as revealed by the latest statistics from the Centers for Disease Control and Prevention (CDC), fewer people dying of HIV/AIDS-related illnesses (*Vittinghoff et al*). Now that there are known benefits to early treatment, counselors can feel justified in encouraging clients to be tested and then begin treatment.

Another trend in early intervention is increased use of medical case management for persons with HIV/AIDS and of case management for those at high risk for becoming infected with HIV, specifically persons with substance abuse disorders. The complex regimens associated with HIV/AIDS care, along with the challenges of substance abuse treatment and aftercare, make it essential to include case managers as part of a substance abuse treatment program's responses. Many treatment centers and HIV/AIDS service organizations are receiving funding for case managers, who are sometimes called early interventionists. This service component targets those at high risk for HIV infection and provides long-term case management services focusing on risk reduction and supportive services. Risk reduction is defined with the client and based on the client's specific needs. This might mean, for example, that the case manager and client are focusing on other care needs such as dental care, mental health care, or finding stable housing.

Once the client with HIV/AIDS is ready to obtain HIV-specific medical care, the case manager or early interventionist will focus on supporting medical adherence and maintenance of sobriety along with assisting with the psychosocial adjustments and the need for continued support and resources. Early intervention also can be supported through the efforts of outreach workers or other community-based workers. Outreach workers have been an important part of HIV prevention work for many years. They have been involved in many high-risk communities and have learned much about the specific needs of high-risk clients. Outreach workers can have a great impact in helping people obtain substance abuse and HIV/AIDS treatment. Outreach workers also recognize that many people at high risk have ongoing medical, housing, and social problems and that neither HIV/AIDS nor substance abuse treatment may be the client's most pressing and immediate need.

Many clients from poorer, disenfranchised communities are dealing with basic survival needs (*see Maslow's Hierarchy of Needs*), such as food, escaping violence from an abusive partner, or keeping the electricity from being cut off. Early intervention within the context of the "culture of poverty" begins with tangible concrete service provision and establishment of trust and rapport. From this perspective--"starting where the client is"--the worker may spend time talking and getting to know the client while helping to find emergency assistance for the electricity bill and food. The worker will gradually shift from helping with the "here-and-now" challenges to developing a trusting relationship based on mutuality, which will allow the client and worker to eventually discuss long-term goals that may lead to sobriety, safer sex practices, and establishment of a more stable environment.

Obstacles to Integrated Care

Because of the many overlapping issues related to substance abuse and HIV/AIDS treatment and prevention, agencies providing both services must coordinate their efforts to offer clients a full array of services. There are, however, significant barriers to complete integration of services. Some of these are:

- **Differences in priority.** A client entering either substance abuse treatment orm HIV/AIDS treatment faces a myriad of required activities and treatments. Some of these activities may appear mutually exclusive, creating significant challenges in developing a treatment plan for clients seeking treatment in both areas.
- **Differences in philosophy.** Substance abuse treatment agencies often operate from an abstinence model. HIV/AIDS service and medical treatment organizations and public health professionals frequently use a risk-reduction

model. This philosophical difference can create dramatic conflict in programs and approaches.

- **Differences in funding**. Public funding of prevention and treatment of substance abuse has generally focused on drug interdiction and prevention. Conversely, HIV/AIDS funding has focused on treatment and research. Although still inadequate, higher levels of social service funding are available for persons diagnosed with HIV/AIDS. Funding sources rarely recognize the challenges of coexisting disorders; however, some resources exist. Although funding amounts are difficult to obtain, both Title I and Title II of Ryan White allow for the funding of substance abuse treatment for HIV-positive individuals.
- **Differences in training.** Many substance abuse treatment providers are experts at detecting substance abuse disorders and developing treatment goals for substance-dependent clients but at the same time do not thoroughly address their clients' medical needs. Similarly, many public health providers do not address a client's possible substance abuse while dealing with the client's latest STD. Clearly there is a need for ongoing staff in-services and cross-training. The recently published CDC/CSAT cross-training curriculum, *HIV/AIDS, TB, and Infectious Diseases: The Alcohol and Other Drug Abuse Connection, A Practical Approach to Linking Clients to Treatment*, is an excellent resource for both mental health treatment providers and alcohol and drug counselors.

Any effort to develop integrated treatment for substance abuse disorders and HIV/AIDS, either within a single agency or through individual care plans, should include the following components:

- **Shared philosophy and priorities between the care providers in regard to the client.** The client must receive clear and consistent messages if he is to act as a full partner in his care.
- **A strong case management model.** One professional within the care system should be designated to work with the client as the lead case manager across all agencies. The case manager must be empowered to negotiate schedules and control resources to develop a care plan with the client. Within each client care team, only one provider should have the title of case manager. (For more information on case management, please refer to TIP 27, Comprehensive Case Management for Substance Abuse Treatment.)
- **Social services at the core of the treatment plan.** For many clients, the first priority is day-to-day survival. The individual's definition of survival may vary and may include housing, food, financial services, family maintenance, or work. Without addressing these basic client priorities, treatment cannot be successful.
- **All providers within HIV/AIDS and substance abuse treatment trained about the services available and requirements of the other setting.** For

example, several federally funded programs subsidize housing costs for persons with HIV/AIDS. These same services may not be available to an individual who is in recovery for substance abuse only. Availability of housing for an individual with coexisting disorders could be the determining factor in maintaining treatment adherence.

- **Cooperative eligibility determinations, which often are a key barrier to achieving integrated care.** Every agency establishes requirements for its own purposes, including varied documentation. It is essential that the client newly in recovery or recently diagnosed with HIV/AIDS be assisted in dealing with bureaucratic requirements that are often redundant. Workers from each agency must be willing to cross agency lines to cooperate with colleagues and advocate on behalf of the client.

Developing integrated services is rarely accomplished at the administrative level. Although solid, formal understandings and agreements are helpful, most success actually is achieved at the direct-care staff level. When working with two closely linked diagnoses that are also tied to other diseases such as TB, hepatitis, and mental disorders, the care provider cannot afford to think or work solely within the confines of his own agency or personal experience. Instead, the provider must build bridges to other providers that enable clients to address all of their needs.

Dealing With Ongoing Substance Abuse

Many HIV-infected substance abusers are unable to maintain total abstinence from substance abuse after the abrupt discontinuation at the start of treatment. In dealing with clients' ongoing substance abuse, treatment programs must find a balance between abstinence and public health approaches to substance abuse treatment.

Abstinence Model

This approach traditionally uses confrontation, consistency of expectations, behavioral contracting, and limit-setting as treatment modalities, with the goal of achieving abstinence from all substance abuse. This approach might require termination from treatment if abstinence is not achieved.

Public Health Model

This approach, sometimes called the risk- reduction model, emphasizes incremental decreases in substance abuse or HIV risk behaviors as treatment goals and tries to keep clients in treatment even if complete abstinence is not achieved. The public health model sacrifices some of the consistency of expectations that is such an important part of abstinence-oriented treatment. Instead, it seeks to keep substance abusers in treatment and to reduce, if not eliminate, substance abuse- and

HIV-related risk behaviors. Each increment of change is viewed as a success, which helps clients see that they can positively affect their lives. By contrast, a model that regards less than complete abstinence as failure may reinforce clients' feelings of helplessness and hopelessness at their inability to sustain behavior change.

Flexibility is needed with HIV-infected clients because of the importance to public health of keeping them in substance abuse treatment; they are likely to continue to put others at risk if they leave treatment and resume injection or other drug use. In order to reduce the spread of HIV, clinicians may need to work with these clients even if they continue to abuse substances. Every substance abuse treatment program must establish a balance between the abstinence and public health approaches, based on the needs of the community it serves. For example, even a program that stresses abstinence may use a risk-reduction model to educate active injection drug users about safer sex and drug use practices, such as using condoms and sterilizing syringes with bleach.

Differential standards of care

One current example of a flexible approach to substance abuse treatment of HIV-infected clients is the differential standards of care approach used by the Opiate Treatment Outpatient Program at San Francisco General Hospital's Substance Abuse Services. This approach applies varying clinical expectations and levels of care to clients based on assessment of the clients' level of functioning in the areas of physical health, mental health, social support, and housing.

The treatment staff use a "standards of care" assessment tool to determine the level of severity of impairment among methadone treatment patients with HIV. Impairment is assessed along three domains of functioning--physical health, mental health, and social resources. The latter domain represents both social support and housing. Assessment of severity of impairment takes place during a team meeting in which substance abuse counselors, the program physician, nurses, and the program social worker offer input regarding each domain. Treatment decisions are subsequently made by consensus in accordance with this assessment. Clients with evidence of severe impairment are generally approached with lower expectations for treatment outcome (i.e., applying risk-reduction principles), and higher functioning clients are approached with higher expectations (e.g., maintaining substance-negative urine tests, attending self-help group activities).

Referral to and Coordination of Linkages

Development of care networks

Counselors who work with HIV-positive individuals with substance abuse disorders should familiarize themselves with the local AIDS Service Organizations (ASOs) and substance abuse treatment services. Listed below are questions that all clinicians who treat substance-abusing individuals with HIV/AIDS should be able to answer:

- ✓ What area physicians or clinics with experience in HIV/AIDS issues accept HIV-positive patients? Which ones accept Medicaid, Medicare, or specific insurance plans?
- ✓ What ASOs exist in the area?
- ✓ Are Ryan White Funds available in the area? If so, who administers them?
- ✓ Are Housing Opportunities for People with AIDS (HOPWA) funds available in the area and if so, who administers them?
- ✓ Does the State provide medical coverage for single adults who have no dependents, for indigent patients, or for undocumented workers?
- ✓ Where can an individual with HIV/AIDS obtain inpatient, residential, intensive outpatient, extended outpatient, or detoxification treatment for substance abuse disorders?
- ✓ Are area substance abuse treatment programs prepared to deal with a client's complicated HIV/AIDS treatment regimen?
- ✓ What forms of support are offered in the area to help with loss, death, and dying? Are there community mental health centers that can provide psychiatric evaluation, medication management, neuropsychological testing, or case managers with skill and sensitivity toward those with mental disorders?
- ✓ Are culturally appropriate local support groups available for persons living with HIV/AIDS and substance abuse disorders?
- ✓ What financial assistance is available to clients to pay for expensive HIV/AIDS treatment?
- ✓ What are the eligibility guidelines for the State's AIDS Drug Assistance Program (ADAP), and what drugs are covered by the program?

Creating medical referral networks or institutional linkages is essential and must be a top priority for anyone working with a person with HIV/AIDS. Counselors and case managers can often make the job of working with persons with substance abuse disorders easier for medical care providers by providing consultations, follow-up, and help acquire resources that affect the client's ability to obtain prescriptions, come to appointments, and so on. Service providers and agencies must coordinate with medical providers, including private doctors, public health

clinics, and specialized HIV/AIDS facilities and treatment centers. Providers should also explore the possibility of becoming members of their community's Ryan White Title II consortium of providers. There are usually two key areas in which providers can begin making contacts:

1) Local city, county, and State health departments. Every State has an HIV/AIDS or substance abuse treatment coordinator, or both (perhaps through the State department of mental health services or substance abuse treatment services). These coordinators should be able to provide information about medical resources and special funding.
2) Regional and area teaching hospitals and medical schools. These programs often have special indigent care funding and specialized HIV/AIDS treatment programming and funding. They might also be research sites for HIV/AIDS clinical trials that could not only help clients access newer treatments but also provide high-quality, specialized HIV/AIDS care within their specific substance abuse treatment protocols.

When attempting to coordinate a service plan between several agencies or resources, counselors may encounter barriers, both expected and unexpected. Here are several issues that could arise:

- The clinic or service provider from whom the counselor is attempting to obtain services may be too busy to talk. The counselor may have difficulty communicating the request directly to a person (rather than voice mail).
- The service provider may consider HIV/AIDS a specialty condition and thus may be unable to provide the level of care the client needs.
- Long waiting lists and applicant pools for services and resources may exist.
- Other service providers may be judgmental or discourteous because the client is HIV positive or substance dependent.
- Few or no services are available for the HIV-positive client living in rural or isolated areas.
- "Turf" issues may cause providers to make inappropriate referrals or be resistant to serving a referred client.

Networking with other agencies is a valuable tool for the counselor who is attempting to coordinate a service plan for a client with HIV/AIDS and a substance abuse disorder. It is essential to find out what services are offered in the local and surrounding areas.

In addition to standard treatment services, less traditional therapeutic interventions or culturally based interventions may be available to clients. For instance, acupuncture is being used for detoxification and outpatient treatment for addictive

behavior. Massage is a nurturing, hands-on therapy that can promote a positive attitude in the client. Yoga and breath training may be available to help a client stay focused on sobriety and a path toward health.

Holistic knowledge of living systems, both physical and mental (the mind(body connection), can be integrated into the treatment plan. Helping the client "tune into" the connections between thoughts, emotions, and physical health can facilitate treatment regimens.

The Internet can provide helpful treatment information and resources to the client. Many public libraries offer free Internet access. Local colleges usually have Internet access available to the public for free or for a small fee. If a remote area lacks resources but a client must live there, the counselor faces challenges in networking and resource coordination that are clearly different from those in urban settings.

When establishing a network of care coordination, the provider must consider the issue of confidentiality. Providers must be aware of State and Federal laws and professional codes of ethics, along with agency and community policies and agreements. Confidentiality raises issues of consent, disclosure, and release of information. Because linkages and referrals for needed resources are part of the client's overall treatment plan, the client should not be surprised that other treatment providers will be contacted and that releases of information will be needed. The client might have fears about disclosure--talking about this fear with the client is important. The counselor and client must develop a partnership that places the client in an active, empowered position so that she understands the value of connecting with other agencies. Eligibility for services at another agency may be based on need, and the agency may inquire about the client's condition to ascertain whether it pertains to the agency's services.

The clinician should also understand the difference between the terms "informed consent" and "consent." "Informed consent" refers to a client's consent to begin treatment after she understands her treatment options and the advantages and disadvantages of each option. "Consent" refers to the client's consent to allow confidential information to be disclosed as needed.

Home health

The home health care team provides skilled nursing care for patients who are homebound. These services may also include social work, physical therapy, occupational therapy, respiratory therapy, and home health aides. Clients receiving

Medicare benefits can receive home care services if they are homebound, have services provided under a plan of care, have only reasonable and necessary services reimbursed, require a skilled service, and require service only on a part-time or intermittent basis. Some coverage also is provided by Medicaid and private insurance policies (which may differ from State to State).

Hospice

The hospice care team provides all the same services as home health but with a focus on palliative or comfort care for the client. The physician's order must certify a life prognosis of fewer than 6 months. The hospice team members focus on spiritual, psychosocial, and emotional issues as well as the physical needs of the client. Coverage is provided by Medicare, Medicaid, and some insurance policies (this may differ somewhat from State to State). Many in the health care field find it difficult to educate clients about home health and hospice services; Figure 5-1 should help distinguish between these two options.

Family caregivers

Whether home health or hospice services are used by the family at home, competent family members will likely be the primary caregivers for the client with end-stage HIV/AIDS and should not be supplanted by professional health care providers. It is helpful to define "family" broadly to include nontraditional families. Family may include significant others--individuals who may be unrelated but have a close relationship with the client and provide for the client's physical, emotional, and spiritual well-being. Family caregivers can include same-sex partners, friends, and fellow support group members.

It is important for clinicians to remember that family members who provide close support to the seriously ill client often need support themselves. Social service support for the family is a cornerstone in the provision of coordinated, comprehensive care to HIV-infected substance abuse disorder clients. Home-based services may be critical in enabling a family to remain together and may be more cost-effective than institutionalizing the ill family member.

Examples of Integrated Treatment

Provided below are examples of successful programs that have linked HIV/AIDS and mental health treatment. Also discussed are common elements of effective programs and future challenges to building effective treatment programs.

Active Referral Linkages for HIV/AIDS and Mental Health Treatment

- **Bailey Boushey:** A successful program in Seattle, Bailey Boushey is a skilled nursing facility originally created for persons with AIDS (given the more recent changes in AIDS treatment, the facility's beds are sometimes used for other kinds of patients such as transplant or oncology patients). The facility's most relevant feature is its day health program, which provides services mostly to HIV/AIDS, mentally ill, and substance-abusing persons. Treatment includes the services of mental health professionals as well as substance abuse treatment specialists.
- **Montrose Center:** Montrose Center, in Houston, Texas, has years of experience working with and strong linkages to the Thomas Street HIV/AIDS Clinic, private doctors, and area substance abuse treatment programs. It includes intensive treatment services, outpatient support/therapy groups at various locations, and outreach programs. Its providers have a good reputation for working with dually and triply diagnosed clients (i.e., HIV/AIDS, mental health disorders, and substance abuse). The staff consists primarily of therapists with licensed professional counselors (LPCs) and masters-level social workers.
- **Hilltop Center:** Hilltop Center, in Longview, Texas, is a new program offering inpatient treatment services for multiply diagnosed clients throughout Texas. The program has developed a strong linkage to traditional treatment programs, but also focuses on a variety of alternative models. Its providers have a positive relationship with funders and a strong commitment from the State drug and alcohol services department. This program also includes an evaluation component. The staff are well trained, motivated, and focused on the importance of preventing clients from "falling through the cracks."
- **The AIDS Health Project:** The AIDS Health Project in San Francisco offers mental health services to HIV-infected clients with and without substance abuse disorders. It works in collaboration with Shanti and the San Francisco AIDS Foundation through the HIV Services Partnership. Shanti provides volunteers for practical and emotional support, and the AIDS Foundation provides case management housing in a treatment-centric model that includes treatment advocates to work one-on-one or in groups with clients struggling with HIV and substance abuse issues and/or mental health issues. The Project is committed to working toward a fully funded "treatment on demand" service for residents with substance abuse treatment challenges.
- **Opiate Treatment Outpatient Program:** The Opiate Treatment Outpatient Program (OTOP) at San Francisco General Hospital treats nearly 160 HIV-positive patients as part of its 250-patient methadone treatment program. OTOP offers substance abuse treatment combined with onsite psychiatric care and HIV/AIDS primary care.

Common Elements of Effective Programs

The challenges to developing effective treatment programs that meet the needs of those who are dually and triply diagnosed continue to be substantial. Few programs across the United States have been able to maintain a high level of success along with the needed funding levels. The cost of these types of programs is a continuing challenge. Some programs are just now exploring new methods of treatment, although some began providing new services simply out of desperation and frustration. Effective treatment programs, although they vary greatly, have common elements that contribute to their success. These traits, discussed below, include the program's treatment philosophy, outreach efforts, staff training, support groups, community linkages, and funding.

Treatment philosophy

The clear and repeated message from effective programs is that counselors must "start where the client is." Offering what the client wants is the key. It is essential that counselors shift from the rigid thinking that there is only one way for clients to become healthier and to recover. Effective programs have discovered that different treatment modalities are not mutually exclusive and can indeed coexist, particularly when it comes to risk reduction. Nontraditional treatment, neurotherapy, biofeedback, acudetox, and other alternative therapies can be encouraged and integrated into clients' treatment programs.

Also, counselors and therapists in effective programs believe that labeling clients, confronting them too strongly or too often, and talking "at them" rather than "to them" are counterproductive approaches, create too much distance, and may be a major factor why many clients never return to programs.

Outreach efforts

Some effective programs send a newsletter to their dually diagnosed clients. The newsletter discusses topics that are supportive; for example, stress might be discussed, including how stress affects the immune system and can trigger relapse, and ways to reduce stress. The newsletter also can be distributed to every treatment program in the community, thus serving as an outreach tool. Although using a newsletter may sound simple, it is not a common practice.

Some treatment programs have brought in HIV/AIDS pre- and posttest counselors and educators to their treatment programs. These counselors are encouraged to run support or therapy groups for dually diagnosed clients. Because of stigmas and confidentiality, the roles of the HIV/AIDS counselors can vary; for example, one

person may conduct the testing, another may serve as the educator, and a third may lead a support group, so that clients have less fear of disclosure of their HIV/AIDS status.

Staff cross-training

Effective treatment programs also are strong proponents of staff cross-training. One view is that substance abuse treatment providers should become experts in mental health and HIV/AIDS, and the HIV/AIDS providers should learn about substance abuse and mental health, and so on. Staff working with HIV-positive clients must pay vigilant attention to the constantly changing world of medications, side effects, and new discoveries. The main point is that the issues of HIV/AIDS, mental health, and substance abuse disorders coexist, and the only way to really effect long-term change is to combine treatments. The best integrated programs encourage continuing education for staff. Continuing education may include buying journal subscriptions, allowing staff time off for coursework, and providing frequent in-service training sessions. It is also important that programs hire highly trained, flexible, open-minded staff. To be successful, these staff must see beyond traditional substance abuse treatment modalities and be able to accept and affirm all cultures and lifestyles.

Support groups

An effective treatment program will integrate support groups. For instance, a special group for HIV-positive substance abusers might integrate relapse prevention with adherence to combination therapy. The aim is to connect the milestones of HIV/AIDS disease with triggers for relapse, so that the group becomes relevant and provides the support needed.

Community linkages

One of the most important community linkages in successful programs is the relationship with the medical community and practicing physicians. This includes nurse practitioners, psychiatrists, internists, nutritionists, and others. Choosing medications, assessing medical status, and ruling out a diagnosis can be very challenging with dually or triply diagnosed clients. When service providers work closely with the medical care team to solve problems and formulate treatment plans, this allows clients and providers to be more proactive. Service providers may have to educate medical care providers about addictions and recovery. Working together is essential so that clients are not overmedicated or medicated in a way that jeopardizes their recovery.

Funding

The most successful programs that effectively treat HIV/AIDS, substance abuse, and mental health problems have learned how to obtain funds from a variety of funding streams. Successful programs apply for funding from sources such as the CDC, the Health Resources and Services Administration, the Substance Abuse and Mental Health Services Administration, and many local and State programs.

Current Challenges

Substantial challenges continue to face providers who wish to develop effective treatment programs that meet the needs of clients who are dually and triply diagnosed (HIV/AIDS, mental health, and substance abuse). Few programs across the United States have been able to develop highly successful programs and maintain the needed funding levels. For the most part, it is believed that these types of programs are quite costly.

When providers examine multiply diagnosed clients, they can see that these clients are a highly vulnerable group of people at great risk: risk for death, as well as risk for numerous medical problems and chronic illnesses, other infectious diseases, physical abuse, rape, poverty, starvation, and so on. They are also often the same clients who most easily "fall through the cracks" and challenge treatment providers' knowledge, skills, and patience. Efforts to create more effective programs that decrease the number of people "falling through the cracks" must be encouraged and these programs thoroughly evaluated in order to ensure that every client receives the best treatment possible.

Commonly Used Substances and HIV Risk

- **Alcohol.** Excessive alcohol consumption, notably binge drinking, can be an important risk factor for HIV because it is linked to risky sexual behaviors and, among people living with HIV, can hurt treatment outcomes.
- **Opioids.** Opioids, a class of drugs that reduce pain, include both prescription drugs and heroin. They are associated with HIV risk behaviors such as needle sharing when infected and risky sex, and have been linked to a recent HIV outbreak.
- Methamphetamine. “Meth” is linked to risky sexual behavior that places people at greater HIV risk. It can be injected, which also increases HIV risk if people share needles and other injection equipment.
- **Crack cocaine.** Crack cocaine is a stimulant that can create a cycle in which people quickly exhaust their resources and turn to other ways to get the drug, including trading sex for drugs or money, which increases HIV risk.

- **Inhalants.** Use of amyl nitrite ("poppers") has long been linked to risky sexual behaviors, illegal drug use, and sexually transmitted diseases among gay and bisexual men.

Prevention Challenges

A number of behavioral, structural, and environmental factors make it difficult to control the spread of HIV among people who use or misuse substances:

Complex health and social needs
People who are alcohol dependent or use drugs often have other complex health and social needs. Research shows that people who use substances are more likely to be homeless, face unemployment, live in poverty, and experience multiple forms of violence, creating challenges for HIV prevention efforts.

***Stigma and discrimination associated with substance* use.**
Often, illicit drug use is viewed as a criminal activity rather than a medical issue that requires counseling and rehabilitation. Fear of arrest, stigma, feelings of guilt, and low self-esteem may prevent people who use illicit drugs from seeking treatment services, which places them at greater risk for HIV.

Lack of access to the health care system.
Since HIV testing often involves questioning about substance use histories, those who use substances may feel uncomfortable getting tested. As a result, it may be harder to reach people who use substances with HIV prevention services.

Poor adherence to HIV treatment.
People living with HIV who use substances are less likely to take antiretroviral therapy (ART) as prescribed due to side effects from drug interaction. Not taking ART as prescribed can worsen the effects of HIV and increase the likelihood of spreading HIV to sex and drug-sharing partners.

The relationship between drug use and viral infections
Drug use increases risk for getting or passing on viral infections because certain viruses can spread through blood or body fluids. This happens primarily in two ways: (1) when people inject drugs and share needles or other drug equipment and (2) when drugs impair judgment and people make unwise, unprotected choices related to intimate contact with an infected partner. This can happen with men and women. Women who become infected with a virus can pass it to their baby during pregnancy, whether or not they use drugs. They can also pass HIV to the baby

through breastmilk. Drug use can also affect the symptoms a person has from a viral infection. The viral infections of greatest concern related to drug use are HIV and hepatitis.

Drug use increases risk for getting or passing on viral infections:

- People can get or pass on a viral infection when they inject drugs and share needles or other drug equipment.
- Drugs also impair judgment and can cause people to make unwise, unprotected choices related to intimate contact with an infected partner.
- Women who become infected with a virus can pass it to their baby during pregnancy, whether or not they use drugs.
- The viral infections of greatest concern related to drug use are HIV and hepatitis.
- People can reduce their risk of getting or passing on a viral infection by not using drugs, getting treatment for drug use, and getting tested for HIV and HCV.

Drugs use can worsen HIV symptoms, including causing greater nerve cell injury and problems with thinking, learning, and memory. Drug and alcohol use can also directly damage the liver, increasing risk for chronic liver disease and cancer among those infected with HBV or HCV.

The Reference Group to the United Nations on HIV and Injecting Drug Use recently estimated that worldwide about three million injecting drug users might be infected with HIV. About 10% of HIV cases worldwide are attributable to injecting drug use (mostly with opioids, although the use of other substances, including stimulants, has been associated with unsafe injecting practices and sexual risk behaviors). Injecting drug users principally acquire HIV through sharing injection equipment, whereas non-injecting use of drugs, such as cocaine or amphetamine-type stimulants, is associated with transmission of HIV through high-risk sexual behaviors. Some drug users practice unsafe sex with multiple partners in exchange for drugs or money, providing a bridge for HIV to spread from populations with high HIV prevalence to the general population.

Interventions that reduce the spread of HIV in injecting drug users include, among others, HIV testing and counseling, needle and syringe programs, opioid substitution therapy and other drug dependence treatment. Drug dependence is associated with particularly high-risk patterns of drug use and related risks of HIV transmission for the following reasons: drug users experience difficulties in controlling drug-taking behaviors and frequent episodes of intoxication and

withdrawal (often accompanied by a strong desire to take drugs); furthermore, they persist with drug use despite clear evidence of harmful consequences or high risk of such consequences. Effective and ethical prevention and treatment at the early stages of drug use and dependence can reduce the drug-related risks of HIV transmission. A recent WHO collaborative study on drug dependence treatment and HIV/AIDS found that substitution therapy of opioid dependence significantly reduced risks of HIV transmission in opioid-dependent individuals in low- and middle-income countries, consistent with the findings in high-income countries.

The incidence of AIDS-defining illness in patients receiving highly active antiretroviral therapy has been reported to be especially high in injecting drug users. In a study conducted in HIV-positive women in the United States of America, chronic depressive symptoms were associated with increased AIDS-related mortality and rapid disease progression independent of treatment and co-morbid substance use.

Mental and substance-use disorders affect help-seeking behavior or uptake of diagnostic and treatment services for HIV/AIDS. Mental illnesses have been associated with lower likelihood of receiving antiretroviral medication. In a study of women who were medically eligible to receive highly active antiretroviral therapy, its non-receipt was associated with substance use and with a history of childhood sexual abuse. Among people with HIV/AIDS, those with drug-use disorders typically experience the greatest barriers in accessing treatment because of negative societal attitudes and reluctance to seek any kind of treatment. Injection drug use has consistently been shown to be associated with low uptake of highly active antiretroviral therapy.

Substance-use disorders affect both the progression of HIV disease and the response to treatment. In untreated co-morbid drug dependence, rates of adherence to highly active antiretroviral therapy are low, and rates of co-infection with hepatitis B and C viruses are high. Several randomized controlled trials have indicated that, with integrated treatment of both drug dependence and HIV/AIDS, rates of adherence approach the rate for the non-drug-dependent population. Recent research suggests that harmful patterns of alcohol use are associated with higher mortality in patients with HIV/AIDS. Several mechanisms appear to be responsible, including a direct effect of alcohol on HIV disease progression, probably mediated through the immune system, and the undermining of adherence to treatment. Even relatively low levels of alcohol consumption, such as one standard drink per day, have been associated with a reduction in adherence to treatment regimens.

The use of alcohol is known to be associated with an increased risk of unsafe sexual behavior. Given the widespread harmful use of alcohol in many countries with a high incidence and prevalence of HIV, levels and patterns of alcohol consumption may substantially influence HIV spread in populations. Several studies, including those conducted in African countries with high prevalence of HIV, have shown a positive association between HIV and alcohol consumption, with a prevalence of HIV infection among people with alcohol-use disorders higher than in the general population.

The National Institute on Alcohol Abuse and Alcoholism reports that the changing patterns of HIV transmission in the United States; the role of alcohol in the transmission of HIV within, and potentially beyond, high-risk populations; the potential influence of alcohol abuse on the progression and treatment of HIV-related illness; and the benefits of making alcoholism treatment an integral part of HIV prevention programs.

While shooting illegal drugs increases the risk of contracting the AIDS virus, drinking alcohol can also contribute to the spread and progression of the disease. According to the Health Resources and Services Administration, non-injection drug use can also lead to contracting the HIV virus, because drug users may trade sex for drugs or money or engage in behaviors under the influence that put them at risk. Binge drinking is also risky. The same is true for people who drink to excess. People who are intoxicated loose their inhibitions and have their judgment impaired and can easily find themselves involved in behavior that would put them at risk for contracting HIV.

National Institute on Drug Abuse research reports that most young people are not concerned about becoming infected with HIV, but they face a very real danger when they engage in risky behaviors, such as unprotected sex with multiple partners.

Alcohol Increases HIV Susceptibility

Risky behavior is not the only way drinking alcohol can increase the risk for becoming infected with HIV. A study by Gregory J. Bagby at the Louisiana State University Health Sciences Center found that alcohol consumption may increase host susceptibility to HIV infection. Bagby's student, conducted with rhesus monkeys infected with simian immunodeficiency virus (SIV), found that in the early stages of infection, monkeys who were given alcohol to drink had 64 times the amount of virus in their blood than the control monkeys. Bagby concluded that

the alcohol increased infectivity of cells or increased the number of susceptible cells (Sources: Health Resources and Services Administration; National Institute on Drug Abuse; Alcoholism: Clinical and Experimental Research).

Virus Progresses Faster

For people who have already been infected with HIV, drinking alcohol can also may accelerate their HIV disease progression, according to a study by Jeffrey H. Samet at Boston University. The reason for this is both HIV and alcohol suppress the body's immune system. Samet's research found that HIV patients who were receiving highly active antiretroviral therapy (HAART), and were currently drinking, have greater HIV progression than those who do not drink. They found that HIV patients who drank moderately or at at-risk levels had higher HIV RNA levels and lower CD4 cell counts, compared with those who did not drink (Sources: Health Resources and Services Administration; National Institute on Drug Abuse; Alcoholism: Clinical and Experimental Research).

Drinking Impacts Medication Compliance

Patients with HIV who drink, especially those who drinking heavily, or less likely to adhere to their prescribed medication schedule. Both the Samet study and research at the Center for Research on Health Care at the University of Pittsburgh School of Medicine found that nearly half of their patients who drank heavily reported taking medication off schedule. The researchers reported that many of the heavy drinkers simply would forget to take their medications. This is potentially a big problem for healthcare providers due to the fact that alcohol dependence in those with HIV runs at rates twice as high as the general population (Sources: Health Resources and Services Administration; National Institute on Drug Abuse; Alcoholism: Clinical and Experimental Research).

Parents who are HIV positive

More and more resources have been developed for single- and two-parent households in which one or both parents are HIV positive and/or the children are HIV positive. There must be a continued awareness of the needs of these families.

These families experience the need for a variety of services, both child-centered and adult-centered. Concerns about guardianship for children after the parent is unable or unavailable to care for them must be a major focus for the parent and the service provider. Unfortunately, many clients who have long histories of substance abuse may have "burned many bridges," and the family support they need for permanency planning and establishing an appropriate guardian for their children is no longer available. All too often, there is only a tired, abused, and used

grandparent who is dealing with chronic ailments, limited resources, and little emotional energy to raise more
children.

If a child also is HIV positive, there will be special needs that the parent may not be able to address while facing her own issues. The already demanding dynamics of childhood, school, and growing up become more challenging for an HIV-infected child and parent. Even if the child is not HIV positive, the demands of parenting can prove rigorous for single parents with HIV/AIDS. Although the parent experiences the relief of knowing the child is all right, the poignant realization that he may not live to see that child grow up can still be painful.

The HIV-infected single parent with a substance abuse disorder is at risk of losing custody of her minor children if convicted of drug possession or substance abuse. If family members disapprove of the single parent's lifestyle, they may seek custody of the active substance abuser's minor children. The counselor may facilitate a plan encouraging the single parent toward goals that support the parenting relationship. This enables the recovery process to take place while the parent and child are working out their own version of permanency planning.

It is difficult for a child to witness the effects of a substance abuse disorder on a parent; surely the difficulty increases enormously when the child is told that the parent has HIV/AIDS. Children whose parents are in recovery from substance abuse disorders or who are maintaining some stability despite periodic substance abuse may experience some changes in their relationships with their parents.

There are support groups and programs for children whose parents are affected by HIV. Although not available in all communities, these groups offer children a chance to talk about their fears regarding their parents' health, learn more about the disease, and socialize with others who are facing these problems. At the same time, the programs can provide the parent with some respite time. In addition, groups like Al-Anon and Alateen can provide children with support and education about the recovery process. If service providers work in a large urban area, chances are there will be an AIDS Service Organization (ASO) listed in the phone book. This agency is likely to have lists of support groups of all kinds. Single parents with substance abuse disorders who are HIV positive should also have a support group.

Stigma of HIV/substance abuse

Many professional caregivers lack education and experience in working with homebound clients with HIV/AIDS and substance abuse disorders. Even though

some home-based service providers employ staff with mental health/substance abuse experience, many do not, and it is important that the counselor intervene in providing coordinated home-based services.

Substance abuse in the home
The client may have a relapse, especially when faced with approaching end-of-life decisions. Both professional and family providers may be unable to continue to provide needed care when faced with a client/family member who has relapsed and who is not capable of following the plan of care. It is critical in these situations that the client and caregivers continue receiving substance abuse counseling and intervention in the home setting. However, providers should be aware that the home setting can present certain problems, including the possibility that other substance-abusing persons in the client's home are stealing or utilizing opioids intended for the client.

Economic needs
Even though home-based services are covered by some Federal, State, and private resources, additional stressors can affect the delivery of services. The loss of income from either the client or the family caregiver can create potential problems with housing, health insurance, nutrition, and medications. The counselor must be aware of how these conditions can disrupt the plan of care.

Emotional needs
As the client continues to need more interventions, the roles of family caregivers change, and health care professionals must be aware of the need to adapt to these changes. Family caregivers will need support in processing the anticipatory grief of losing their family members. After the client's death, help with funeral arrangements and further support of family members, who may also be dealing with their own addiction issues, may be needed.

6. Human Trafficking and HIV/AIDS

Human trafficking and forced labor are global human rights abuses. Over the past ten years, the United States has supported some excellent programs but it has also adopted an ideologically driven approach to the sex sector that harms women and their families, increases the vulnerability of sex workers to violence, trafficking and HIV infection, prevents health care workers from accessing sex workers, and does little or nothing to prevent trafficking. Sex workers who do not want to be “saved” are being subjected to violent raids and rescues and some of them are being arrested, abused, and deprived of their livelihood. Recipients of U.S. funding

must sign a pledge that undermines their ability to work non-judgmentally and collaboratively with sex workers to stop trafficking, child prostitution and violence, and fight HIV/AIDS. The American University Washington College of Law and the Center for Health and Gender Equity co-hosted a symposium, "Human Trafficking, HIV/AIDS, and the Sex Sector," to explore these challenges and present examples of organizations that provide human-rights based approaches and partnerships with sex workers. Distinguished authorities from the field presented at the symposium, and their articles are included in this publication—Gabriela Leite, director of Davida, a Brazilian NGO devoted to human rights of prostitutes and the regulation of the industry; Sara Bradford, the former technical advisor in Cambodia for the Asian Pacific Network of Sex Workers; Dr. Shilpa Merchant, the pioneer of a groundbreaking AIDS prevention program and sex worker collective in Mumbai; and Sylvia Mollet Sangaré, the co-founder of DANAYA SO, a Malian sex worker collective that provides health services, literacy education, legal protection, and job training. In order to change the negative attitudes and judgments that lead to harmful laws and policies, it is essential to increase public understanding about the lives, hopes, and accomplishments of sex workers and to support human-rights-based programming and partnerships with sex workers. This report brings the voices of women in the sex sector to the center of discussions around prostitution, human trafficking and HIV/AIDS, and offers analysis and recommendations based on what is happening on the ground. We hope it will contribute to meaningful, nonjudgmental discussions that can lead to new policies and programs to improve health and lives of women in the sex sector.

Over the last ten years, the United States has helped make important inroads both in combating human trafficking and treating HIV and AIDS. The anti-prostitution policies that are imbedded in the U.S. response to these issues, however, undermine U.S. success in myriad ways. Such policies ignore the very promising models of sex worker empowerment that have transformed lives around the world and successfully confronted both HIV and trafficking. Human rights must be an essential component to defeating the world's most difficult problems. However, the United States government's opposition to prostitution eclipses human rights and evidence of effectiveness in developing human trafficking and HIV/AIDS approaches. This ideological foundation for U.S. policy has created critical failures and blind spots that severely limit U.S. success in ending these scourges. From 2000 to 2008, as part of its response to both human trafficking and the global HIV epidemic, the U.S. government developed anti-prostitution policies and Congress passed anti-prostitution provisions that directly undermine U.S. efforts to prevent trafficking and HIV/AIDS. The focus of these policies is directed at stopping women from selling sex to earn a living. However, sex work is not the same as

human trafficking into the sex sector and should not be conflated as such.1 Conflating human trafficking with prostitution results in ineffective anti-trafficking efforts and human rights violations because domestic policing efforts focus on shutting down brothels and arresting sex workers, rather than targeting the more elusive traffickers. Moreover, a growing body of research finds that sex workers' high risk of HIV infection is due in part to their marginalized and illegal status. Criminalizing sex work thwarts workers' access to health care services and government benefits and makes them vulnerable to police abuse and exploitation.

Mali's DANAYA SO is another example of a democratically-run sex worker organization. It has grown into a national organization operating in five towns. Malian society and government do not provide services for sex workers and their children, so the women organized themselves into a collective. The collective seeks to stop the marginalization of sex workers by removing the difficulties women have in accessing health care (such as HIV/AIDS prevention and treatment programs) and social services; reducing dangers from police raids; fighting housing discrimination; and facilitating participation in social events and religious practice. DANAYA SO meets the immediate and long-term needs of sex workers and their families by providing medical, financial planning, banking, credit, education, and children's services to its members. Sister organization LAKANA SO works to protect children of sex workers from the impact of stigma and discrimination. Before LAKANA SO, most children of sex workers did not attend school. LAKANA SO helps mothers enroll their children in school and professional training programs, pays half or all of each child's school fees, and monitors the progress of the children. As a result of the work of LAKANA SO, all members' children are now in school or professional training and highly unlikely to enter prostitution. Most children accompanied by LAKANA SO turn to professions and succeed in finding their place in the society. Brazil offers a promising example of the contributions sex workers make to society when fully empowered. The mission of Davida—Prostitution, Civil Rights, Health—is to create opportunities for strengthening the citizenship of prostitutes, through the organization of sex workers, the defense and promotion of rights, and the mobilization and monitoring of public policy. Davida coordinates the Brazilian Network of Prostitutes; assists in the formation of new organizations; advocates for public policies in the area of prostitution and health; consults public and private entities nationally and internationally; and produces, distributes, and promotes videos, publications, and manuals on STD and HIV prevention. On a regional and local level, Davida trains organizations that want to work with sex workers and promotes educational actions and citizenship formation with sex workers. One of Davida's most important early achievements was the formation the Sex Worker Steering Committee that is a part

of the Brazilian Ministry of Health's National STD and AIDS Program in 1995. As a result, any official initiative or research project for the sex worker population in Brazil is evaluated in this committee prior to implementation. As illustrated in the examples from India, Mali, and Brazil, innovative and human-rights-based interventions can make a difference when it comes to preventing HIV, human trafficking, and child prostitution. However, as shown in the case of Cambodia, when governments enact policies and laws that conflate human trafficking and prostitution, they are likely to violate human rights of sex workers, compromise efforts to prevent sexual transmission of HIV, and waste resources that could otherwise be used to locate and assist trafficked persons and minors. I

Fighting HIV/AIDS with Human Rights Human rights are universal and apply to all individuals in every sector of society. Denying human rights to any one person perpetrates an injustice that has ramifications far beyond the local level. Indeed, it cripples globally-supported attempts to stem the spread of a plague that has no regard for gender, age, race, marital status, sexual orientation, immigration status, or religion. HIV/AIDS policies and programs at the global, national, and local levels must support universal access to prevention, treatment, and care in order to effectively address the pandemic. This requires a staunch adherence to basic human rights, without judgment or hesitation. Policies cannot, for any reason, bar any individual or group from accessing necessary health services—it is both immoral and automatically handicaps the HIV/AIDS prevention effort. This principle has also been articulated at the global level: At the United Nations High Level meeting on HIV/AIDS in 2006, world leaders reaffirmed that "the full realization of all human rights and fundamental freedoms for all is an essential element in the global response to the HIV/AIDS pandemic."3 As stated in the Universal Declaration of Human Rights, "all human beings are born free and equal in dignity and rights," and that encompasses: Right to life, liberty, and security of person—the basis for individual bodily autonomy Right to make informed choices about their lives free from coercion, violence Right to not be held in slavery or to be trafficked Right to highest standard of health, privacy Freedom from violence and arbitrary arrest4 In addition to the United Nations affirmation and reaffirmation of the universality of human rights, the world's major religions and traditions also teach that all persons are deserving of dignity and freedom from coercion. Yet despite these pronouncements of justice, both secular and religious, denying what has been promised at the global level is a regular and accepted practice.

The Sex Sector and HIV/AIDS

Sexual transmission is by far the most common way to contract HIV. Globally, the vast majority of HIV infections—some 80 percent—are sexually transmitted, making sex workers among the groups most vulnerable to infection. As a result, ensuring access to HIV and AIDS prevention, treatment, and care among communities of female, male, and transgender sex workers is critical to the overall strategy for ending HIV transmissions.

The sex sector is a diverse community. It is not restricted to a certain sex, gender, or age group. Each sex worker enters the sector for different reasons and self-identifies differently: some call themselves prostitutes, sex workers, or even whores.6 Designing effective HIV/AIDS policies and programs based on human rights depends on understanding the depth and breadth of the entire community. For example:

- ❖ The sex sector includes women, men, and transgender adults, as well as young adults ("young adults" is defined as 18 to 24 years of age and does NOT include children).
- ❖ Women in the sex sector are often wives and mothers. Sex work itself may be formal and organized.
- ❖ Sex work may be also informal, such as independent or self-employed sex workers. Sex work may be legal, criminalized, or tolerated.

People enter the sex sector for a range of reasons. For some, sex work is a profession of choice. For others, it may be a decision made based on certain life circumstances, such as:

- ✓ Poverty and indebtedness
- ✓ Low levels of education
- ✓ Lack of access to other employment opportunities
- ✓ Family abuse
- ✓ Drug use or addiction
- ✓ Gender inequality
- ✓ Rape and other violations
- ✓ War and post-conflict situations

Each of these reasons represents a breach of different human rights, and while every effort should be made to assist all individuals who do not want to work in the sex sector, respect and assistance should also be given to those who choose—without force or coercion—to work in the sex sector.

Laws, policies, and attitudes that criminalize sex workers perpetrate human rights violations and actually work against creating safe and healthy communities. As illustrated in this publication, when sex work is illegal, sex workers face societal and legal barriers in accessing safe housing, other forms of employment, birth certificates for their children, and health care services, including HIV/AIDS prevention, treatment, and care. Criminalizing sex work also puts sex workers at an increased risk of violence, be it perpetrated by clients, brothel madams, or even law enforcement officers, and makes it challenging to pursue protection. For example, in Cambodia, police frequently target parks and other soliciting areas in an effort to empty the streets of all sex workers. As described in Sara Bradford's article, Cambodia's recently passed law criminalizing prostitution along with human trafficking provides no guidance on how the police are to enforce it, resulting in a violent anti-prostitution campaign rather than a concerted effort to arrest and prosecute traffickers. Children often bear the collateral damage of anti-sex worker laws. The repercussions of such laws go beyond the sex worker—their children experience the same stigma, discrimination, and institutional exclusion directed at their parents, and it is not uncommon for them to drop out of school as a result. Sex Work vs. Trafficking Sex work is not the same as trafficking in persons for the purpose of sex and should not be conflated as such. Conflating human trafficking and into the sex sector with prostitution results in ineffective anti-trafficking efforts and human rights violations. Anti-trafficking efforts based on an anti-prostitution ideology often target the victims and not the perpetrators—the traffickers themselves. They lead to violence, as evidenced by the raids in Cambodia, and misguided trafficking interventions. According to the UNAIDS Reference Group on HIV and Human Rights, an advisory body to UNAIDS: "The blurring of trafficking and sex work and/or treating all sex workers as 'victims' can lead to support for coercive efforts to control or reduce sex work, which rarely produce beneficial and lasting outcomes and have even been associated with abuse of sex workers and their families. Mandatory medical treatment or procedures, forced rehabilitation, or programs implemented by police or based upon detention of sex workers are all examples of coercive programming. All such strategies either represent, or are prone to, human rights abuses and corruption. In particular, sex workers should not be subjected to the violence and related human rights violations that all-too-frequently accompany 'raid and rescue operations,' whether these are directed by state agents or non-state actors."8 To end trafficking and effectively address HIV/AIDS, trafficking and sex work have to be treated differently. And in both cases, human rights must be paramount.

Human rights are critical to any global, national, or local effort addressing HIV/AIDS and human trafficking. The U.S. invests significant financial assistance in national and global efforts to stem the HIV/AIDS epidemic and end human trafficking. In order for this funding to be most effective, U.S. foreign policies and programs must use human rights as a foundation. Stemming global health epidemics and creating a healthy worldwide population depends on it.

The number of females between 15 and 49 in some form of sex work is substantial, certainly in the millions. The estimates in major cities alone are shocking: an estimated 14,108 women in Mumbai, India; 32,448 in Jakarta, Indonesia; and 11,249 in Niamey, Niger. Because sex workers have a high HIV/AIDS prevalence rate worldwide, the above numbers mean that hundreds of thousands, if not millions, of women in the sex sector are infected. The rate of infection among trafficked women and girls is certainly as high as or higher than non-trafficked sex workers given their inability to have any control over their bodies. Even though sex work, trafficking, and HIV/AIDs are inextricably linked, policies and programs aimed at combating them always operate independently despite the fact that anti-trafficking programs can have a tremendous impact upon the work being carried out by health care providers. For example, a typical concern of health care providers is the harm caused by ill conceived mass raids of brothels in which all women, not just trafficked women and minors, are taken out and detained. These raids typically result in health care workers having less or no access to sex workers in brothels. For this reason, it is important for the government and civil society to engage in greater cooperation and information sharing to ensure that they (1) ‘do no harm’ to sex workers as a result of anti-trafficking efforts, and (2) protect the rights of children and trafficked women and support people who want to exit from prostitution. It is counterproductive and ultimately harmful to the persons who are intended to benefit from these programs for governments and agencies to work at counter purposes. Only a few governments (e.g., Mali and Brazil) and NGOs (e.g., the Global Alliance Against Trafficking in Women) view sex workers as partners to combat trafficking, child prostitution, and HIV/AIDS. Most governments and NGOs do not collaborate with sex workers or sex worker collectives. In fact, most are hostile to all women in prostitution and treat them as obstacles rather than as potential partners. A challenge to such negative thinking and counterproductive practices is contained in the reports on sex worker collectives in Mali, India, and Brazil. Their impressive accomplishments demonstrate a more productive, and rights protective way forward. U.S. Law and Policy From 2000 to 2008, the U.S. government developed a set of anti-prostitution policies and Congress passed a number of anti-prostitution provisions that directly undermine U.S. efforts to

prevent trafficking and HIV/AIDS and have caused harm to women and their families. The focus of these policies is directed at stopping women from selling sex to earn a living.

7. Resources

Mental Health

Womenshealth.gov provides information on mental health & HIV/AIDS, including topics like depression, brain function, other mental health issues, and suggestions for help.

The Substance Abuse and Mental Health Services Administration has a behavioral health treatment services locator and helpline.

CDC provides basic information on mental health, including mental illness and mental health indicators. You can learn more about depression from CDC, the National Institute of Mental Health, and the Mayo Clinic.

Harvard Medical School offers info on meditation to ease anxiety and mental stress.

Substance Use

The Substance Abuse and Mental Health Services Administration (SAMHSA) has a treatment locator and national helpline for those facing substance abuse and mental health issues. It operates 24 hours a day, 7 days a week.

SAMHSA also provides a buprenorphine treatment locator and an opioid treatment program directory.

CDC offers guidance to help people reduce or stop substance abuse, including people living with HIV/AIDS

Older Adults

The Graying of AIDS has much information on aging with HIV.

Age Is Not a Condom offers information about staying healthy with HIV as you age and other resources.

CDC has a fact sheet on HIV among older Americans.
The National Institute on Aging has an overview of Aging with HIV.

These hotlines are available to provide information and support about living with HIV/AIDS:

1-800-CDC-INFO (1-800-232-4636) offers basic info on HIV and testing in English and Spanish. After you select your language, press 9 and then 1. TTY service for the deaf: 1-888-232-6348

The Health Resources and Services Administration provides a list of all state HIV/AIDS hotlines.
Project Inform has an HIV Health InfoLine with staff, many of whom live with or are impacted by HIV, to provide insight and support. (This is a call-back service – leave a message and your call will be returned.)

Disclosure, Discrimination, and Stigma

CDC's HIV Testing page includes a section about sharing positive test results with others and a brochure on notifying partners.

The U.S. Department of Justice explains HIV/AIDS anti-discrimination laws and how to file an HIV/AIDS discrimination complaint.

CDC's Let's Stop HIV Together campaign fights stigma by showing that persons with HIV are real people.

HIV.gov offers advice on supporting someone with HIV.

The Health Resources and Services Administration provides a history of stigma and the Ryan White HIV Program and a videos of stories from the program.

Additional Resources

- AIDS.org: Mental Health

  Articles and publications on depression and coping, stress and anxiety, and death and

- AIDS.org: Telling Others You Are HIV Positive

  Issues and guidelines about telling family members, friends, and others that you are HIV positive.

- American Academy of Family Physicians: HIV: Coping With the Diagnosis

  Q and A about coping with fear, legal issues, and other information.

- American Psychiatric Association's Coping with AIDS and HIV: An Overview

  Information on psychiatric reactions, treatment, and getting help.

- The Body: Mental Health

  Articles and links on depression, anxiety, stress, relationships, and other mental health issues.

- The Body: AIDS Hotlines and Organizations

  A comprehensive listing of HIV/AIDS hotlines and organizations, including a state-by-state breakout of HIV/AIDS organizations and support groups.

- Centers for Disease Control and Prevention's Caring for Someone with AIDS at Home: Providing Emotional Support

  Information for caregivers and loved ones on providing emotional support.

- HIV InSite Links: Hotlines

- HIV InSite Links: Mental Health

  Links to organizations and other resources dealing with depression, anxiety, stress and other mental health issues.

- Pets Are Wonderful Support (PAWS)

  A non-profit organization that focuses on pets as a way to improve the mental health and well-being of people with HIV/AIDS. Includes information on health issues and international list of organizations.

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