



## HIV Services and Supportive Housing

The first supportive housing projects serving people with HIV (Human Immunodeficiency Virus) were developed in the mid to late 1980s, a time when life expectancy following an AIDS (Acquired Immune Deficiency Syndrome) diagnosis was extremely short. Since then, a better understanding of HIV and the development of more sophisticated diagnostic and treatment protocols have decreased mortality rates and the prevalence of opportunistic infections. In general, people can take full advantage of these new treatments if they have access to quality medical care and adequate supports.

HIV/AIDS has taken well over half a million lives in the United States since the disease was first discovered. In the United States, intravenous drug users and men who have sex with men have been at the greatest risk for HIV infection, although this is currently shifting because of dramatic increases in the transmission of the disease among heterosexuals, especially women. A significant increase in the incidence of HIV has also occurred among people living in poverty, particularly among African American men. Recent medical research has focused on controlling HIV with an emphasis on preventing the progression of the disease and reducing the risk of transmission.

Supportive housing serving people with HIV should provide a stable environment with the opportunity to access quality medical care and necessary psychosocial supports. Even supportive housing programs that do not have a focus on HIV should be prepared to work with people living with the illness due to the likelihood that the tenancy will include individuals with HIV disease. This chapter provides an overview of HIV and the core program components and support services to be developed to help tenants manage the disease.

### HIV Disease

“HIV disease” refers to the entire continuum of illness from the point of infection with the human immunodeficiency virus through the duration of an AIDS diagnosis. Untreated, HIV is relentlessly progressive and diminishes the capacity of the immune system to protect against a wide range of infections, some of which are fatal. These are known as opportunistic infections.

### The Current State of HIV Treatment

Recent advances in HIV research have dramatically expanded the medication and treatment protocols that are available. New combination regimens of anti-HIV drugs have demonstrated surprising effectiveness in preventing and treating opportunistic infections. Increasingly, the medical community views HIV as a chronic, treatable, and potentially curable disease, rather than one that is relentlessly aggressive and always fatal. Current medical treatment for HIV disease includes prevention against opportunistic infections and antiretroviral therapy.

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Note: This document is included within the *Supportive Services* section of CSH’s *Toolkit for Developing and Operating Supportive Housing*, which is available at [www.csh.org/toolkit2](http://www.csh.org/toolkit2). This document has been adapted from CSH’s publication *Developing the “Support” in Supportive Housing*, which is available at [www.csh.org/publications](http://www.csh.org/publications).

### Prevention against opportunistic infections:

Routine prescription of antimicrobial medications that suppress or prevent various opportunistic infections such as pneumocystis pneumonia (PCP), herpes, fungal and bacterial infections, and tuberculosis.

### Antiretroviral therapy:

Highly active antiretroviral therapy (HAART) refers to prescribed combinations of medications that inhibit the virus' ability to replicate itself and thus decrease the amount of HIV in the body. People who respond well to HAART show increased appetite and energy levels, as well as general improvement in appearance, health, and sense of well-being. However, since 1987, when the first approved antiretroviral drug became widely available, expectations of drug therapies have been tempered. While many people with HIV are now living longer, there are numerous barriers to the success many believed could be achieved. There is still no cure for HIV disease, and not everyone responds well to available treatments. Although HAART can result in an increase in CD4 and T-cell counts, which are signs of the immune system being restored, the ultimate public health goal is the development of a vaccine that would effectively prevent HIV infection. Vaccine research is ongoing.

Successful outcomes from antiretroviral therapy currently require an indefinite commitment to adhere to complex medication regimens that have associated risks. HAART requires individuals to take medication at precise intervals throughout the day. Resistance and cross-resistance to medication can occur even with successful adherence to the regimen. Many of the medications can also cause severe side effects in some people. To obtain the full advantages of treatment, an individual must be able to manage the medication regimen and have access to medical services, health education, support services, a healthy diet, and a suitable place to live.

***Note: The list of [HIV/AIDS-Related Internet Sites](#) at the end of this document can help people keep up to date on the current status of medical treatment for people with HIV disease.***

## **HIV Transmission**

HIV can spread by any activity that allows the blood, semen, ejaculatory fluids, vaginal secretions, or breast milk of a person with HIV to gain entry into the body and bloodstream of another person.

These activities include:

- Unprotected anal, vaginal, or oral sex
- Sharing sex toys
- Sharing needles for injecting drugs, tattooing, or body piercing
- Sharing razors and tooth brushes (potential presence of blood)
- Pregnancy
- Breast-feeding
- Receiving blood products (e.g., transfusions) that contain HIV (The risk of transmission in this manner in the U.S. is small since all blood products are supposed to be screened for HIV.)

HIV is not transmitted through casual contact. HIV is not passed through the air or by any of the

following:

- Holding hands or hugging a person with HIV
- Eating food prepared by a person with HIV
- Sharing dishes or food with a person with HIV
- Sneezing or coughing
- Sharing toilet seats
- Sharing a household with a person with HIV
- Contact with saliva, tears, sweat, urine or feces (unless they contain blood)
- Mosquitoes

## **Core Program Components**

The health status and service needs of people living with HIV can vary tremendously and change repeatedly. A supportive services program should have the flexibility to reach out to those who are living independently, while accommodating individuals who require extensive support. In scatter-site programs, staff members visit with tenants in their apartments or homes, although many services are provided in neighboring hospitals, clinics, day treatment programs, AIDS service organizations, and other off-site locations. Although there are multiunit, single-site supportive housing projects exclusively for people with HIV, an increasing number of single-site housing initiatives are mixing people living with HIV with other tenant groups, creating more integrated settings.

In any housing setting, it is the responsibility of all staff members to create a supportive environment that helps tenants make the adjustments that are part of living with HIV disease. Access to counseling, educational programs, support groups, health care, and HIV drugs are essential. Similarly, due to compromised immune systems, tenants are often particularly concerned with food safety and handling, housekeeping, and personal hygiene. During periods of serious illness, some tenants may also need more extensive medical supports and services.

There are specific considerations in developing supportive housing programs that serve individuals who have HIV/AIDS. Providing supportive housing for people with HIV requires the capacity to assist individuals who will have wide ranging medical and psychosocial needs. The remaining sections of this chapter discuss key strategies and core program components for developing a supportive services program for individuals living with HIV.

## **Medical Assessment and Supports**

### Tenant Selection/Intake:

Sponsors need to assess their ability to arrange for or provide services and determine what, if any, health-related criteria impact eligibility for tenancy. It is advisable to consult an attorney for final approval of selection criteria since the Fair Housing Act and the Americans with Disabilities Act may apply. Supportive housing programs should have standardized assessments to determine the services the individual is receiving and the level of need.

In addition to information provided directly by prospective tenants, health care providers are usually able to provide information about current health status, as well as any support that may be required

for the housing applicant. Release of confidential information requires individuals to sign consent forms allowing for the exchange of information between other organizations and housing staff. Generally, per legal guidelines, no information that might identify a person as having HIV disease and related illnesses can be shared without specific up-to-date authorization.

#### Ongoing Assessment:

People with HIV disease may experience long periods of good health, although the nature of the illness may result in a decline in health and a need for additional short- or long-term assistance. Some tenants will initiate a dialogue with staff about requiring more help, while others will not. Depending upon the circumstances and program protocols, staff members can maintain consistent communication with tenants through both casual conversations and meetings in which they assess and document the need for services. In some instances, staff may identify cognitive, emotional, or medical issues that the tenant is unaware of. Some service programs develop formal disease-management plans with each tenant to identify the range of needs that an individual living with HIV may have, such as medication and medical services, nutrition counseling, mental health and substance use services, legal counseling (e.g., wills and health care proxies), and alternative therapies.

Some individuals experience debilitating health conditions that may not be temporary, and services or arrangements must be in place to support the individual in his/her home or in a medically supported facility. During periods of extended absence (e.g., hospitalization), sponsors also need guidelines that address the status, security, and personal contents of housing units that remain vacant for extended periods.

#### Access to Health Care:

A principal component of any supportive housing program serving people with HIV is assistance in the management of health care and medication regimens. This usually involves collaborative relationships with medical providers. Frequently, supportive housing projects establish relationships with one or two primary health care providers who have expertise in HIV treatment. Some projects arrange for health care providers to deliver routine services on-site. In some states, health aides may be available to come into the home and assist with personal care and housekeeping. Linkages with pharmacies, visiting nurse services, specialized medication clinics, day treatment programs, and other support services are usually essential.

In general, program staff should make it a priority to help tenants obtain health services. This includes addressing barriers to care, such as communicating health concerns to physicians, providing escort assistance and/or subsidies for transportation, and helping people obtain public benefits and entitlements, including health insurance. Program staff should routinely assist tenants with issues regarding their medications and closely track those who are having difficulties. Additionally, to avoid potentially dangerous interactions, it is important to help tenants keep the primary care physician and other health care providers informed of medication adherence issues, illicit drug use, and over-the-counter medications.

## HIV Education and Resource Networks

If individuals living with HIV disease are to actively participate in their own care, they should have an understanding of the continuum of HIV disease, special issues posed by the infection, and available interventions. An informed consumer is in the best position to make decisions about medication, nutrition, substance use, alternative therapies, exercise, and stress management. In addition, learning about the illness can reduce feelings of powerlessness and increase self-reliance, advocacy skills, and investment in decision making.

Supportive services programs should include staff members who are versed in the area of HIV and are able to serve as basic educators and make referrals as needed. Programs should also make available to tenants and staff up-to-date materials and information about health issues specific to HIV and the range of topics to be addressed in a comprehensive disease management plan, including:

- Information about HIV and hepatitis A, B, and C
- Treatment and medication guidelines and specific information about anti-retrovirals and medications used in the prevention and treatment of opportunistic infections
- Information about reinfection issues
- Impact of substance use (including tobacco and alcohol)
- Safe sex
- Hygiene
- Exercise
- Nutrition
- Use of alternative therapies

In supportive housing that also serves individuals who do not have HIV disease, HIV prevention and testing information should be made available to all tenants. In general, all tenants benefit from HIV education and from information about safe sex practices and negotiating safer sex. Programs may also need to consider providing education on safer substance use practices, including referrals to harm reduction and needle exchange programs. Education can occur through access to written materials and the media, engaging in informed conversations, and attending seminars and workshops.

The Internet is also an invaluable source of information that is often provided in various languages. Providing tenants and staff with computer access and an Internet connection can foster independent research and even provide connections to physicians, dietitians, and others who can provide current information about disease management in an interactive format. Note: The list of [HIV/AIDS-Related Internet Sites](#) at the end of this document can help people keep up to date on the current status of medical treatment for people with HIV disease.

The services necessary to adequately support people with HIV are extensive, and a single organization will probably not provide all needed services. Supportive services programs should maintain an up-to-date listing of community resources that may be needed by tenants with HIV. Some providers have also developed collaboratives, consortia, and partnerships to help ensure access to a range of services including housing, health care, case management, food/nutrition, assistance with activities of daily living, legal assistance, substance use services, support groups, psychiatric treatment, employment/job training, and education. These efforts allow for more support and can include services that accommodate the healthy and the ill. The inclusion of non-

HIV-specific services also encourages integration into the community at large, reducing the marginalization of people with HIV.

## **Individual Counseling and Support**

For a person living with HIV, individual counseling can be especially helpful in adapting to the life changes brought about by the illness. Counseling can also be helpful in response to critical events that occur throughout the course of the disease. Counseling can assist individuals to cope with their diagnosis, change in health status, and modifications in lifestyle. It can also be central in the treatment of depression, which occurs frequently in people who have HIV. Treating depression is critical because the condition adds to an individual's pain, can weaken the immune system, and compromises the person's ability to assist in the management of HIV. Not surprisingly, a higher mortality rate occurs among those who have HIV and chronic depression.

Individuals who respond well to treatment and are not seriously compromised by health barriers to employment, education, or other goals may nonetheless experience a reluctance to switch into a healthier mode. Some may relapse or return to self-destructive behaviors that had previously ended only because they were too ill to participate. In other words, some individuals never made a conscious decision to choose a healthier lifestyle and instead were forced into it through illness. For tenants experiencing these situations, individual counseling can help overcome obstacles to continued growth and independence. Support services that focus on substance use and mental health support services are key components of work in the area of HIV, and this toolkit contains chapters devoted to each of these topics.

To experience a significant decline in health or to be dying of AIDS-related conditions can cause a level of anguish that did not exist during earlier stages of illness. Fear, anger, and frustration may also occur for people who continue to fail on medication that originally held promise, particularly when others achieve better outcomes. Counseling can offer those experiencing such feelings a safe place to voice resentment, an environment in which to address feelings of despair, and a means to reconcile these feelings in a constructive manner.

## **Peer Support and Volunteers**

The support, knowledge, and shared experiences of others living with HIV can be a lifeline, particularly for those who are newly diagnosed or are dealing with transitions in their disease. There are many roles that staff members can play to facilitate peer support and the development of volunteer programs within supportive housing.

A volunteer mentor/buddy program links the individual who is newly diagnosed or dealing with a transition in the disease with another individual who has HIV. From the peer perspective, the mentor can talk about the illness, answer questions, and give advice on how and where to get help. Additionally, the mentor may be able to serve as a bridge to an existing network of informal and formal supports and educational opportunities. Most important, perhaps, is that the mentor can be a powerful catalyst for diminishing anxiety, reducing isolation, and motivating a person to actively manage the disease. It is both unrealistic and unnecessary to expect a volunteer to commit him/herself indefinitely. A match made between a mentor and a tenant is usually intended to assist an individual through a crisis, particularly when the individual is newly diagnosed. The goal is to

help the individual develop his/her own support and service network. Of course some people still maintain a friendship when the mentorship has formally ended.

Having a diagnosis of HIV is not a sufficient criterion to be a volunteer mentor/buddy. That is, those who provide support need to be reliable, good listeners, and have a grasp of the fundamentals of HIV disease management. Some people may have difficulty maintaining appropriate boundaries and not imposing their own values and beliefs. Mentors must also understand and be able to respect confidentiality. Training for volunteers is a crucial component of a successful mentoring program. In many localities, there are HIV/AIDS services organizations that train volunteers (those with and without HIV disease) to do mentoring and support work. Mentoring/buddy arrangements and other peer support programs for individuals living with HIV provide important assistance. Hopefully, they are complements to an overall environment that is free of discrimination and hostility toward individuals with HIV. Staff members or trained volunteers can also facilitate peer support groups or activities that are less formal, such as community meals or outings. The staff should recognize that supportive relationships frequently occur among tenants without program and staff intervention.

## **Volunteers**

A volunteer program requires an investment of staff time to train, supervise, and support the volunteers. Written policies and procedures provide clarity and structure for volunteer involvement and help avoid problems. Agencies utilizing volunteers should also seek legal counsel regarding liability issues. The use of volunteers requires the development of a protocol to process requests for help as well as a system for recruiting, assigning, and supporting volunteers. At a minimum, volunteers must have a basic understanding of the treatment of HIV disease and know the basics of transmission and universal precautions. Preferably, training should also include fundamental information pertaining to counseling and support, substance use and recovery, and responding to crisis and conflict.

## **Supporting Improvement and Stability**

Many people with HIV disease experience a stabilization or improvement in immune system functions through the use of antiretroviral medication. People often live longer than expected and have futures that may not have seemed possible when initially diagnosed. However, the good news of health stabilization and improvement can also present a new set of stressors.

Ironically, contracting HIV sometimes enables people to access stable housing, adequate nutrition, medical care, substance use counseling, and mental health services for the first time in their lives. These individuals often respond with enthusiasm about going to work and school and pursuing an improved lifestyle. On the other hand, some people will relapse into substance use and/or unsafe sexual behavior as their health improves. This may be an individual's way of reintegrating into the community or responding to the demands or feelings of being well again, even though these behaviors can undermine the improvements in health that the person has achieved.

A return to drug use can expose the person with HIV to multiple complications, including interference with prescribed medications and taxing the liver and immune system. Shared needles and straws and unsafe sex are also modes of transmission for hepatitis C and introduce the risk of

re-infection with drug resistant HIV or other sexually transmitted diseases that can further harm an individual's health. Staff must carefully monitor medication compliance as an individual's health improves. A more active lifestyle can make it more difficult to follow dosing requirements. In addition, new situations that require discretion about disclosure of one's HIV status can make a rigorous medication regimen inconvenient.

### **Safe Sex Awareness**

Most people who know they are HIV-positive would not want to pass the virus to others; however, many who have HIV are not aware of it. Awareness of being HIV positive and engaging in unsafe sex cannot be condoned and can result in criminal prosecution. Fortunately, people can reduce the risk of transmitting HIV by always practicing safe sex. People who are sexually active can reduce the risk of infection or re-infection by using latex condoms during vaginal, anal, and oral sex. Other latex products, such as dental dams, finger cots, and gloves, also help to prevent contact with body fluids, thereby reducing transmission risks. Some kinds of sexual activity, including erotic massage, licking or kissing intact skin, masturbation, and stimulation with unshared sex toys do not involve contact with potentially infected body fluids, thereby eliminating risk of transmission.

### **Vocational and Employment Services**

Going to work will be a possibility for tenants whose health has stabilized. Some people, especially those with good work histories, may return on their own with little or no assistance. Other tenants may want to upgrade their skills prior to entering or re-entering the workforce. Since some people will not enter the workforce, volunteer work or classes for personal enrichment can also offer fulfillment, enhance quality of life, and decrease feelings of isolation. Tenants returning to work should speak to a benefits/entitlement specialist who can discuss the impact of earned income on medical and financial benefits.

### **Managing Medical Decline and Death**

To experience a serious decline in health or to be dying of AIDS-related conditions can bring on a heightened level of need and significant distress. During periods of declining health, an individual may have to contend with multiple hospitalizations for the treatment of opportunistic infections and various conditions related to HIV and/or side effects of medication. Physical deterioration can occur, resulting in changes in appearance and motor and cognitive abilities. People at this stage of the disease will also experience a series of losses such as decreased independence and privacy. If the supportive housing project does not have the capacity to provide needed services, the individual could face losing his/her home and an integral part of his/her support system. Pain, limited energy, time-consuming care, and restricted movement will contribute to decreasing opportunities to spend time with others. Additionally, changes in appearance and depression can contribute to self-imposed isolation. Peers and fellow tenants who may have offered supportive relationships may not be as comfortable remaining close to someone who is dying.

As the quality of life declines, it is not uncommon for a person to think about terminating his/her life. The possibility of suicide allows some individuals to maintain a perspective of having ultimate control over their lives, even though they may never choose to exercise it. Others will take action

toward ending their lives by either terminating treatment or actively engaging in behavior that is destructive. Of course, all staff should be advised that it is illegal under any circumstances to assist an individual to terminate his/her life.

When a tenant becomes increasingly incapacitated by illness, program staff must give priority to the safety and essential service needs of the individual. Whenever possible, the individual should participate in this planning. Preferably, an individual can remain at home for as long as possible by arranging for a visiting nurse, personal care, hospice services, and the assistance of family, friends, and volunteers. If illness requires placement in another setting, staff can remain involved by maintaining as much of the support system as possible, including making visits, making phone calls, and sending letters.

The final stages of illness are very hard for everyone involved. As a practical matter, staff may need to assist in burial arrangements and memorial services. The way the community handles and memorializes a person's death is often a concern to other tenants and staff, particularly those who are living with HIV disease. Memorial services and life celebrations give people the opportunity to honor the life of the individual, to say good-bye, and to share their grief. Death is a great hardship not only for family and friends, but also for staff. Both tenants and staff may need support when dealing with death, and it is important that sponsoring agencies provide opportunities to address these feelings.

## **Staffing and Training**

Program staff should have at least a basic knowledge of and access to current information about HIV disease. Sources for HIV information include conferences, training workshops, newsletters, journals, the media, and the Internet. Formal and informal mechanisms that enable employees to seek information and support from supervisors, fellow staff, and colleagues are of tremendous value. Even though individuals may share the commonality of being HIV positive, differences in ethnicity, language, sexual orientation, gender, alcohol and drug use, and mental health status are important to anticipate. Staff should be sensitive to these differences and reflect that awareness in programming. Sponsors should provide sensitivity training for staff, as needed, and staff members should be models of respectful.

Enforcement of anti-bias and harassment policies is important. Sponsors should also ensure that all staff are aware of the risks that their own behaviors may pose for people with compromised immune systems. This includes personal hygiene (especially washing their hands regularly) and the handling, preparation, and storage of food. Myths and fears concerning the transmission of HIV persist among individuals of all educational and professional backgrounds. Creating a safe, harmonious environment in which there is no reluctance to interact and provide services to tenants with HIV disease requires ongoing training at all levels.

Training should include information about modes of HIV transmission and guidelines for universal precautions. Staff should be able to ask questions, have opportunities to express their doubts and fears, and be able to assess the risks of transmission in any situation they may encounter in the workplace.

## HIV/AIDS - Related Internet Sites

*Note: Not all web sites have the capacity to immediately post new material or to delete what is no longer accurate. Some maintain a large archive of information that will include items that are no longer up to date, while they simultaneously provide regular postings of the latest materials available. It is important for the reader to check the dates of all materials and verify information elsewhere, as needed.*

### **AIDS Education Global Information System - <http://www.aegis.com>**

The AIDS Education Global Information System (AEGIS) site offers an HIV-related multi-issue database, with numerous links and daily updates.

### **AIDS Housing of Washington - <http://www.aidshousing.org>**

This web site offers a variety of resources, including information about AIDS housing development, funding sources, technical assistance, and advocacy issues, and an on-line searchable resource library.

### **AIDS Treatment News - <http://www.aidsnews.org/>**

This treatment newsletter contains information for people living with HIV/AIDS who are looking for news regarding HIV therapies.

### **Centers for Disease Control - <http://www.cdc.gov/hiv>**

This federal agency's web site provides health and prevention information as well as epidemiological data.

### **HIV Education Prison Project - <http://www.hivcorrections.org>**

Sponsored by the Brown Medical School Office of Continuing Medical Education and the Brown University AIDS Program, this site targets correctional administrators and HIV and hepatitis service providers and offers information regarding HIV and hepatitis care in the correctional environment.

### **HIV/AIDS Treatment Information Service - <http://www.hivatis.org>**

This web site provides treatment information, including regularly updated treatment guidelines.

### **HIV and Hepatitis - <http://www.hivandhepatitis.com>**

This web site offers information about HIV, hepatitis, and coinfection issues. It also provides daily updates, with access to free interactive teleconferences that coincide with major national and international scientific meetings and conferences.

### **Johns Hopkins University AIDS Service - <http://www.hopkins-aids.edu>**

This site is a resource for health care professionals and consumers interested in the treatment of people with HIV/AIDS.

### **AIDS Infonet - <http://www.aidsinfonet.org>**

This web site provides fact sheets on numerous HIV-related topics, including medication, opportunistic infections, and lab work.

### **Project Inform - <http://www.projectinform.org>**

This national nonprofit organization provides on line information about the diagnosis and treatment of HIV disease.

### **University of California at San Francisco - <http://hivinsite.ucsf.edu/>**

This University of California at San Francisco-sponsored web site has in-depth HIV-related information on topics including, treatment, prevention, policy, and international issues. It also contains an on-line HIV textbook, *The HIV InSite Knowledge Base*.