# 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, 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 support.

HIV/AIDS has claimed more than 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 there has been a dramatic increase in the transmission of the disease among heterosexuals, especially women. A significant increase in the incidence of HIV also has 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 support. Even supportive housing projects that do not 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 components of 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.

## *HIV Transmission*

Any activity that allows the blood, semen, ejaculatory fluids, vaginal secretions, or breast milk of a person with HIV to enter the body and bloodstream of another person can spread the disease These activities include:

- Unprotected anal, vaginal or oral sex
- Sharing sex toys
- Sharing needles for injecting drugs, tattooing or body piercing
- Sharing razors and toothbrushes (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 United States 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

## *Key Components of HIV Services*

The health status and service needs of people living with HIV vary tremendously and change repeatedly. Supportive service providers should have the flexibility to reach out to those who are living independently, while accommodating individuals who require extensive support. In scattered-site housing, staff members visit 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, staff members should create a supportive environment that helps tenants adjust to 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 also may need extensive medical support and services.

There are specific considerations in developing supportive housing that serves 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 components for developing a supportive services plan 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 whether health-related criteria impact eligibility for tenancy. Consult an attorney for final approval of selection criteria since the Fair Housing Act and the Americans with Disabilities Act may apply. Supportive housing 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 needing more help, while others will not. Depending upon the circumstances and protocols, staff members can consistently communicate 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 concerns of which the tenant is unaware. Some service providers 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 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 assist with personal care and housekeeping. Linkages with pharmacies, visiting nurse services, specialized medication clinics, day treatment programs and other support services are essential.

In general, 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. Staff should routinely assist tenants with issues regarding their medications and closely track those 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 care, they should understand the continuum of HIV disease, special issues that the infection poses, 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.

Organizations providing supportive services should include staff members who are versed in the area of HIV and are able to serve as basic educators and make necessary referrals. They also should 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, 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. Staff also may 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 services necessary to adequately support people with HIV are extensive, and a single organization probably will not provide all needed services. Supportive services providers should connect tenants with HIV to community resources. Some providers also have developed collaboratives, consortia and partnerships to 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, 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 associated with the illness. Counseling also can be helpful in response to critical events that occur throughout the course of the disease. Counseling also can assist individuals to cope with their diagnosis, change in health status and modifications in lifestyle. It also can 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, those who have HIV and chronic depression have a higher mortality rate.

Individuals who respond well to treatment and are not seriously compromised by health barriers to employment, education or other goals may be reluctant 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 make a conscious decision to choose a healthier lifestyle and instead are 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.

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. 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 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 support and service networks. Some people maintain a friendship when the mentorship formally ends.

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 also must 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 also can 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 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 also should 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 minimum, volunteers must have a basic understanding of the treatment of HIV disease and know the basics of transmission and universal precautions. Preferably, training also should 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 their immune systems 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 also can 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. 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 any health improvements.

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

Tenants whose health has stabilized may be able to work. Some people, especially those with good work histories, may return with little or no assistance. Others 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 also can 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 also will 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 destructive behavior. 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, 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. 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 living with HIV disease. Memorial services and life celebrations give people the opportunity to honor the life of the individual, to say goodbye 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*

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 their service delivery.

Enforcement of anti-bias and harassment policies is important. Sponsors also should ensure that all staff is aware of the risks that their behavior 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 they may encounter in the workplace.