

# Long-Term Care and People Living with HIV

As a result of vast improvements in HIV treatment, more and more people with HIV are reaching retirement and enjoying the “golden years” that lie beyond. Sadly, however, some are facing discrimination as they seek living arrangements and long-term care services suitable for seniors. Long-term care providers may have very limited knowledge about HIV and/or be unaware of their legal obligation to provide housing and services to individuals living with HIV. Knowing your rights will help ensure that you receive the same respect and care afforded others.

## DISCRIMINATION BECAUSE OF HIV IS ILLEGAL

Many people seek the services of a long-term care provider at some point in their lives. Long-term care often includes a place to live and related services that allow for varying degrees of independence.<sup>1</sup> People living with HIV—and those who are helping them find long-term care—need to know that it is *unlawful* for a provider to discriminate against a person, during the application process or in providing long-term care services, merely because the person has HIV.

Several federal laws prohibit discrimination based on disabilities, including HIV.<sup>2</sup> If a long-term care provider offers a *place to live*, the disability antidiscrimination provisions of the federal Fair Housing Act (FHA) apply. Discriminatory treatment in offering or providing long-term care *services* violates both the FHA—if the services are sufficiently related to the housing being offered—and the Americans with Disabilities Act (ADA). If the long-term care service provider receives federal financial assistance, such as Medicare or Medicaid, the federal Rehabilitation Act prohibits it from discriminating based on disability. For example, if a long-term care facility accepts Medicaid payments and refuses to admit anyone who has HIV, that facility likely is violating the FHA, ADA and the Rehabilitation Act. In addition to these federal statutes, many states have similar laws prohibiting disability discrimination.<sup>3</sup>

Though these federal antidiscrimination statutes may apply in different ways and under different circumstances, the concepts discussed below come into play under all of them.

## Qualifying for the Services

A long-term care facility is allowed to have eligibility requirements. A person seeking protection under any of the

federal statutes addressing disability discrimination must be able to show that he or she is qualified to live in that type of facility and/or receive the services allegedly denied on account of disability. Typically, state regulations limit the types of services that a particular kind of facility can provide, which allows for the exclusion of some applicants. However, in the application process, the long-term care provider must conduct an *individualized assessment* as to whether the applicant is eligible for the services offered and whether the applicant’s needs can be met at the facility in question. In other words, the provider’s decision must be based on the particular applicant seeking the services; it cannot have a “blanket policy” refusing to provide services to all people living with HIV.

Factors related and unrelated to HIV potentially may disqualify a person from being eligible for a particular long-term care facility. A person living with HIV must be able to show that s/he would be eligible to reside in the facility at issue because he or she: 1) meets the eligibility requirements of the facility that do not relate to having HIV; and 2) meets the other eligibility requirements despite the fact that s/he has HIV.

- **The applicant must meet the non-HIV-related eligibility requirements that the facility applies to everyone.** For instance, a facility may have a minimum age for its residents or a requirement that an applicant demonstrate the ability to pay for services. Furthermore, the facility must be licensed to provide the necessary level of care for any non-HIV-related medical conditions that an applicant might have. For example, a person who is not sufficiently mobile may not qualify for certain kinds of assisted-living facilities.

- **The applicant must be able to show that s/he is eligible for the services *despite* the fact s/he has HIV.** The level of care a facility provides may be an issue if the person’s HIV care and treatment require services the facility does not provide to anyone (for example, injection medications may not be provided at some facilities), or if an HIV-related condition requires a higher level of care than the facility is authorized or equipped to provide (for example, HIV-related dementia may require placement in a facility that works with people who have dementia).

There are, however, long-term care facilities authorized and equipped to provide care at almost any level a person living with HIV might require. The important thing is to find a facility that meets the specific needs of the person seeking the services.<sup>4</sup> Many people require nothing more than daily medications and regular check-ups with an infectious disease specialist to treat their HIV. Assisted-living facilities typically provide assistance with medication and transportation to doctor visits and can meet these very minimal needs. For most people living with HIV, their HIV-related needs will not make them ineligible for the services of a long-term care provider (though more extensive HIV-related needs may affect the type of facility for which a person is eligible).

### Refuting the “Direct Threat” Defense

Federal disability discrimination statutes include an exception that allows a long-term care facility to exclude someone *if* the facility can show that the person would present a “direct threat” to the health or safety of others. A “direct threat” is defined as “a *significant* risk to the health or safety of others that cannot be eliminated by a modification of policies, practices, or procedures or by the provision of auxiliary aids or services.”<sup>5</sup> The existence of a direct threat, however, must be supported by objective, scientific evidence and cannot be based on misconceptions, stereotypes or subjective fears regarding HIV.<sup>6</sup>

The assertion that someone with HIV poses a “direct threat” in the context of long-term care lacks scientific support. HIV is not easy to transmit and is not transmitted through casual contact in a household or social setting. HIV is not airborne or food-borne and does not live long outside the body. A person cannot get HIV from sweat, saliva, tears, clothes, toilet seats, sharing a drinking glass, eating from the same plate or simply by being around someone who has HIV.<sup>7</sup>

Only specific body fluids—blood, semen, vaginal secretions and breast milk—potentially contain enough of the virus to

transmit HIV. And these specific body fluids must come into contact with a mucous membrane or damaged tissue, or be directly injected into the bloodstream, for transmission to possibly occur. Whenever staff members of a long-term care provider might come in contact with any of these particular body fluids while providing care to *any* resident of a long-term care facility (whether or not the person’s HIV status is known), the staff members should follow universal precautions to prevent infection (e.g., wearing gloves) recommended by the Centers for Disease Control and Prevention.<sup>8</sup>

The assessment of whether the applicant presents a “direct threat” must be based on an *individualized* inquiry regarding this person’s HIV-disease and the alleged threat presented by allowing this particular person to reside in and/or receive services at *this facility*. The vast majority of people with HIV do not present a risk to the health or safety of other residents or staff while receiving services at a long-term care facility and, therefore, cannot legally be excluded from a long-term care facility on that basis.

### BEING ACCEPTED INTO LONG-TERM CARE

If you are living with HIV, keep the points below in mind as you move through the process to gain admittance to a long-term care facility. Taking these actions may help smooth the acceptance process. And if you are rejected based on your HIV, having taken these steps during the application process may help if you later decide to file a claim in court.

- **Ask a friend or relative to be a part of the process.** It may be helpful to have a friend or relative who knows about your HIV status accompany you to the facility when you visit and to be a part of any conversations you have with representatives of the facility. That way, there will be more than one “set of ears” that has heard everything that has been said – which can be particularly helpful if you do experience discrimination and take the matter to court. Ideally, this person should be someone with whom you previously have shared your personal medical information, including your HIV status, and that you can trust to maintain confidentiality, if necessary.
- **Be honest.** The last thing you want is for the provider to be able to say that you lied about something on your application or that you were hiding relevant information to get admitted. You should answer all questions completely and honestly.

Typically, you will be required to provide information about your medical conditions (including diagnoses and medications) and have a medical assessment performed by a doctor as part of the application process – and this inquiry *is* legally permissible. If you get to choose the doctor who will conduct this medical assessment, try to see a doctor who understands infectious disease and, in particular, HIV. You want to be completely honest with the doctor performing the evaluation, accurately complete all forms, and answer any questions the doctor has to the best of your ability and recollection.

- **Pin them down.** If possible, get a commitment that you are otherwise qualified to reside at the facility before revealing your HIV status. That way, if you are rejected after disclosing, it will be harder for the facility to say the rejection was based on something other than your HIV—and the true motivation for the facility’s refusal to admit you will be easier to prove in court. Regardless of whether you can control the sequence of events in this way, if you are rejected at any point in the process, be sure to ask someone at the facility to explain *why* you are being rejected. If possible, get them to put the reason(s) in writing. Just requesting that they “put it in writing” may cause them to have second thoughts about rejecting your application and to think about whether they are engaging in unlawful conduct.
- **Take notes and keep everything.** If you suspect that discrimination may be taking place, try to make notes about everything that happens, including details of the conversations you have with any representative of the facility – what was said, who said it, and the dates and times of those conversations. Keep everything that you are given in writing by the facility and make copies of all the forms, applications, and other documents you give to them (preferably *before* you give these things to them).
- **Seek legal assistance.** If you feel that your rights are being violated at any point, you should consider reaching out to someone who understands these issues for advice and/or legal assistance. Lambda Legal wants to hear about this kind of illegal conduct and provides information about local attorneys and other resources to those who contact our Help Desk (see “For more information,” below). A local HIV/AIDS organization also may be able to provide some assistance.

**Make sure your rights are respected!** Hopefully, the precautions outlined above will not turn out to be necessary. But you won’t know if you are going to be discriminated against before it happens, so these “protective measures” are probably a good idea. No one—and certainly not our community’s seniors—should have to put up with disrespect and discrimination.

**For more information:**

Visit our website: [www.lambdalegal.org](http://www.lambdalegal.org); call our Help Desk at (866) 542-8336; or write us at 120 Wall Street, Suite 1500, New York, NY 10005.

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<sup>1</sup> Assisted-living facilities and nursing homes (sometimes called “skilled-nursing facilities”) are common types of long-term care providers, but there are other types, including some that are non-residential.

<sup>2</sup> For purposes of antidiscrimination laws, the term “disability” has a special meaning, and a person can be “disabled” even though s/he can work or live independently without assistance. If you bring a lawsuit claiming you were discriminated against based on HIV (or any other medical condition), you will be required to show that you are “disabled” as a result of having that medical condition or that the person who discriminated against you regarded you as being “disabled.” A person with HIV should be able to meet that requirement. (“Disability” has a different meaning in other contexts, such as eligibility for Social Security disability benefits.)

<sup>3</sup> This document focuses on the protection under federal law. State laws may differ in terms of who is protected, who must comply, what is prohibited, and what remedies are available.

<sup>4</sup> In certain circumstances, a person could even be “overqualified” for a particular facility. A facility legally may choose to admit only people who require the services it is licensed to provide. For example, at least in some states, a skilled nursing facility may refuse to admit someone who doesn’t need skilled nursing care.

<sup>5</sup> 42 U.S.C. § 12182(b)(3) (emphasis added); *accord* 42 U.S.C. § 3604(f)(9); *cf.* 29 U.S.C. § 705(20)(d) (making the “direct threat” defense available in the employment context under the Rehabilitation Act).

<sup>6</sup> *Bragdon v. Abbott*, 524 U.S. 624, 649 (1998).

<sup>7</sup> Centers for Disease Control and Prevention (CDC), *Questions and Answers: HIV Transmission*, available at <http://www.cdc.gov/hiv/resources/qa/transmission.htm> (last visited Sept. 14, 2010); CDC, *HIV and AIDS: Are You at Risk?* (2007), available at <http://www.cdc.gov/hiv/resources/brochures/pdf/at-risk.pdf>.

<sup>8</sup> Other body fluids (such as saliva, nasal secretions, sweat, tears, and urine), feces and vomit do not pose a risk of transmission—and therefore gloves and other precautions are not needed, unless the fluid or material contains visible blood.

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