Legal Issues for People with HIV

Duke Legal Project
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Duke Legal Project is a clinical legal education program of Duke Law School. Legal Representation is provided by Duke Law Students under the close supervision of licensed attorneys.
More than 20 years into the AIDS epidemic, fear, stigma, and misinformation still abound in our communities. The law strikes an uneasy balance between protecting the public health and the rights of people infected with HIV. For the broader community, there is an urgent need to stop the spread of the disease. For people with HIV, there are concerns about privacy, autonomy, and discrimination, along with a desire to live a full and productive life in the best possible health.

This pamphlet answers some questions about the law that are important to people with HIV.

GETTING HELP

Since I Have HIV, Can I Get Disability Benefits And Medicaid?

Being HIV positive does not automatically qualify you for Social Security Disability, SSI, or Medicaid. To qualify for these programs, you must be too sick to work on a regular basis. If you are too sick to work, you can apply for disability at the Social Security Administration and for Medicaid at your county Department of Social Services. If you are turned down, and still think you’re disabled, be sure to appeal. Your chances of winning your appeal will be stronger if you have a lawyer.

Who Can Help Me Coordinate Benefits And Care?

AIDS services agencies in your local community can help you get the care and assistance you need. To connect with a local agency, call the AIDS Care Unit of the HIV/STD Prevention and Care Branch of the Division of Public Health at (919) 733-7301.

I Need Help With A Legal Problem Related To HIV. Where Can I Get Help?

People with HIV who can't afford a lawyer can contact the Duke Legal Project at (919) 613-7169 or toll free at 888-600-7274. This program takes cases that have some connection with HIV status. Cases are handled by advanced law students under the supervision of licensed attorneys. All services are free.

Legal Aid of North Carolina assists low income people with civil legal problems including public benefits, landlord-tenant, consumer, some family law cases, and other matters. They have offices across the state. Call 866-219-5262.
discriminated against in school or day care because of HIV.

If your child’s doctor believes your child may pose a significant risk of transmission in a school or day care because of open, oozing wounds or because of behaviors such as biting, the doctor must notify the local health director. You will participate in a process with school officials and a medical expert to determine whether intervention is needed. If necessary, adjustments can be made to your child’s school program or environment, or your child can be placed in an alternative educational setting. However, any adjustments to your child’s program must be based on scientifically sound evaluation of the risk of transmission of HIV, not on fear or ignorance. And all information shared during the assessment must be kept confidential. Only school staff with a need to know may be told of your child’s infection.

I have minor children. How can I make sure they will be taken care of if something happens to me?

You should plan ahead to make sure your children will be taken care of if you become too sick to care for them yourself. If the child’s other biological parent is available and involved, this is an easy option. Otherwise, you should consider having a “standby guardian” appointed, making custody arrangements, and establishing a trust for the children in the event of death.

PLANNING

What Estate Planning And Other Arrangements Should I Make?

It is important for all adults to prepare documents that will allow their loved ones to handle their affairs if they become unable to do so themselves. A Durable Power of Attorney will allow a trusted friend or family member to take care of finances and business if you are too sick to do so yourself. A Health Care Power of Attorney will ensure that someone who understands your health care goals and preferences will make medical decisions if you are unable to. A Living Will is a document you can use to make clear your wishes about end-of-life care. A standard will may be important if you own your home or other real estate or if you are not legally married to your partner.

HIV TESTING

Can I Get An Anonymous HIV Test?

No. North Carolina does not allow anonymous HIV testing. All testing is confidential, but name-based. All positive HIV test results must be reported to the state.

Does My Doctor Have To Report My HIV Infection?

Yes. If a doctor or medical facility has a positive test result or has reason to suspect that a patient is infected with HIV, the patient’s name and address must be reported to the local health director. After any positive HIV test result, a trained specialist from the Health Department may contact you to provide counseling.

May I Be Tested For HIV Without My Consent?

As a general rule under North Carolina law you must give informed consent before you can be tested for HIV. Testing can be offered as part of routine lab tests using a general consent, as long as you are notified that you are being tested for HIV and given the opportunity to refuse. North Carolina no longer requires pre-test counseling.

What Happens When I Have A Positive Test Result?

First, your doctor is required to tell you about specific measures -- called “control measures” -- that you should take to reduce the risk of spreading HIV. If your doctor ever has reason to believe that you are not following these control measures and pose a significant risk of transmission, the doctor must notify the local health director.

If you are married, your spouse must be notified of your positive HIV test. If you consent, your doctor can do this. Otherwise, if your doctor knows who your spouse is, he or she must report your spouse’s name to the state. Your spouse will then be contacted and counseled by a trained specialist.
There are a few situations where you can be tested without your consent:
(1) Donated blood or semen is required to be tested; (2) Testing can be done for research or epidemiological purposes as long as your identifying information is removed; (3) The Commission for Health Services can require testing without consent when necessary to protect the public health; (4) Children under 18 may be tested without a parent’s consent in some instances; (5) Newborn babies may be tested without parent consent if there is no record of an HIV test for the mother; (6) A pregnant woman in labor may be tested without consent if she has no record of an HIV test. (7) A victim of a sexual offense may ask for a court to have the alleged perpetrator tested. (8) If you are unable to provide consent, and there is no one who can provide it on your behalf, a doctor may order an HIV test if it is necessary to diagnose or care for you appropriately.

Testing Of Pregnant Women and Newborns

Every pregnant woman must be offered HIV testing at her first prenatal visit and in her third trimester. At these times, pregnant women will be tested for HIV unless they refuse. However, if a pregnant woman has no record of an HIV test at the time of labor and delivery, she will be tested with or without consent unless the doctor determines that the test would endanger the woman. If an infant is delivered to a woman with no record of the result of an HIV test, the infant shall be tested for HIV, with or without parent consent.

RESPONSIBILITIES OF PEOPLE WITH HIV

What Are My Responsibilities As A Person With HIV?

The law requires you to take certain precautions to stop the spread of HIV. The required “control measures” are:

- You must not have sexual intercourse without a condom;
- You must not share needles or other drug-related equipment;
- You must not donate or sell blood products, semen, organs, or breast milk;
- You must tell all future sexual intercourse partners that you have HIV;
- If you know when you became infected, you must tell any sex or needle partners since that time about your infection. Otherwise, you must notify partners from the previous year.

Health care workers who know that they are HIV infected and who perform certain invasive procedures must take steps to avoid transmission to patients. If you do these kinds of procedures, you must notify, in writing, the Chief, Communicable Disease Branch, 1902 Mail Service Center, Raleigh, NC 27699-1902. If it is determined that there is a significant risk of transmission to patients, the state health director will appoint an expert panel to evaluate your practice and patient environment. If the expert panel recommends restrictions as necessary to prevent transmission, the state health director may restrict your practice.

I’m on Disability. Can I work?

Disability benefits are generally meant for people who are unable to work because of their disability. If you get Social Security Disability or SSI (Supplemental Security Income), you must report any work activity to the Social Security Administration. Social Security may need to adjust or stop your benefits based on your earnings. If you don’t report your income, you may end up with a large overpayment when Social Security eventually finds out about your work.

There’s good news, though. Social Security has special incentives to help people with disabilities return to work. If you follow their rules, you can go back to work and keep most or all of your benefits for a certain period of time. You can also keep your Medicaid and Medicare. The rules for returning to work are complicated, though. If you are thinking of working, you should talk to Social Security ahead of time. The Work Incentive Planning and Assistance (WIPA) Projects can help you figure out how best to return to work. Call Social Security to find out the program in your area.

HIV AND CHILDREN

I Have A Child With HIV. Do I Have To Tell The School Or Day Care Provider?

No. You do not have to tell your child’s school or day care provider about your child’s HIV infection. However, if your child has special medical needs, you may choose to disclose in order to make sure these needs are met. Your child cannot be
If you have a job offer, you could not be refused the job on the basis of your HIV unless the decision is job related and consistent with business necessity. In general, this is the case only if your HIV would make you unable to perform the job or pose a serious safety risk (called a “direct threat”). These concerns sometimes come up in the food service and health care fields, but in all but the most rare circumstances, there is little or no risk of transmission of HIV in these fields or elsewhere in the workforce, so there is no excuse for refusing you a job based on your HIV.

Sadly, North Carolina law does not prevent an employer from refusing to hire someone with HIV.

**Can I Be Fired For Taking Too Many Sick Days Or Coming To Work Late?**

Generally, yes. Attendance is considered an essential function of any job. However, if your illness is causing your attendance problems, you can ask your employer for a “reasonable accommodation” under the ADA. If you ask for an accommodation, you need to do so clearly and you will have to explain your illness to your employer. Your employer does not have to agree to your suggested accommodation, but must discuss it with you. If you work at a company with at least 50 employees, the Family and Medical Leave Act (FMLA) can provide you with up to 12 weeks of unpaid leave for medical needs. You do not have to take all 12 weeks at the same time. If you or your doctor thinks you need time off for illness, ask your employer about FMLA leave.

I Work In Health Care. Are There Any Special Concerns For Me?

Yes. The risk of getting HIV from a patient is much greater than the risk that you will spread HIV to patients in your care. To protect themselves and patients, all health care workers must use “universal” precautions with all patients, to prevent the spread of blood borne pathogens, such as HIV or hepatitis B. The Centers for Disease Control and Prevention recommends the use of examination, procedure or surgical gloves as a barrier to such diseases, as well as other sterilizing procedures. Health care workers should know their HIV status as well as the status of their patients. But you must keep your patients’ HIV status confidential.

If you violate any of these control measures you can be placed under an “isolation order” which sets up an individual plan to reduce the risk of transmission. You can also be criminally prosecuted for violating control measures.

**INFORMATION ABOUT MY HIV STATUS**

**Is HIV Status Confidential?**

Yes. Information relating to HIV is confidential. However, there are a few exceptions. First, information about your HIV status can be disclosed with your consent. Also, as discussed above, your doctor has to report your HIV infection to the state. The state can inform your spouse. There are several situations when your HIV status can be disclosed for medical, research or public health reasons: (1) for medical or epidemiological purposes provided no identifying information is given; (2) to provide proper medical care; (3) when necessary to protect public health, if disclosure is made according to law; (4) by the Department of Health Services for bona fide research purposes; (5) when required by a court order or subpoena; (6) when someone is exposed to your blood or body fluids. Any person who reports confidential medical information under these rules is immune from civil or criminal liability. However, the law makes it a misdemeanor to reveal information about HIV infection in any other way.

The federal HIPAA (Health Insurance Portability and Accountability Act) law also requires anyone handling health information to keep it confidential, including health insurance companies and health care providers. If a health care provider or insurer does not properly protect your private health care information, you can make a complaint to the Office of Civil Rights of the U.S. Department of Health and Human Services. The health care provider can be fined for violations of HIPAA.

**Should I Tell People I Have HIV?**

In spite of these privacy protections, if your confidentiality is breached, there is no way to repair your damaged privacy. Also, legal remedies for breach of confidentiality are very limited, so it is best to be very careful about disclosing your HIV status. Your health care providers need to know about your HIV so they can properly care for you, and they are legally bound to keep your HIV status confidential. Control measures require that you disclose your status to sexual or needle partners, but except in very limited circumstances, you are not required to disclose your
HIV status to your employer, school, day care provider, or anyone else.

Can Anyone Ask Me About My HIV Status?

If you apply for health, disability, or life insurance, you may be asked about your HIV status in a questionnaire or medical exam. If you refuse to answer, or answer untruthfully, you can be denied coverage. Your best approach is to answer truthfully. However, you should be careful about who sees your application. If you are getting insurance through your employer, try to avoid the risk of disclosure by sending the questionnaire directly to the insurance company, rather than through your employer.

An employer can only ask about HIV or other medical matters after you have been given a conditional offer of employment, but only if this is done for all employees entering the particular job category. The Americans with Disabilities Act requires employers to keep confidential any health information obtained through pre-employment medical examinations or insurance questions.

Health care providers may ask you about your HIV status. It is best for your health if you let your provider know all important aspects of your medical history, including your HIV status. Except in very limited circumstances, a health care provider cannot refuse to serve you because of your HIV status.

Can A Health Insurer Screen For HIV?

Group Health Insurance: The law prohibits group health plans and most major insurance companies from denying coverage based on an individual's health status. Group health insurers are also prohibited from charging higher premiums or denying coverage to due to AIDS or HIV infection. Although most health insurance policies do not exclude coverage for AIDS and HIV infection, many have preexisting condition clauses that may exclude coverage for a period of time if you are infected when the insurance coverage starts. However, if you had comparable insurance before joining another group insurance, the HIPPA law prohibits most group health plans from applying a pre-existing condition limitation. If you did not have insurance, or your prior insurance had less coverage, your new group plan can only apply a pre-existing condition limitation for a maximum of 12 months.

In order to take advantage of this protection against pre-existing condition limitations, you must make sure you maintain insurance coverage with no more than a 63-day gap.

Individual Health Insurance: If you do not have group insurance through your employer, you may seek an individual health insurance plan. In many situations, persons with serious health conditions, including HIV, can be turned down for individual health insurance policies or charged substantially higher rates for individual health insurance policies.

DISCRIMINATION

Can I Be Discriminated Against Based On HIV?

Federal law prohibits discrimination against people with disabilities in employment, housing, public services, and public accommodations. HIV infection may qualify as a federal disability. Disability is defined as a physical or mental impairment that substantially limits a person in one or more major life activities.

Under the Americans with Disabilities Act (ADA), otherwise qualified individuals with a disability must be permitted to remain in their jobs so long as they can perform the essential functions of their jobs and do not pose a direct threat to the health or safety of themselves, their co-workers, or other persons in the workplace.

Disabled employees can ask for a “reasonable accommodation” to help them continue to do their job. The ADA covers employers that have at least 15 employees. A similar law covers employers that receive money from the federal government.

What Are My Rights To Public Services And Accommodations?

The ADA prohibits discrimination against people with disabilities in public service and places of public accommodation. Public accommodations include hotels, restaurants, medical or dental offices, mental health agencies, substance abuse treatment centers, hospitals, public transportation, colleges, schools, day care centers, swimming pools, and exercise or recreational facilities, among others. The federal Fair Housing Act prohibits discrimination against people with disabilities in housing.

WORKING WITH HIV

Can I Be Refused A Job Because Of My HIV Status?

Generally, no. Remember, an employer covered by the ADA can’t even ask about your health status or have you take a medical exam until you have been given a conditional job.