

ACCESS TO TREATMENT



programs that provide access to healthcare and treatment for people living with hiv

Treatment and quality healthcare are among the top needs of people living with HIV/AIDS. However, many people are not familiar with the programs that provide access to HIV care and treatment. This publication provides an overview of these programs. If you have questions or difficulty in getting help, contact Project Access's toll-free hotline at 1-800-822-7422.

A PUBLICATION FROM

PROJECT
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Information,
Inspiration and
Advocacy for People
Living With HIV/AIDS

JULY 2003

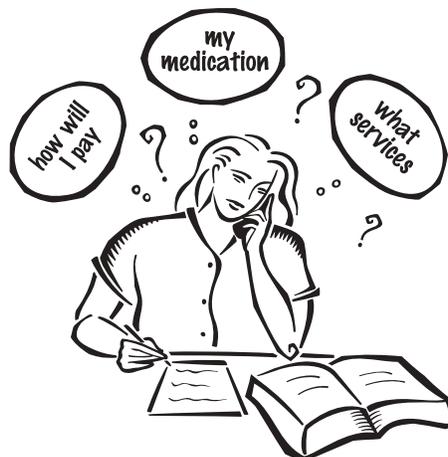
In the United States, most people living with HIV are aware that treatment options have improved dramatically. Many are living longer and enjoying a better quality of life due to more effective drugs and a growing understanding of HIV care.

However, changing, complex and expensive treatments create an even greater need for quality healthcare, including an experienced HIV doctor and adequate drug coverage. Access to care and treatment, while better in some areas, remains a challenge for many people.

It is estimated that one-half to two-thirds of HIV-positive people are not in regular quality care. Some face real barriers including race, ethnicity, immigration status, income level, education, gender, sexual orientation, language and other factors. Given all this, quality healthcare—including a doctor experienced in treating HIV-positive people who is respectful of his or her patients and their unique healthcare needs—is essential and sometimes difficult to find.

One of these basic barriers is inadequate insurance. It can be hard for HIV-positive people to get comprehensive insurance, either public or private. The criteria for public programs are strict and it can be difficult to qualify. Private insurance can be expensive and difficult to get unless your employer offers it. Even those lucky enough to have insurance can still face problems.

Private insurance can restrict coverage or the doctors you can



see, and public programs vary in scope and quality and may lack important benefits. In addition, the cost of private insurance is increasing rapidly, as are the “co-payments” that people must pay.

To better understand the challenges that positive people face, let us consider some facts. In the U.S., 41 million people are uninsured—about 16% of the population. Among those most

likely to lack coverage are young adults between the ages of 19–24 and members of racial and ethnic minorities, some of the same groups heavily impacted by HIV. The two largest studies of HIV care found that 53% rely on public programs (Medicaid and Medicare), 28% have private insurance and 19% are uninsured.

According to a report released by the Institute of Medicine in 2002, the lack of health insurance in America leads to delayed diagnoses, life-threatening complications and, ultimately, premature deaths in HIV-positive people. The researchers estimated that a lack of insurance translates annually into 1,200–1,400 deaths among HIV-positive adults.

With persistence and effort, people with HIV in the U.S. can usually manage to access care and treatment. However, piecing together and maintaining adequate healthcare on one's own can be frustrating and difficult. A friend, an advocate or a specialist in healthcare benefits is often necessary to help people navigate the healthcare system and create reasonable care plans.

medicaid

Medicaid is a public health insurance program that serves low-income people who fit certain categories. It is a joint federal and state program, run by the state. Medicaid is the largest source of federal funding for HIV care. It serves about 55% of adults and 90% of children living with AIDS. Although Medicaid generally provides good care, there can be some gaps in coverage for people with HIV.

Eligibility

Most adults with HIV disease who qualify for Medicaid do so because they are disabled, have low income and limited assets. Another entry category is association with the Temporary Assistance to Needy Families (TANF) program.

People who meet the disability criteria but make too much money to qualify for Medicaid may qualify through a “medically needy” program. This allows people to subtract their medical care and/or treatment expenses from their income before applying. As of March 2002, 34 states had these programs. As well, some states cover disabled people who are working at slightly higher income levels than standard Medicaid limits.

Benefits

The federal government defines mandatory and optional Medicaid services, provides half or more of the funding, and establishes eligibility guidelines and rules. Mandatory services covered by all Medicaid programs include: hospital care (both overnight and

day care), doctor visits, lab tests, x-rays, and nursing home and home health services. However, each state determines the amount of coverage. States also determine optional coverage; the amount, duration, and scope of services; and the rate of payment for services.

Optional services include prescription drugs, clinic services, case management and dental care. Currently, all states cover all Food and Drug Administration (FDA)-approved prescription drugs, including anti-HIV drugs. However, prior approval processes and monthly caps can make it difficult or impossible to access all the drugs that are needed.

Some concerns:

DISABILITY

In most states, most people living with HIV must prove they are disabled before they can qualify for Medicaid, even if they meet the income requirement. Therefore, a person living with HIV has to wait until he or she becomes sick in order to get Medicaid. Additionally qualifying for Medicaid can be a difficult process. TIPS: Qualifying for Medicaid can be lengthy and complicated, requiring a lot of paperwork. Keep a file with copies of all paperwork. Requirements for disability are similar state to state, but could be subject to change. Consult an experienced benefits counselor or case manager for assistance in filing.

INCOME AND ASSETS

Most often, in order to qualify for Medicaid, people must have very little in income or assets. Therefore, many people can't qualify, but also can't get or afford other types of insurance. Working even part-time may make it hard to keep Medicaid benefits unless the state offers a program to help disabled workers keep coverage. TIPS: Eligibility can vary state to state. There are also programs, such as medically needy and back-to-work that allow increased income levels in some states. It is important to understand what programs are available and be clear on the requirements.

medicaid services



Services that are covered by all Medicaid programs include:

- lab tests
- hospital care
- doctor visits
- x-rays
- nursing home & home health services



- Each state determines the amount of coverage; optional coverage; amount, duration, and scope of services; and rate of payment for services.
- Approval processes and monthly caps can make it difficult or impossible to get all the drugs that are needed.

PRESCRIPTION DRUGS

Although all states currently provide prescription drug benefits, they can vary. Some states limit the number of prescription drugs, and some require Treatment Authorization Requests (TARs) or prior approval for certain drugs. **TIPS:** It is important to understand what your state offers. People can think that certain services or prescription drugs are not available simply because their doctor doesn't have the expertise or the time to file a TAR. If there are any questions regarding coverage for a drug, consult an experienced benefits counselor, treatment advocate or case manager.

COST TO THE INDIVIDUAL

Medically needy programs within Medicaid require a *share of cost*—the amount of money you pay before getting services each month. As health-care costs continue to increase and state budgets are squeezed, more programs may require some individuals to pay for a portion of medical services, similar to private insurance. **TIPS:** Other state programs may help with some Medicaid expenses, like share of cost and co-payments. Work with a treatment advocate, benefits counselor or case manager to identify local or state programs that may be of assistance.

PROVIDER ACCESS

It can be hard to find a doctor who takes Medicaid because it doesn't pay much for office visits. In rural areas and inner cities where it's often hard to find doctors, it can be even harder to find an HIV-experienced provider who takes Medicaid. **TIPS:** Finding an HIV-experienced doctor who takes Medicaid is often done best by word of mouth. Peers, friends or even a local AIDS service organization (ASO) can be excellent resources for finding doctors. The American Academy of HIV Medicine's web site (www.aahivm.org) lists members, although not all accept Medicaid. The HIV Medicine Association provides doctor referrals through a toll-free number at 1-888-844-4372. In the cities most impacted by HIV, urban public health clinics can have excellent HIV care and accept Medicaid clients.



TALKING TO A CASE MANAGER OR BENEFITS COUNSELOR MAY HELP YOU CHOOSE HEALTHCARE PLANS

MEDICAID MANAGED CARE

Many Medicaid programs use managed care organizations to deliver services. Although some deliver good HIV care, others cut corners in ways that can compromise care. In some, but not all states, HIV-positive people are not required to enroll in managed care. **TIPS:** If contacted about choosing a managed care plan, it's important to take action because a state can, and usually will, automatically enroll people in a plan if they don't make a choice. Sometimes people don't find out their healthcare plan has been changed until they're at their regular doctor, who may or may not take the new plan. If contacted to choose a managed care plan, contact a benefits counselor or a case manager at a local ASO to determine how to proceed. In some states it may be possible to get an exemption. If managed care is the only option, they should be able to provide information and help make decisions regarding a plan.

THE BUREAUCRACY

Medicaid can be a very frustrating and bureaucratic system. It can be difficult for people to understand the full range of their benefits, rights and responsibilities and how to advocate for themselves in the system. **TIPS:** In general, the best way to ensure good care is to become or find a good advocate. Consult an experienced benefits counselor, treatment advocate or case manager. Friends and family members can also be good support. Learn as much as you can about your own state Medicaid and your benefits.

medicare

Medicare is public health insurance for the elderly and the disabled and is run by the federal government. Medicare is the second largest federal payer of HIV care. It covers about one in five people living with HIV who receive care. Since 1995, the amount that Medicare spends on HIV/AIDS care has increased by 70%.

ELIGIBILITY

Most Americans get Medicare coverage when they reach 65 and are eligible for Social Security payments. Most people with HIV who receive Medicare benefits do so as a result of their Social Security Disability Insurance (SSDI) status. Eligibility for SSDI, however, is limited to those who have sufficient work histories and who are fully disabled. In addition, federal law requires a five-month waiting period after disability determination to receive SSDI benefits and then a two-year waiting period before an SSDI beneficiary can join Medicare, resulting in a total of 29 months before getting health benefits.

BENEFITS

There are three components to Medicare. Part A covers inpatient hospital services, skilled nursing care, home health services and hospice care. Hospital care is subject to deductible as well as daily co-pay. This portion of Medicare is available to everyone who qualifies.

Part B covers physician services, outpatient hospital care (hospital procedures not needing overnight stays), medical equipment and supplies, and other health services. Part B is voluntary, but individuals choosing to participate must pay a monthly fee for these services. Over 90% of eligible people choose it. Unlike Medicaid, most providers accept Medicare.

Part C allows people to enroll in Medicare managed care plans. This benefit is known as Medicare+Choice and is available to all Medicare recipients if plans serve their areas. Most Medicare managed care plans provide some prescription drug benefits, although they're often very limited. The plans still require premiums and co-pay.

One of the most important services not covered by Medicare is prescription drugs.

PROGRAMS FOR LOW-INCOME PEOPLE

Two programs help low-income people cover some Medicare costs. The Qualified Medicare Beneficiary (QMB) and Specified Low-Income Medicare Beneficiary (SLMB) programs work by using Medicaid to pay costs, like premiums and deductibles, that would otherwise have to be paid by the individual.

DUAL ELIGIBILITY

Some low-income Medicare beneficiaries are also eligible for Medicaid. This is called dual eligibility. Basically, this means that Medicaid is combined with Medicare to provide comprehensive benefits with very little or no cost to the individual. People living with HIV who are dually eligible can benefit from the additional services provided by Medicaid, especially prescription drug coverage.

medicare has 3 components

PART A



INPATIENT CARE,
SKILLED NURSING,
HOME AND
HOSPICE CARE

PART B



DOCTOR FEES,
OUTPATIENT CARE,
MEDICAL EQUIPMENT
AND SUPPLIES

PART C

MEDICARE
+CHOICE

MEDICARE MANAGED
CARE PLANS

Concerns about Medicare for people living with HIV

ELIGIBILITY

One of Medicare's biggest challenges for people living with HIV is the 29-month waiting period that is required before receiving Medicare. In addition, they must have worked a long enough period of time before becoming disabled to qualify. TIPS: It is usually best to work with a benefits counselor or case manager, if possible, while applying for Medicare. This will help to ensure that all deadlines are met, the correct paperwork is done, and the scope of benefits is clear.

MEDICARE+CHOICE

This is the managed care option of Medicare. Unfortunately, it's difficult to find a plan that provides more than very limited drug coverage. It is usually far less than is needed by someone living with HIV. TIPS: When considering a change to managed care, it's important to get as much information as possible about your options, including the providers in the system. It is also important to get as much information as possible on the financial stability of the Medicare managed care plans in your area. In the past several years, many plans have left whole areas due to financial problems. People have to return to fee-for-service, which could mean changing doctors.

CONTINUING DISABILITY REVIEWS

Crafting a definition of AIDS has been a painstaking and difficult effort. AIDS is considered a disabling condition that is subject to continued review in Medicare. This process can be lengthy and involve both the patient and doctor. One person who recently underwent a review found that the Social Security administrators had difficulty understanding the disabling conditions related to AIDS, like chronic diarrhea and fatigue. In spite of a doctor's statement of disability and several interviews—including one in his home—he was denied continued disability. After appealing, his disability status was upheld. TIPS: If called to a review, it's very important to work with your provider to ensure that disability requirements are documented clearly in your medical records. Keep copies of the records and keep notes on interviews

with the reviewers. Be sure to meet all deadlines and requests for information. If denied, appeal the decision. Consult an experienced benefits counselor, treatment advocate or case manager for guidance.

PRESCRIPTION DRUGS

One of the biggest problems in Medicare is that it doesn't cover outpatient prescription drugs. Although *Medigap* provides a number of supplemental prescription plans, they're expensive and don't provide enough coverage to be useful for people with HIV. TIPS: In some states, the AIDS Drug Assistance Program (ADAP) is available for people on Medicare.



MEDICARE DOES NOT COVER OUTPATIENT MEDS

There may be other options in particular states through Ryan White CARE programs, state high-risk medical pools or state prescription drug assistance programs. The Medicare web site (www.medicare.org) and help line for Spanish and English speakers (1-800-633-4227) provide contact for and information on programs that may assist with prescription drugs. They also link to state health insurance assistance programs that employ counselors to assist with options and applications for benefits. The one drawback of this resource is that they do not have enough HIV/AIDS specific information.

COST TO THE INDIVIDUAL

Even though Medicare gives good basic coverage, it can be expensive. Individuals are responsible for paying premiums and deductibles, and there's no cap on how much people can spend out of pocket each year. A recent study showed people on Medicare paid 50% more out of pocket in 2001 than in 1998. TIPS: Eligibility for low-income assistance programs should be explored. Again, there may be state or local programs to assist with deductibles and co-payments.

Sources of healthcare coverage for people living with HIV

With almost all the situations listed below, people generally are able to get better care by working closely with “helpers” who know the healthcare systems. These include providers, benefits counselors, treatment advocates, case managers, or other specialists. Contact local AIDS service organizations, healthcare organizations, or other public health services to locate these helpers. Ask questions and don't give up.

Private insurance

Nearly one-third of people with HIV have private insurance, usually through work.

ADVANTAGES

- Private insurance can offer relatively good coverage.
- People usually get better coverage through the *group market*.

DISADVANTAGES

- People being covered through the *individual market* may find it difficult to get coverage they can afford.
- Private insurance can be costly, especially with out-of-pocket expenses.
- People with pre-existing conditions may have difficulty getting coverage.

- As insurance costs rise, fewer employers may offer coverage.
- Some managed care may limit services, like prescriptions or referrals to specialists.

TIPS

- If leaving employment, know the rules of COBRA and federal HIPAA standards.
- Some states have programs that help people afford and maintain insurance.
- Pursue appeals processes in managed care plans for denied care.

Drug company programs

Patient Assistance Programs provide free or very low cost meds to eligible people. Expanded Access and Compassionate Use programs provide certain meds (approved for study in humans but not FDA-approved) to eligible people.

ADVANTAGES

- Sometimes a good short-term solution to getting no or low cost meds or drugs that have not yet been approved.

DISADVANTAGES

- These programs are not good long-term solutions for healthcare.
- Most require frequent re-application.

TIPS

- Discuss these programs with your doctor.

Medicaid

Medicaid is the largest source of federal funding. Serves low income people who fit certain categories. Covers about 55% of adults and 90% of children living with AIDS. Mandatory services include hospital care, doctor visits, lab tests, x-rays, nursing home and home health-care. Optional services include prescriptions, clinics services, case management, and dental services. Most people with HIV qualify through a) disability or b) Temporary Aid for Needy Families.

ADVANTAGES

- Medicaid generally provides good care.
- All states currently provide prescription drug coverage.

DISADVANTAGES

- Finding a doctor who takes Medicaid may be hard.
- Qualifying for Medicaid can be lengthy and complicated.
- Some drugs may need prior approval.
- Some drugs may have a monthly cap.

TIPS

- Keep track of all your paperwork.
- As of March 2002, 34 states provide *medically needy* programs to help some qualify for Medicaid.
- Learn about the scope of your benefits.
- Word of mouth may help locate doctors who take Medicaid.
- Go online at www.aahivm.org or www.hivma.com for information.
- If contacted about choosing a managed care plan, it's important to take action.

Indian Health Service

Provides health services only to members of federally recognized tribes.

ADVANTAGES

- There are a few dedicated Native clinics in the U.S.

DISADVANTAGES

- In 1997, only 20% of Natives reported access through IHS.
- Mostly provides service through reservations, where only 30% of Native Americans live.

TIPS

- Seek people experienced in understanding how to get adequate IHS care.

Veteran's benefits

The Veterans Health Administration acts as both an insurer and a medical provider for veterans. Since 1982, has served over 50,000 people with HIV.

ADVANTAGES

- Eligible vets can usually get a full range of HIV services.

DISADVANTAGES

- Not all vets live near VA clinics.
- Not all veterans clinics are experienced with treating HIV.

TIPS

- Some larger VA clinics offer transportation.
- Visit www.va.gov for information.
- Call toll-free 1-877-222-8387 for more information.

ryan white c.a.r.e. act

The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act, passed by Congress in 1990, provides health and support services for people living with HIV in the U.S. and its territories. The CARE Act was intended to be the program that fills gaps in the healthcare system. It is also meant to be the payor of last resort.

The CARE Act is now the third largest federal source of funding for HIV care. However, it has never gotten enough money to serve all who need it, especially in states with significant gaps in services. The CARE Act is structured to give states and cities control of the funding. Therefore, funding, eligibility and services vary greatly.

ELIGIBILITY

CARE funds services for uninsured or underinsured individuals and families living with HIV/AIDS. States and cities decide eligibility for most services.

BENEFITS

The CARE Act funds mostly medical care that is not provided in hospitals and essential support services and does not pay for hospitalizations and long-term institutional care. Services include outpatient medical and dental care, prescription drugs, case management, home health and hospice care, and others.

The CARE Act is made up of four parts, called titles. **TITLE I** supports the cities and urban areas most heavily impacted by HIV, called EMAs (eligible metropolitan areas). Title I funds are used for a wide range of services, including medical and dental care and support services (case management, food delivery, etc.). Local planning councils decide how the money should be spent. In 2002, 51 EMAs received funding.

TITLE II grants go to states, the District of Columbia, Puerto Rico and other territories. Title II services include home and community based

services, programs that continue healthcare insurance coverage, and AIDS Drug Assistance Program (ADAP). ADAP pays for prescription drugs for people who have limited or no coverage for medications and can't otherwise afford them. The program is managed by states, and most states also contribute to the funding. The benefits and eligibility vary widely. For example, some ADAPs have a list of over 400 available drugs, while others have as few as 20.

TITLE III supports community clinics providing early intervention and ongoing medical and support services to people with HIV. This title focuses on rural and underserved urban areas as well as women, youth and people of color.

TITLE IV provides family-centered and community-based services to children, youth and women living with HIV and their families. These include primary and specialty medical care, support, outreach and prevention.

Part F of the CARE Act provides services in three other areas. *Dental Assistance* helps cover costs for accredited dental schools and post-doctoral dental programs that serve people with HIV at low or no cost. *AIDS Education and Training Centers (AETCs)* provide targeted, multidisciplinary education and training for AIDS healthcare providers. *Special Projects of National Significance (SPNS)* are demonstration projects that study new ways to better serve underserved and vulnerable communities.

concerns for people living with hiv

ADEQUATE SERVICES

The amount of money given to the CARE Act has to be decided each year by the President and Congress. It has never been "fully funded"—given all the money that it could get under law. The bottom line is that there isn't enough money in CARE for all the needed services. One example is ADAP, where states have had to limit eligibility, create waiting lists and limit the number of available drugs. Other CARE services also vary throughout the country. **TIPS:** The most effective way to get more CARE funding is through advocacy. Letting your federal representatives, the President and the administration know about the need for CARE services can make a difference. There are many ways you can participate to increase these funds. For more information, contact Project Inform's Policy Department at 415-558-8669.

VARIABLE SERVICES

Because the CARE Act is intended to help heavily impacted urban areas and states, not all areas receive the same amount of funding or provide the same services. Sometimes even people living very close to one another may not have access to the same services. **TIPS:** Knowing what CARE services are available can be difficult because of the extreme variability. Contacting local ASOs or working with a case manager or benefits counselor will help. This is another important local opportunity for advocacy. Local and/or state planning bodies make funding decisions. Getting involved with those decisions is an important way to make your voice heard.

It is estimated that less than one-third of HIV-positive people who are in care have private insurance. The vast majority gets insurance through their work. However, as the cost of offering insurance continues to rise, fewer employers may participate in plans, pay as much for coverage, and fewer options may be available to employees who do get coverage. We have seen an increase in the number of people who don't have insurance and this could continue to rise.

Most employers offer coverage through the group market—individuals are covered as members of a group. People insured in this way generally get the most comprehensive and least expensive insurance. People who get their insurance through the individual market—particularly if they live with HIV or other chronic condition—may find it very difficult to get enough coverage at rates they can afford. It is important to be aware of the state laws and agencies that protect you.

At the federal level, the Health Insurance Portability and Accountability Act (HIPAA) of 1996 provided some basic standards that all U.S. insurance companies must meet when they cover small groups of 2–50 workers and, in some cases, for individual insurance policies.

HIPPA PROTECTIONS INCLUDE:

NON-DISCRIMINATION: Insurance companies can't use a person's health status to deny insurance to people in a small group coverage plan. This does not apply to individual policies.

PORTABILITY: People can only be excluded from coverage for a maximum of twelve months for a pre-existing condition (a health condition you have before applying for insurance). If a person living with HIV completed the twelve-month period and then changed jobs and insurance plans, he or she cannot be excluded from the new employer's plan. However, this only works if the gap between insurance coverage is less than 62 days. Also, if someone served part of the exclusion period and then changed insurers, they get credit with the new

insurance company for the exclusion time already served. For example, if a person had a twelve-month exclusion period and changed insurers after six months, the new insurance company must take six months off their exclusion period.

GUARANTEED ISSUE: Insurance companies have to offer all of their small-group policies to any small employer who wants to buy insurance for their workers.

GUARANTEED RENEWAL: Insurance companies must allow all policies—group and individual—to be renewed.

The Consolidated Omnibus Budget Reconciliation Act of 1986 (COBRA) allows people who leave group coverage with their employer to continue their insurance for a period of time. Anyone can use COBRA for up to 18 months after leaving employment. Disabled people can extend their coverage up to 29 months to fulfill the full waiting period for Medicare. Employers have to notify employees who are eligible for COBRA. Employees have 60 days to take advantage of COBRA and can lose their rights to it if they don't respond within that time period.

concerns for people living with hiv

COST AND ACCESS

Although private insurance can offer relatively good coverage, it can also be problematic even with HIPPA protections. HIPPA guarantees an offer of insurance for those with previous insurance, but it doesn't address cost. This is especially difficult for people seeking individual insurance that is often unaffordable, especially for people with pre-existing conditions. Also, HIPPA doesn't help people who have never had insurance.

Private insurance can be costly. In some cases, the cost of private insurance has tripled in the last five years. Even if the premium is covered, many people have difficulty meeting the co-payments or deductibles. The costs of insurance policies, co-payments and deductibles have also risen dramatically in many cases over the last few years, and this trend is likely to continue.

There may be caps on the amount of coverage that can be used in a year or over the life of the policy. Once the cap is exceeded, people have to pay full medical expenses out of pocket. Such caps can be as little as \$500,000, but are more often \$1 million.

As people with HIV live longer, more people reach these caps. A single week's hospitalization can easily cost \$100,000 or more. It can also be a long and arduous process to appeal a denial of care in private insurance. TIPS: Knowing the laws that cover your insurance is important. Getting assistance with understanding your rights can be helpful. The state agency that oversees the insurance industry may be very helpful. For example in California, a Department of Managed Care has been established. Among its other duties, it works to ensure that patients know their rights. In terms of cost, some states have programs that can help people living with HIV afford and maintain insurance. Research the options that may help with the cost of healthcare.

MANAGED CARE

In some managed care plans, there may be limits on services, including access to specialists and coverage for prescription drugs. The systems of managed care and insurance coverage can be very difficult to understand, and people can feel confused and helpless. Finally, since most insurance regulation is done at the state level, protections, rules and services available to help the consumers vary greatly from state to state. TIPS: It's important to know your rights under state and federal law and identify people in the insurance plan, government agencies and community-based organizations who can assist if there are problems getting care. Managed care plans have appeals processes for care that is denied. Most states have a state agency that helps with insurance problems. Your state may also have a state advocate to assist consumers with ensuring adequate care. Consult an experienced benefits counselor, treatment advocate or case manager for more assistance.

drug company programs

PATIENT ASSISTANCE PROGRAMS (PAPS)

Drug companies sponsor PAPS that provide free or very low cost medications to eligible people. These programs are set up after the drug has been FDA-approved. It is not known exactly how many people are served through them. Many PAPS will also help applicants find other sources of reimbursement for treatment.

ELIGIBILITY:

The criteria vary and are not usually disclosed by the company. They say this allows them to make application and verification processes less complex. However, it's generally thought that the income criterion tends to range around \$20,000 annually for one person. The entry criteria, however, are generally not rigidly enforced and most companies claim to exercise flexibility in reviewing individual cases. Once a person qualifies for a PAP, they generally are asked to re-qualify every three months. Usually, this only requires signing a statement that the conditions, which led to qualification, have not changed.

Concerns for people living with HIV

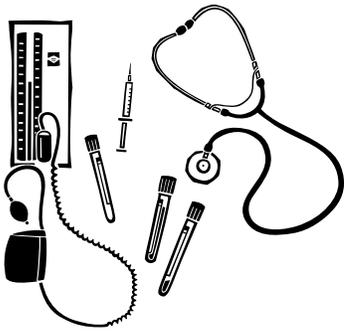
The general concern with these programs is that they're not good long-term solutions for getting treatment. Most companies ask you to re-apply at least every three months. Paperwork has to be completed and signed by a qualified doctor. Some companies have reportedly told individuals that "they had been on the program too long" after more than a year of service. TIPS: Because PAPS are programs run by private companies, the most effective way to ensure better access and availability is through advocacy directly with the companies. A good place to start is ATAC, www.atac-usa.org.

EXPANDED ACCESS AND COMPASSIONATE USE PROGRAMS

These programs are basically the same, but the two terms are used to refer to different stages in the life of such programs. They make drugs that are in the last stages of FDA approval available to people in need of other effective or tolerable treatment options. Typically, the earliest stage of such a program is called *compassionate use* and availability is restricted to people with the most serious medical conditions. Months later, but still prior to full FDA approval, the program is called *expanded access* and is widened to make the drug available to all people for whom treatment is warranted, but who lack a satisfactory choice among existing, approved drugs. The drug company sets the exact eligibility requirements in collaboration with treatment activists and physicians. A doctor must participate in registering individual patients for the program.

Concerns for people living with HIV

Less is known about the drugs offered through expanded access programs because the clinical studies are not completed. However, some people with advanced disease or who have developed resistance or intolerance to the available drugs may have no satisfactory options for treatment. Expanded access and compassionate use programs are offered to them when preliminary studies indicate that the treatment could help. It is important to get as much information as you can about these treatments before making a decision with your doctor. TIPS: Some treatment advocates work with companies and consult on these programs. Many groups that provide treatment newsletters offer information about new drugs prior to their approval by the FDA. Contact with advocates or accessing information about new treatments under study is one way to better understand the drug you're considering. Contact Project Inform at 1-800-822-7422 or www.projectinform.org.



clinical trials

HIV clinical trials are research studies that look at the safety and effectiveness of new anti-HIV drugs and other related therapies for people living with HIV. Pharmaceutical and biotech companies conduct clinical trials. There are also other networks of trials throughout

the U.S. including the AIDS Clinical Trial Group (ACTG) and the Community Programs for Clinical Research Association (CPCRA).

Any new treatment must go through a series of clinical trials before the FDA considers approving it.

Clinical trials are not intended to provide care, but they sometimes provide a high level of monitoring and care associated with the trial. They often monitor viral load and CD4+ cell counts frequently as well as other blood work. However,

people should not expect the medical personnel running these trials to give them the same healthcare expected from their regular doctors.

ELIGIBILITY

Eligibility varies from trial to trial. Generally, there are strict medical criteria. In addition, guidelines must be followed to ensure the safety of the participants. Everyone should get, understand and sign an informed consent document before participating.

concerns for people living with hiv

Very little is known about how a drug works in human beings while it's in early phases of clinical trials. Even in the later phases, there are many unknowns. Drugs generally go through three phases of trials, called Phase 1, 2 and 3. The early Phase 1 trials are least likely to benefit individuals, as the safety, efficacy and dosage of the drug is almost completely unknown at this point. People participate in Phase 1 trials primarily as a form of activism or service to the community, a way of making a personal contribution to our knowledge about a new drug. The trials most likely to benefit individuals are the Phase 3 studies, the last stage of research before FDA approval. At this time, the proper dose of a drug is usually known, as well as the most common side effects. Phase 2 studies bridge the gap between Phase 1 and 3, and

may offer some hope of benefiting volunteers, but with a higher degree of risk than in Phase 3. People should fully understand what they're getting into when volunteering for clinical trials and understand their own motives and hopes. In order to ensure that you understand the risks and the benefits, there should be an *informed consent*, a document that gives you the information you need to understand potential risks and benefits. Unfortunately, it is often long, technical and difficult to understand. TIPS: Carefully discuss with your doctor your interest and reasons for entering the trial. Question anything you don't understand. Consult an experienced benefits counselor, treatment advocate or case manager. Research the available information on the treatment before making final decisions.

safety net providers

People who are uninsured or underinsured often rely on community and migrant health centers, public hospitals, private "free clinics" and individual providers who offer care free of charge. These providers are funded from various sources including federal, state and county monies. Services vary, and many clinics provide quality HIV care. However, there's often not enough money to support all needs. Also, people living with HIV could have a difficult time accessing an HIV-experienced doctor among these "safety net" providers.



veterans benefits

The Veterans Health Administration acts as both an insurer and a medical provider for veterans. It is the nation's largest, single provider of HIV services. In 2001, it provided care to more than 20,000 HIV-positive veterans, and since 1982 has served more than 45,000 people with HIV.

ELIGIBILITY

Eligibility is immediate for most veterans upon discharge, except under dishonorable conditions. Private insurance must pay for care if the veteran has a private plan. Veterans contribute based on a system of ranking (from their service) and means testing (how much income or money they have).

BENEFITS

Eligible veterans can receive a full range of HIV services, including testing, counseling, medical care, prescription drugs, hospital care, nursing homes and extended care programs.

Concerns for people living with HIV

ACCESS

Although the VA provides comprehensive HIV care, not every veteran lives near a VA clinic. TIPS: Some of the larger VA sites offer transportation. The VA's web site, www.va.gov, lists sites and clinics by state and region. They also provide a toll-free help line, 1-877-222-8387. Sometimes when access is a real problem, veterans may be offered a private healthcare option. People facing these concerns should call the site nearest to them and explore their options.

QUALITY CARE

Veterans living with HIV may face the same problem that others face when they live outside urban areas: finding quality care in a site where few HIV-positive people are served. Studies show that people get better HIV care with providers who have more HIV-positive patients. As with any other healthcare system, it can also be hard for people to understand the full scope of their benefits, rights and responsibilities. TIPS: People working with their providers, advocates and the VA system can get excellent HIV care. Consult an experienced benefits counselor, treatment advocate or case manager for more assistance.

indian health service

The U.S. government has a responsibility to provide healthcare to members of federally recognized tribes. The Indian Health Service (IHS) fulfills only a part of this because its services are available mostly through tribal reservations, and most Native Americans—as many as 70%—don't live on reservations. The federal government can also contract with urban Native organizations to provide health services, but the funding has not matched needs. For example, Los Angeles County is the urban area with the largest number of American Indians and Alaska Natives, but it doesn't have a Native health clinic.

In addition, because services are only available to federally recognized tribes, members of tribes recognized only by their home state are not eligible for services. In 1997, only 20% of Native Americans reported using IHS care. Even among those, half also have private or Medicaid coverage.

ELIGIBILITY

Native Americans must be a member of a federally recognized tribe and, often, access services on their home tribal reservation.

BENEFITS

IHS services should be comprehensive health services, similar to Medicaid. However, it may be difficult to find an HIV specialist within the system.

Concerns for people living with HIV

ACCESS

There is a general difficulty in accessing quality HIV care through the IHS. However, there are a few dedicated HIV clinics, such as the HIV Center of Excellence at the Phoenix Indian Medical Center. TIPS: Accessing better care is a complex effort given the basic inadequacies of the system. Advocates have to pay much more attention to the concerns of Native Americans and support the provision of more adequate care. Consult an experienced benefits counselor, treatment advocate or case manager for assistance.

the bottom line on access to therapy

Understanding how to get good HIV care in the U.S. can be complex and difficult. Very few people research insurance or healthcare programs until they're sick or worried about their health status. Dealing with these systems can be overwhelming under those

conditions. Each barrier a person faces, such as speaking a language other than English, having to care for a family or lack of transportation, adds another level of difficulty. Investigating your options early, before you really need them, is very helpful.

It is also good to find an advocate or benefits counselor to assist you through the maze of healthcare programs or with any barriers that you face. With work, advocacy and understanding of benefits, there are solutions to most healthcare access problems.