

**H
I
V**

and
**Public
Benefits**

YOUR LEGAL RIGHTS

UPDATED AUGUST 2006

published by:



**AIDS Legal Council of Chicago
180 North Michigan Avenue, Suite 2110
Chicago, Illinois 60601
(312) 427.8990**

This is one in a series of booklets published by the AIDS LEGAL COUNCIL OF CHICAGO. All are designed to help you understand **YOUR LEGAL RIGHTS** in Illinois. The booklets in this series are:

HIV and Confidentiality

HIV and Discrimination

HIV and Insurance

HIV and Public Benefits

HIV and Undocumented Immigrants

HIV in the Workplace

HIV: Issues for Families with Children

HIV: Issues for Youth and Young Adults

HIV: Returning to Work

HIV: Wills and Powers of Attorney

All of these booklets are free and available at:

AIDS LEGAL COUNCIL OF CHICAGO
180 N. Michigan Ave., Ste. 2110
Chicago, Illinois 60601
(312) 427.8990
www.aidslegal.com

This guide is intended as an overview of HIV-related Illinois and federal law. As with any legal matter, it is always a good idea to consult an attorney concerning the particular circumstances of your case.

HIV AND PUBLIC BENEFITS

	Page
Introduction	4
1. Getting Social Security Benefits	5
2. Getting Health Care Coverage (Medicare and Medicaid)	13
3. Other Help with Health Care Costs	21
4. Illinois Department of Human Services Programs for People with HIV	23
Appendix	
List of Medical Conditions Social Security Considers Disabling	28

INTRODUCTION

Many people who need to apply for public benefits, like Social Security, Food Stamps or a Medicaid card, have no idea where to begin. And once they start the process, they often find it extremely confusing and frustrating. This booklet is designed to make that process easier to understand, and to provide the information you need to get the benefits you are entitled to.

If you have more questions after you're done reading, you can call the AIDS LEGAL COUNCIL OF CHICAGO at **(312) 427.8990**. Someone there will be happy to speak with you.

Chapter One

GETTING SOCIAL SECURITY BENEFITS

1) What do I have to do to get Social Security benefits?

There are two different kinds of Social Security benefits for people disabled by HIV or AIDS. One is called Social Security Disability Insurance Benefits (or SSDI). The other is called Supplemental Security Income benefits (SSI). You can apply for either one at your local Social Security office or by calling Social Security at 1-800-772-1213. If you don't know which program is right for you, Social Security will help you figure it out.

2) What is the difference between SSDI and SSI benefits?

SSDI benefits are for people who have worked a lot and had money taken out of their paychecks for Social Security. If you qualify for SSDI benefits based on your earnings and your disability, then you will get your benefits no matter how much money or how many assets you have.

SSI benefits are for people who haven't worked much and have little money. You can only get SSI benefits if you have less than \$2,000 in assets (things like bank accounts). Some assets don't count toward this \$2,000 limit. For example, Social Security won't count your home if you own it, or your car if you use it to get to the doctor. The asset rules are the same for SSI as they are for Medicaid. For a longer list of assets that do or don't count for SSI and Medicaid look at question 9 in Chapter Two. To qualify for SSI, your income must also be below the SSI limit. The SSI income limit changes every year, and for 2006 it is \$623 per month. If your income is more than \$623 a month, you will not qualify for SSI.

The rules about how disabled you have to be to get benefits are the same for SSI and SSDI.

3) How much will I get?

How big an SSDI check you get depends on how much money you made when you were working. It can be as little as \$150 or as much as \$1,600 each month.

Social Security will give you an estimate of how much your check will be if you are found disabled. Contact your local Social Security office or call 1-800-772-1213. They will mail you the estimate.

If your SSDI check is very small, you may be able to get a partial SSI check too.

SSI pays a fixed amount. Most individuals on SSI in Illinois in 2006 will get \$603. Married couples will get \$904. People living with someone else who is helping them with room and board will get about \$402 each month. All of those amounts increase a little each year.

4) How does Social Security define "disabled?"

For Social Security, being "disabled" basically means being unable to work because of a severe medical condition. You will be considered disabled if you can't do any kind of "substantial" work. Usually, Social Security believes that anyone working and making more than \$860 a month is doing substantial work and is therefore not disabled.

Being HIV positive or having AIDS doesn't automatically qualify you for Social Security benefits. Some people with HIV or AIDS are healthy and able to work. Social Security won't find you disabled unless there is strong medical evidence that you have severe physical or mental health problems which make it impossible for you to work.

5) How does Social Security decide whether I'm disabled?

Social Security has very strict rules about how disabled you have to be to get SSI or SSDI benefits. It's not enough that you have a diagnosis of AIDS or that your doctor says you can't work.

Social Security will evaluate your case following a step-by-step process.

First, Social Security will look to see if you are working when you apply. If you are working and making more than \$860 per month, then Social Security will conclude that you can work, even if you've had to cut your work way back because of your health problems.

Second, Social Security will determine whether you have a severe condition which they consider automatically disabling. Social Security has a long list of HIV-related impairments that meet this standard. Here are some of those conditions:

- ◆ cytomegalovirus disease (CMV)
- ◆ mycobacterium avium complex (MAC)
- ◆ toxoplasmosis of the brain
- ◆ pneumocystis carinii pneumonia (PCP)
- ◆ stage II cervical cancer
- ◆ pulmonary tuberculosis resistant to treatment
- ◆ Hodgkin's disease or lymphoma
- ◆ HIV wasting syndrome

These are just a few examples. The complete list of HIV-related impairments is included in the Appendix of this booklet. The list contains a lot of medical terms which many people find confusing. If you have any questions about the list, you can call the AIDS Legal Council.

It's also important to know that sometimes these conditions have to be at a certain level of severity to be automatically disabling. For example, HIV wasting syndrome is automatically disabling only if you've lost 10% of your body weight and had chronic diarrhea or chronic fevers.

Third, if Social Security doesn't find that any one of your problems is automatically disabling, they will look at all your problems together and how they affect your ability to function. Social Security will look at three things: how well you can carry out your daily activities, how well you get along with others, and how well you can stick to a job and get it done on time. If Social Security determines that your combined problems seriously interfere with your ability to function, you may be found disabled. If not, Social Security will go on to the fourth step.

Fourth, Social Security will evaluate whether your medical conditions prevent you from doing work you have done before. If you can still do any job you've ever had, then you will not be found disabled. But if you can't do any job you've ever had, then Social Security will go on to the fifth step.

Fifth, Social Security will look to see if you can do any other type of work based on your age, education, skills and past work experience. If Social Security believes you can't do any type of work, your claim for benefits will be approved.

It's important to remember that your health problems must be documented. Documentation means medical records, laboratory test results, x-rays, etc. This is why it is very important for you to get regular medical care before you apply for Social Security.

6) How long will it take until I get my benefits?

If you're applying for **SSDI**, it usually takes Social Security about three months to look at all your medical records and decide whether you are disabled. In addition, Social Security has a mandatory "waiting period" for SSDI benefits. That rule says you can't get SSDI benefits *until you've been disabled for five months*. As you can see, it's usually a good idea to apply for SSDI as soon as you quit work because then Social Security can be evaluating your case while you're waiting the five months.

Of course, if Social Security decides you're not disabled, it will take longer to get your benefits. Look at question 8 to see what to do if Social Security finds you not disabled.

If you're applying for **SSI benefits**, you don't have to be disabled for five months before your benefits start. But you still have to wait for Social Security to evaluate your case and decide whether you're disabled. That usually takes about three months, unless you qualify for "presumptive benefits." Presumptive benefits are discussed next.

7) Is there any way to get Social Security benefits quickly?

Social Security has a program that lets some people get **SSI** benefits almost immediately. These are called "**Presumptive Benefits**." To get presumptive benefits you must

- ◆ meet the SSI income and asset rules (described in question 2)
- ◆ submit a Presumptive Eligibility Form signed by your doctor or health care provider that says you have one of the conditions that Social Security says is automatically disabling (these conditions are listed in the Appendix).

You can get the Presumptive Eligibility Form from Social Security when you apply. If you apply by phone ask them to send you the form. You can also get the form from many doctors' offices, case managers' offices, or the AIDS Legal Council.

You may be able to get Presumptive SSI Benefits even if you've worked enough to get SSDI benefits. If you meet the SSI income and asset rules, and your doctor fills out the Presumptive Eligibility Form, you may be able to get SSI while you are waiting the five months for your SSDI to start.

If you apply for Presumptive SSI Benefits, Social Security will still go through the whole process of evaluating your case, but they will give you benefits in the meantime. Presumptive benefits can begin in as little as three to four weeks after Social Security gets the form from your doctor.

8) What if Social Security decides I am not disabled?

If Social Security determines that you are not disabled, they will send you a letter telling you that. You have the right to appeal that decision. Usually, you have to appeal within 65 days of the date on your Social Security denial letter.

The first level of appeal is called **reconsideration**. It usually takes about three months to complete. When you file for reconsideration, Social Security will review your case again. You should submit any new medical records you have.

If you are denied at reconsideration, you can appeal again. This time you are requesting a **hearing** before an Administrative Law Judge. It can take more than a year for your hearing to be scheduled, and after the hearing the judge may take several months to issue a decision.

There are also two levels of appeal above the Administrative Law Judge. You should check with a lawyer or other advocate if your appeal is at that level.

Don't be afraid to appeal if Social Security denies your initial application.

Social Security often makes mistakes in its decisions. Many people with HIV win their Social Security case either at reconsideration or in front of an Administrative Law Judge.

9) When should I get a lawyer or other advocate to help me with my Social Security claim?

It depends. If you have one of the conditions Social Security always thinks is disabling (look in the Appendix) and you have recent medical records to prove it, then you will probably get your benefits without any trouble, and you won't need an attorney or advocate to help you.

You should think about getting help from a lawyer or other advocate if you:

- ◆ think your case is complicated,
- ◆ have already lost once in front of Social Security,
- ◆ are worried that Social Security won't understand why you can't work,
- ◆ don't understand something Social Security said or sent to you.

Groups like the AIDS Legal Council have a lot of experience assisting people with Social Security problems.

10) Are there any things I can do to make it more likely that I'll win my Social Security case?

There are many things you can do to make it more likely that you'll be able to get Social Security benefits:

- ◆ Get regular medical care for your HIV and any other health problems you may have. It is important for Social Security to see that you have an on-going medical condition that requires regular visits to a doctor.
- ◆ Remind your doctor of your on-going problems at every visit, even if they seem like "little" problems or there doesn't seem to be much you can do about them. This includes things like fatigue, diarrhea, night sweats, skin problems, depression, headaches, or any side effects to your medications. You want to make sure all of your medical conditions are fully documented in your medical records.
- ◆ Keep a diary of how your HIV affects you on a day-to-day basis. For example, does HIV make you feel fatigued? What kinds of activities make you feel fatigued? How long do you have to rest when you're feeling fatigued? Do you have diarrhea or nausea after taking your medications? Do you have night sweats? The AIDS Legal Council has a form you can use for this.
- ◆ Think carefully as you fill out Social Security's forms. You need to focus on the kind of physical and mental limitations that prevent you from working. If you tell Social Security that your hobby is riding your bike, for example, be sure to also tell them how your ability to ride your bike has changed since you got sick. If you have any questions about any of the forms, ask a lawyer or other advocate about them.
- ◆ If you need help for a substance abuse problem or a mental health problem, try to get the help you need.

11) I have had problems with drugs or alcohol. Will that make it easier to get Social Security?

No. If you are an active substance user or a heavy drinker, then it may be *harder* for you to get Social Security benefits. There are two reasons for this. First, if you are spending a lot of money on drugs or alcohol, Social Security might decide that whatever you do to get that money is work, and therefore you're not disabled. They might decide you're working even if you get "paid" in drugs, not in cash.

Second, heavy drug or alcohol use makes it harder to get Social Security to figure out if your problems are caused by your HIV or your substance use. **Social Security won't give you benefits if they think by not drinking or using drugs you might be able to work.** For example, if you say you don't sleep well, have bad headaches and fainting spells, and forget things, Social Security might decide those problems would go away if you stopped drinking. Then they won't give you benefits.

If you have a problem with drugs or alcohol, you will have better luck with your Social Security case if you get treatment for your drug or alcohol problem. It will be important for you to be able to prove that you went through treatment.

12) I have other health problems besides my HIV. Will Social Security look at those too?

Yes. Many people with HIV have other conditions which Social Security may find disabling. For example, some people with HIV get Social Security benefits because they have severe depression, or pancreatitis, or another serious medical problem.

Social Security also looks at your combined problems. For example, let's say you have HIV and chronic depression. Maybe neither one is severe enough to qualify you for Social Security benefits. But together, your HIV and your depression might make you disabled by Social Security's definition. **Be sure to tell Social Security about all of your health problems.**

Chapter Two

GETTING HEALTH CARE COVERAGE (MEDICARE AND MEDICAID)

1) If I can't work and don't have insurance, how will I pay for my health care?

There are two major public programs that help people with HIV and other disabilities pay for their health care. They are **Medicare** and **Medicaid**. The two programs are very different. Some people with HIV can get both Medicare and Medicaid.

There are also some programs available for people who can't get either Medicare or Medicaid. They are discussed in Chapter Three.

2) What's the difference between Medicare and Medicaid?

Medicare is part of the Social Security system. If you've been on SSDI (not SSI) for two years, you will be automatically eligible for Medicare (see Chapter One for more information on the difference between SSDI and SSI). There is no cost for Medicare Part A, which pays for your hospital bills. If you want Medicare Part B, which pays for your doctor visits and lab tests, you will have to pay about \$88 per month. If you want Medicare Part D, which helps pay for prescription drugs, you may have to pay an additional premium depending upon which prescription drug plan you choose. These premiums will be deducted from your SSDI check automatically.

Medicaid is run by the Illinois Department of Human Services (IDHS). It is free but often hard to get. IDHS has very strict rules about how poor you have to be to qualify for Medicaid. You have to apply for Medicaid at your local IDHS office. For general information about IDHS, see Chapter Four.

3) What does Medicare cover?

Medicare Part A pays for hospitalization, home health care, nursing home care, and rehabilitation. Part B pays for doctor's visits, most laboratory tests, and medical equipment. Part D pays for prescription drugs, although there are often large costs for people on Part D.

See the chart at question 5 for more information.

4) How do I get Medicare?

You are automatically eligible for Medicare 24 months after the month you became entitled to SSDI benefits. At that time you can decide whether you want just Part A, which is free, or if you want to spend the extra money to also get Part B and Part D.

If you elect only Part A, but then later on change your mind and decide you want Part B or Part D also, you can sign up for Part B and Part D only during certain months of the year. But if you sign up late you will have to wait for your coverage to begin and will have to pay a higher premium.

5) What does Medicaid cover?

Medicaid pays for just about everything, including hospital bills, doctor visits, lab tests, nursing home care, **and** prescription drugs. See the chart on the following page.

	MEDICARE (through Social Security)	MEDICAID (through IDHS)
What is covered?	<p>Part A: hospitals, hospice, home health care</p> <p>Part B: doctors, outpatient services and therapy, lab tests, medical equipment</p> <p>Part D: prescription drugs</p>	Everything that Medicare covers, plus nursing home care
How much does it cost?	<p>Part A: Free</p> <p>Part B: \$88 a month</p> <p>Part D: Varies, depending</p>	Free
What are the financial eligibility requirements?	None	Under \$2000 assets Very low income
Do I have to be disabled to get it?	Yes, unless elderly	Yes, unless elderly or eligible through TANF

6) How do I get Medicaid?

You must apply for Medicaid at the local office of the Illinois Department of Human Services (IDHS).

Generally there are only two ways for adults under 65 to get Medicaid in Illinois. Either you have to be poor and disabled, or in a low-income family with dependent children.

If you are in a low-income family with children, you may be eligible for a program called **Temporary Assistance for Needy Families (TANF)**. Apply for TANF at your local IDHS office. If you are eligible for TANF, you and your children will get a Medicaid card automatically.

If you are not in a low-income family with children, you will have to prove to IDHS that you are poor and disabled before you can get Medicaid.

Note: the Medicaid rules are very complicated and even the workers at the local IDHS offices often get them wrong. The information in this booklet is very general. Call the AIDS Legal Council or another advocacy organization for help with your specific Medicaid questions.

7) How long will it take for my Medicaid application to be processed?

IDHS has 60 days to process most Medicaid applications.

8) How do I prove to IDHS that I'm disabled enough to get Medicaid?

There are several ways that you can show IDHS you are disabled and therefore eligible for Medicaid:

- ◆ If you are already on SSI or SSDI, IDHS will accept that as proof that you are disabled.
- ◆ If you are not already on SSI or SSDI, go apply for benefits at your local Social Security office. Ask Social Security for a receipt proving you've applied. Take that to your local IDHS office when you apply for Medicaid. If you have copies of your medical records, take them too. If your doctor filled out a form so you could get Presumptive SSI Benefits, take a copy of that form to IDHS. (See Chapter One, question 7 for more information on Presumptive SSI Benefits.)
- ◆ If IDHS gives you a form to take to your doctor, be sure your doctor lists all your problems on the form.

If you are denied Medicaid because IDHS says you are not disabled, be sure to contact the AIDS Legal Council or another advocate for assistance.

9) How poor do I have to be to get Medicaid?

Only people who are very poor can qualify for Medicaid. To determine if you are eligible for Medicaid, IDHS looks at two things: your **assets** (the things you own) and your **income**.

Medicaid eligibility is very much like SSI eligibility. Most people who get SSI also qualify for Medicaid.

Here are the rules.

Assets: *You can only get Medicaid if you have \$2000 or less in assets. Assets include:*

- ◆ cash
- ◆ savings and checking accounts
- ◆ stocks, bonds, IRAs
- ◆ retirement plans, pension, or profit-sharing accounts
- ◆ the cash value of any life insurance policies
- ◆ any valuables, like expensive jewelry or art
- ◆ a second home
- ◆ a second car

Let's say the only assets you have are \$200 in your checking account, \$500 in your savings account, and a diamond ring worth \$1,000. The total value of these assets is \$1,700. Since that amount is less than \$2,000, your assets would not stop you from getting Medicaid.

Some things do not count as assets, even if they are worth more than \$2,000. Things that do **not** count as assets include:

- ◆ your home, if you live in it
- ◆ ordinary furniture and clothing
- ◆ a car that you use to get to medical care
- ◆ cemetery plots and burial goods (caskets, vaults, markers)
- ◆ life insurance policies with no cash value

Income: *You must also have a very low income, or a small income and very high medical bills, to be eligible for Medicaid.*

People who only get SSI are poor enough to get Medicaid.

People who get income other than SSI may still be eligible for Medicaid if their income is low enough. You can qualify for Medicaid if your monthly income is below \$816, which is the federal poverty level for 2006.

If your income is more than the Medicaid income limit, then you will only be able to get Medicaid with a "spenddown." A spenddown is the amount of medical bills you have to get each month before you can get a Medicaid card. For example, if you have a \$200 spenddown, then you have to get \$200 in medical bills each month before you can get a Medicaid card. Your Medicaid card will not pay for your first \$200 in medical bills each month.

IDHS uses a formula to calculate the amount of your spenddown. Generally, IDHS will subtract \$816 (or whatever the current federal poverty level is) from your monthly income to get your spenddown amount. Let's say your monthly income is \$916 from SSDI. IDHS will subtract \$816 from your \$916 to give you a monthly spenddown of \$100. ($\$916 - \$816 = \100).

If you have income that is above the federal poverty level (\$816 a month in 2006) your Medicaid application will probably be denied *unless you have recent medical bills that are more than your spenddown amount*. To get a Medicaid card, you will have to prove to IDHS each month that you've already gotten bills for more than your spenddown amount.

Being put on a spenddown can be very confusing. If you have applied for Medicaid and been put on a spenddown, contact the AIDS Legal Council or another legal organization for advice on how to best manage your Medicaid case.

10) I need medical treatment right away. Is there any way I can get an emergency Medicaid card?

Probably not. Unless you are pregnant, IDHS will not give you a medical card until your application has been approved.

But if your doctor will see you without a Medicaid card, then when your card is approved he can bill Medicaid for the care he gave you while IDHS was processing your application.

If you already have been approved for Medicaid, but haven't received a card in the mail, you can get a temporary medical card at your local IDHS office.

11) Can I use Medicaid or Medicare to pay for my old hospital bills?

Generally Medicare or Medicaid will only pay for your hospital bills if you were on Medicare or Medicaid when you went into the hospital.

But there is one time Medicaid will pay for some old hospital bills. When you apply for Medicaid, your application can go back three months before the month you apply. For example, let's say you apply for a Medicaid card in April. You can ask for Medicaid to go back three months earlier, all the way to January. When your application is approved, you could then tell the people who gave you medical care in January to bill Medicaid for your care.

If you are applying for Medicaid and have medical bills from the three months before the month you apply, be sure to ask IDHS to pay those bills.

12) Do I have to be a U.S. Citizen to get Medicare or Medicaid?

If you are a lawful permanent resident of the United States, you can probably get Medicare or Medicaid even if you are not a U.S. citizen. But *you must have been in the U.S. before August 22, 1996 to get Medicaid*. If you came to the U.S. after that date, talk to someone at AIDS Legal Council about your Medicaid eligibility.

If you are undocumented, you can get Medicaid only if you are pregnant or need "emergency" care. Emergency care usually means care in a hospital emergency room.

13) Can I get Medicare or Medicaid if I'm still working?

To get **Medicare**, you have to already be on SSDI, which means you're disabled by Social Security's standards. If you're working, you're probably making more than \$860 a month, and Social Security thinks anyone making more than \$860 a month can't possibly be disabled. So that would disqualify you from SSDI and therefore Medicare.

To get **Medicaid**, you also have to be disabled (unless you are in a family with children).

The only time you can work and still get Medicare or Medicaid is if you've been disabled and are trying to go back to work. For more information about going back to work and Medicaid and Medicare, see our booklet in this series entitled HIV: Returning to Work.

Chapter Three

OTHER HELP WITH HEALTH CARE COSTS

1) I can't qualify for Medicaid or Medicare. How will I get my health care?

Many health care providers get special federal funds from the Ryan White Program to provide health care to people without insurance. The *HIV Services Directory*, published by the Test Positive Aware Network (TPAN), lists the health care providers in the Chicago area who get Ryan White funds to provide services. If you don't have the TPAN directory, you can get a free copy by calling 1-773-404-8726.

Local public health clinics and public hospitals (like Cook County Hospital) will also help you even if you can't pay and don't have insurance.

2) I can't qualify for Medicaid or Medicare. How will I get my medications?

The Illinois Department of Public Health runs a program that pays for many HIV drugs for people who are financially eligible. It is called the **AIDS Drug Assistance Program**. It pays for HIV medications for low-income people who cannot qualify for Medicaid and don't have any other way of paying for their prescriptions. Ask your case manager for an application, or call the Illinois Department of Public Health at 1-800-825-3518, or 1-217-524-5983.

3) I have my own health insurance, but now that I'm not working, I can't afford to keep paying for it. Are there any programs to help me?

There are two programs that may help you pay your health insurance premiums. If you are keeping your health insurance from your last job through COBRA, the

Illinois Department of Public Health has a program to pay the premiums for you. That program is called the **Continuation of Health Insurance Coverage Program**. To get an application for that program, ask your case manager or call the Illinois Department of Public Health at 1-800-825-3518 or 1-217-524-5983.

The Illinois Department of Human Services also pays health insurance premiums for people who are eligible for Medicaid. If you are on Medicaid (even if you are on a spenddown) and have your own health insurance policy, ask IDHS to evaluate you for its **Health Insurance Premium Payment** program.

For more information about health insurance laws, refer to the AIDS Legal Council's booklet, *HIV and Insurance*.

4) I am on Medicare. Can I get any help paying my premiums or my deductibles and co-payments?

If your monthly income is low enough, then the Illinois Department of Human Services will pay your Medicare premium and all your Medicare deductibles and co-payments. This program is called **Qualified Medicare Beneficiary (QMB)**. Apply at your local IDHS office.

Here's how you calculate if you qualify for this program. Take your monthly income amount and subtract \$25. If this number is lower than the federal poverty level (\$816 in 2006), then you qualify. For example, let's say you get \$575 a month SSDI, and \$100 a month from part-time work. Your total monthly income is $\$575 + \$100 = \$675$. If you subtract \$25 from this amount, you get \$650. Since \$650 is less than the federal poverty level of \$816, you qualify for QMB.

If your monthly income is a little bit too much to qualify for QMB, you might still be able to get IDHS to pay for your Medicare Part B premium. This program is called **Specified Low Income Medicare Beneficiary (SLIB)**. To see if you qualify for SLIB, you again subtract \$25 from your monthly income. If that total is less than 135% of the federal poverty level (\$1102 in 2001), then you qualify. Just like the QMB program, you apply for SLIB at your local IDHS office.

Chapter Four

ILLINOIS DEPARTMENT OF HUMAN SERVICES PROGRAMS FOR PEOPLE WITH HIV

1) I hear horror stories about people trying to get Medicaid or food stamps from the Illinois Department of Human Services. Is there anything I can do to make it easier?

The Illinois Department of Human Services is a huge agency. IDHS rules are complicated and change often. Employees often appear overworked and under trained. Almost everyone who deals with IDHS gets frustrated at times. But if you are eligible for programs such as Medicaid or food stamps you have a right to get them. Here are some tips for dealing with IDHS.

- ◆ **Don't be afraid to apply.** Your friends, or even an IDHS caseworker, may tell you you're not eligible for any help from IDHS. They might be wrong. You have a right to apply for benefits and the right to get a written decision on your application.
- ◆ **Keep all the papers you are sent or given.** This will help in case you have to ask someone about them later.
- ◆ **Keep track of who you talk to and what they tell you.** If you talk to someone on the phone, be sure to get their name. *Many people find it helps to use a little notebook to keep track of their dealings with IDHS.*
- ◆ **When you are given a deadline, meet it.** If you can't meet it, call and explain why. If you are told you can have more time, be sure to keep track of who told you that.
- ◆ **If you are asked for something you don't have and can't get, ask the worker to help you get it.** These might be things like bank records from another state, or something that will be very expensive for you to get because you will be charged processing fees.

- ◆ **If you have to send something to the office, keep proof that you sent it.** Either send it by certified mail or send it using a fax machine that will give you proof you faxed it. If you drop something off at the IDHS office, ask for a receipt.
- ◆ **Always keep a copy of any paper or form you give to IDHS.** That way, if IDHS loses your paper or form, you can make another copy for them.
- ◆ **If you need an accommodation for your disability, ask for it.** If you are too sick to come into the local office, the worker should either make a home visit or do the interview over the phone.
- ◆ **When something goes wrong, file an appeal.** If your application is denied, often a worker will tell you that there's nothing you can do, or you have to apply all over again. Sometimes that's true, but often it's not. If you didn't get papers in on time, you may be able to get them in later if you file an appeal. If you are told that your Medicaid or food stamps are being cut off, you may be able to keep them by filing an appeal.
- ◆ **File appeals quickly.** If IDHS sends you a notice saying that your benefits will end on a certain date, you can keep your benefits *if you file an appeal within 10 days of the date on the notice or before the date the notice says the benefits will end.*
- ◆ **Get help with your IDHS problems and appeals.** Staff at the AIDS Legal Council and at most other legal service programs in Illinois have detailed information about IDHS rules and programs and can help you with an appeal.

2) Can I get financial help from the Illinois Department of Human Services?

Most people with HIV or AIDS who cannot work get their main financial help from Social Security. But there are some financial aid programs from IDHS that people with HIV may qualify for.

- ♦ **TANF** stands for Temporary Assistance for Needy Families. If you are living in a poor family with children who are related to you, you may be eligible for a cash grant through the TANF program to help you and your children.

If you get TANF, you will also get a Medicaid card.

- ♦ **P-3**, also called Interim Assistance or P-3 Transitional Assistance, pays \$100 a month to people who have no other income and are waiting for their SSI or SSDI application to be approved. To get P-3, you must convince IDHS that your Social Security application will probably be approved. To apply for P-3, you first need to apply for Social Security. After you've applied, ask Social Security for proof that you've applied, and bring that proof to your local IDHS office along with any medical records you have. IDHS will probably give you some more medical forms to take to your doctor.

If you get P-3, you will also get a Medicaid card.

- ♦ **AABD** (Aid to the Aged, Blind and Disabled) provides a small cash grant to disabled people with very low incomes. The AABD grant is in addition to an SSI or SSDI check, and is sometimes called SSP, for "State Supplemental Payment." Most people on AABD receive checks of less than \$40 per month.

You should apply for AABD cash if **both** of the following things are true:

- ♦ Your income is less than \$600 per month;
- ♦ You live alone and pay more than \$100 per month rent.

In addition, tell your worker if any of the following things are true:

- ♦ You need a telephone because of your disability;
- ♦ Your doctor has prescribed a special diet, such as a high calorie diabetic diet;
- ♦ You need to eat meals out because you can't cook;
- ♦ You need help with your laundry or shopping and there is no one who will do it for free.

Apply for AABD at your local IDHS office. Tell your worker you want to apply for AABD cash.

If you get AABD cash, you will also get a Medicaid card.

- ♦ **TA (Transitional Assistance)** pays \$100 a month to some people who don't qualify for any other programs. Even if you are not disabled enough to get SSI, SSDI or P-3, you can still get TA if you regularly take medications to control seizures, high blood pressure, or diabetes. You can also get TA if you live with someone who needs your full-time care.

People on TA do not get Medicaid. They get what's called a "General Assistance Medical Card." That medical card pays for doctors and most prescriptions, but not for hospitalizations.

3) How long will it take IDHS to process my application for cash assistance?

IDHS must process applications for cash grants within 45 days. Eligibility for cash begins 30 days after the date of application. Food Stamps applications must be processed within 30 days and paid from the date of application. If you have waited longer than the allowed time for IDHS to process your application, file an appeal.

4) Do I have to be a citizen to get a cash grant from IDHS?

Most non-citizens who are in the U.S. legally are able to qualify for TANF, TA, or AABD. The main exception is lawful permanent residents who arrived after August 22, 1996. They will not be allowed to receive cash benefits until they have been in the United States at least five years. People who are undocumented cannot receive any cash assistance programs except TANF for pregnant women.

Some non-citizens are worried that if they apply for help from IDHS they may not be able to become citizens or may be deported. That is not likely to happen.

But if you are worried about how public benefits may affect your immigration status, you should talk with an immigration attorney.

5) How do I get Food Stamps?

Apply for Food Stamps at your local IDHS office. If you need help right away, ask for Expedited Food Stamps. If you qualify, you must be given food stamps no later than five days after you apply. Your full application must be processed within 30 days.

6) Will I have to go into some sort of work program if I get help from IDHS?

There are no work requirements for people getting Medicaid, AABD, P-3, or TA. There are work requirements for most people getting TANF or Food Stamps. If you are unable to participate in a work program, be sure to explain the reasons to your caseworker. If you are told to go to a meeting about the work programs, go to the meeting and tell the people there why you can't work. Call the AIDS Legal Council or another legal advocate if you are having problems with IDHS work requirements.

Appendix

LIST OF MEDICAL CONDITIONS SOCIAL SECURITY CONSIDERS DISABLING

Bacterial Infections

Mycobacterial infection (for example, *M. avium-intracellulare*, *M. kansasii*, or *M. tuberculosis*) other than in the lungs, skin, cervical or hilar lymph nodes

Pulmonary tuberculosis resistant to treatment

Nocardiosis

Salmonella bacteremia recurrent non-typhoid

Syphilis or neurosyphilis, (for example, meningovascular syphilis) resulting in neurologic or other sequelae

Multiple or recurrent bacterial infections, including pelvic inflammatory disease, requiring hospitalization or IV antibiotic treatment three or more times in one year

Fungal Infections

Aspergillosis

Candidiasis (thrush) other than in the skin, urinary tract, intestinal tract, oral or vulvovaginal mucous membranes

Candidiasis involving the esophagus, trachea, bronchi, or lungs

Coccidioidomycosis other than in the lungs or lymph nodes

Cryptococcosis other than in the lungs

Histoplasmosis other than in the lungs or lymph nodes

Mucormycosis

Diarrhea

Lasting at least one month, which is resistant to treatment, and requires IV hydration, IV feeding or tube feeding

Viral Infections

Cytomegalovirus (CMV) other than in the liver, spleen or lymph nodes

Herpes Simplex Virus causing:

- mucocutaneous infection (such as in the mouth, genitals or anus) lasting at least a month, or;
- infection at a site other than the skin or mucous membranes, or;
- disseminated infection

Herpes Zoster (Shingles) either disseminated or with multiple skin eruptions that are resistant to treatment

Progressive Multifocal Leukoencephalopathy (PML)

Hepatitis, if it is severe enough

Neurological Abnormalities (Nerve Problems)

HIV encephalopathy with cognitive or motor dysfunction that limits function or progress

Other neurological manifestations of HIV infection, like peripheral neuropathy, if they are severe enough

Protozoan or Helminthic Infections

Cryptosporidiosis, Isosporiasis or Microsporidiosis with diarrhea lasting at least one month

Pneumocystis Carinii Pneumonia (PCP)

Extrapulmonary Pneumocystis Carinii Infection

Strongyloidiasis not in the intestinal tract

Toxoplasmosis in an organ other than the liver, spleen or lymph nodes

Nephropathy (Kidney Disease)

If it is severe enough

Hematologic Abnormalities (Blood Problems)

Anemia requiring one or more blood transfusions at least once every two months

Granulocytopenia with neutrophil counts repeatedly below 1000 cells per cubic millimeter, and at least three recurrent systemic bacterial infections in the previous five months.

Thrombocytopenia with platelet counts repeatedly below 40,000 per cubic millimeter, and:

- at least one spontaneous hemorrhage requiring transfusion in the past five months, or
- bleeding within the skull in the past twelve months.

Malignant Neoplasms (Cancers)

Cervical Cancer if it is invasive and at least at stage II

Kaposi's Sarcoma (KS) with:

- extensive oral lesions, or;
- involvement of the GI tract, lungs or other visceral organs, or;
- involvement of the skin or mucous membranes

Squamous Cell Carcinoma of the Anus

Lymphoma including lymphoma of the brain, Burkitt's lymphoma, immunoblastic sarcoma, other non-Hodgkin's lymphoma or Hodgkin's disease

Skin or Mucous Membrane Conditions

Extensive fungating or ulcerating lesions not responding to treatment, such as eczema, psoriasis, vulvovaginal or other mucosal candida, condyloma caused by human papillomavirus, or genital ulcerative disease.

Cardiomyopathy (Heart Disease)

If it is severe enough

HIV Wasting Syndrome**Loss of 10% of baseline weight and:**

- chronic diarrhea with two or more daily episodes lasting one month or longer, or
- chronic weakness and fever greater than 100.4 degrees for one month or longer

Repeated Signs and Symptoms of HIV Disease

Infections resistant to treatment or requiring hospitalization or IV treatment three or more times in one year:

- Sepsis
- Meningitis
- Pneumonia
- Septic Arthritis
- Endocarditis

General HIV symptoms (like fatigue, diarrhea, night sweats, thrush, etc.) which cause at least one of the following:

- marked restrictions in activities of daily living
- marked difficulties in maintaining social functioning
- marked difficulties in completing tasks in a timely manner due to an inability to concentrate or work at an adequate pace

