



# A Guide to Social Security and SSI Disability Benefits

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The first section provides some brief background information about HIV infection and Social Security.

## BACKGROUND INFORMATION

Acquired immunodeficiency syndrome (AIDS) is characterized by the inability of the body's natural immunity to fight infection. It is caused by a retrovirus known as human immunodeficiency virus, or HIV. Generally speaking, people with HIV infection fall into two broad categories:

1. those with symptomatic HIV infection, including AIDS; and
2. those with HIV infection but no symptoms.

Although thousands of people with HIV infection are receiving Social Security or Supplemental Security Income disability benefits, we believe there may be others who might be eligible for these benefits. And some may be eligible even if their condition improves or stabilizes enough for them to return to work. Social Security is committed to helping all men, women, and children with HIV infection learn more about the disability programs we administer. And if you qualify for benefits, we are just as committed to ensuring that you receive them as soon as possible.

## WHAT BENEFITS ARE YOU ELIGIBLE FOR?

This section explains the nonmedical rules and eligibility factors for Social Security Disability Insurance benefits and Supplemental Security Income Disability payments.

We pay disability benefits under two programs: Social Security Disability Insurance, sometimes referred to as SSDI, and Supplementary Security Income, often called SSI. The medical requirements are the same for both programs, and your disability is determined by the same process. However, there are major differences in the nonmedical factors, which are explained in the next two sections.

### Social Security Disability Insurance Benefits: The Nonmedical Rules of Eligibility

Here are some examples of how people qualify for SSDI:

- Most people qualify for SSDI by working, paying Social Security taxes, and, in turn, earning "credits" toward eventual benefits. The maximum number of credits you can earn each year is 4. The number of credits you need to qualify for SSDI depends on your age when you become disabled. Nobody needs more than 40 credits, and younger people can qualify with as few as 6 credits.
- Disabled widows and widowers age 50 or older could be eligible for a disability benefit on the Social Security record of a deceased spouse.
- Disabled children age 18 or older could be eligible for dependents' benefits on the Social Security record of a parent who is getting retirement or disability benefits, or on the record of a parent who has died. (The disability must have started before age 22.)
- Children under the age of 18 qualify for dependents' benefits on the record of a parent who is getting retirement or disability benefits, or on the record of a parent who has died, merely because they are under age 18.

For more information about Social Security disability benefits in general, ask Social Security for a copy of the booklet *Disability* (Publication No. 05-10029).

### **How Much Will Your Benefits Be?**

How much your Social Security benefit will be depends on your earnings history. Generally, higher earnings translate into higher Social Security benefits. You can find out how much you will get by contacting Social Security and asking for an estimate of your benefits. We'll give you a form you can use to send for a free statement that contains a record of your earnings and an estimate of your benefits.

In addition to checking your benefits, we encourage you to use this statement to verify that your earnings have been properly recorded in our files. It's important that you do this because any missing or unreported wages could lower your Social Security benefit or even prevent you from qualifying for disability benefits. If you find a problem, contact your local Social Security office right away, show them proof of your actual wages, and the record will be corrected. **This can be particularly important for people who have tested positive for HIV but have not developed symptoms, so that any potential benefits will not be delayed by wage correction efforts.**

Disabled widows, widowers, and children eligible for benefits as dependents on a spouse's or parent's Social Security record receive an amount that is a percentage of the worker's Social Security benefit.

### **Supplemental Security Income: The Nonmedical Rules of Eligibility**

SSI is a program that pays monthly benefits to people with low incomes and limited assets who are 65 or older, blind, or disabled.

As its name implies, **Supplemental** Security income **supplements** a person's income up to a certain level. The level varies from one State to another and can go up every year based on cost-of-living adjustments, so check with your local Social Security office to find out more about SSI benefit levels in your state.

We don't count all the income you have when we figure out if you qualify for SSI. And if you work, there are special rules we use for counting your wages. Again, check with Social Security to find out if you can get SSI.

In addition to the rules about income, people on SSI must have limited assets. Generally, individuals with assets under \$2,000, or couples with assets under \$3,000, can qualify for SSI. However, when we figure your assets, we don't count such items as your home, your car (unless it's expensive), and most of your personal belongings.

Your Social Security office can tell you more about the income and asset limits. For general information, ask for a copy of the booklet *SSI* (Publication No. 05-11000).

This section explains Social Security's definition of disability and how it relates to claimants with HIV infection.

## **HOW DOES SOCIAL SECURITY DEFINE DISABILITY?**

In this section, we'll explain the criteria you must meet in order to be considered "disabled." First, we'll explain in general terms how Social Security defines and determines disability. Then we'll discuss how it applies to people with HIV infection.

### **The General Definition of Disability**

Disability under Social Security is based on your inability to work because of a medical condition. You will be considered disabled if you are unable to do any kind of "substantial" work for which you are suited. (Usually, monthly earnings of \$500 or more are considered substantial.) Your inability to work must be expected to last at least a year. Or the condition that keeps you from working must be so severe that you are not expected to live.

For children, we decide how the condition affects their ability to function—to do the things and behave in the ways that other children of the same age normally would.

### **How This Definition of Disability Applies to People With HIV Infection**

A person with symptomatic HIV infection is often severely limited in his or her ability to work. In other words, if the evidence shows that you have symptomatic HIV infection that severely limits your ability to work, and if you meet the other eligibility factors, the chances are very good that you will be able to receive Social Security or SSI benefits.

On the other hand, some people with HIV infection may be less impaired and able to work, so they may not be eligible for disability.

## **HOW DOES SOCIAL SECURITY EVALUATE YOUR DISABILITY?**

This section explains how Social Security evaluates disability claims involving HIV diseases in general. And it includes up-to-date information about the way we process claims, especially those involving women and children with HIV infection.

Social Security works with an agency in each state, usually called a Disability Determination Service (DDS), to evaluate disability claims. At the DDS, a disability evaluation specialist and a doctor follow a step-by-step process that applies to all disability claims, thus ensuring a consistent national approach to evaluating disability.

First, the DDS specialists decide whether your impairment is "severe." This simply means the evidence must show that your disability interferes with your ability to work.

The next step in the process is deciding whether the disability is included in a list of impairments. This list describes, for each of the major body systems, impairments that are considered severe enough to prevent an adult from doing any substantial work, or in the case of children under the age of 18, impairments that are severe enough to prevent a child from functioning in a manner similar to that of other children of the same age.

Because HIV research is a dynamic process and medical knowledge concerning the disease and its symptoms is constantly growing, Social Security continually updates its evaluation criteria for HIV infection. Recently, for example, we issued special guidelines on the immune system, including criteria for evaluating the claims of women and children with HIV infection.

If you have symptoms of HIV infection that are not specifically included in (or are not equal in severity to those included in) our current guidelines, then DDS disability specialists will evaluate all available medical evidence to determine your ability to work. They will be looking for documentation of signs, symptoms, and laboratory findings that can result from HIV infection. They will also look for evidence of restrictions in daily activities caused by HIV infection. The signs, symptoms, and laboratory findings include:

### *Signs*

- Evidence of opportunistic infections
- Malignancies specifically associated with HIV infection (e.g., certain lymphomas)
- Recurrent bacterial infections
- Documented weight loss
- Documented fevers
- Lymphadenopathy
- Candida infection
- Hairy leukoplakia
- Abnormal skin conditions
- Mental changes
- Central or peripheral neurologic deficit
- Gynecologic conditions

### *Symptoms*

- Low energy, easy fatigability, generalized weakness
- Fevers/night sweats
- Weight loss
- Dyspnea on exertion
- Persistent cough
- Depression/anxiety
- Forgetfulness, loss of concentration, slowness of thought
- Other symptoms such as headache, anorexia, nausea, or vomiting (Possible drug side effects are considered as many individuals are taking antiviral agents, immune modulators, or other medications that have serious side effects.)

### *Laboratory Findings*

- Positive HIV antibody test (including confirmatory test)
- Depressed helper T-cell count (CD4)
- Leukopenia, lymphopenia, anemia, thrombocytopenia
- Other indicators of immune status such as elevated beta-2-microglobulins or detectable p24 antigen
- Inverted helper/suppressor ratio
- X-ray or imaging changes
- Microbiology or pathology reports

If a disability decision cannot be made on medical factors alone, the DDS specialists evaluate a variety of physical and/or mental limitations you may have that prevent you from working. These include:

- Your ability (or inability) to perform physical tasks such as walking, standing, lifting, carrying, pushing, pulling, reaching, and handling objects; or
- Your ability (or inability) to perform mental tasks such as understanding, carrying out, and remembering instructions; responding appropriately to supervision and co-workers; and dealing with work pressures.

### **Evaluation of HIV Infection in Women**

Statistics show that there is an increasing percentage of women with HIV diseases. Social Security's new guidelines for the immune system recognize that HIV infection can show up differently in women than in men. In addition to following the criteria outlined in the previous section, DDS disability evaluators consider gynecologic problems when assessing the degree to which the disease affects a woman's ability to function. Examples of gynecologic problems evaluators consider include:

- **Vulvovaginal Candidiasis (yeast infection)** Although this condition usually heals quickly with appropriate treatment, in women with weak immune systems the disorder may become chronic and poorly responsive to therapy.
- **Genital Herpes** Although the lesions usually occur in limited areas (such as the cervix), as HIV infection progresses, the herpes may involve more widespread anatomical areas and be resistant to typical therapy.
- **Pelvic Inflammatory Disease** A woman's pelvic structures may be infected by a sexually transmitted disease such as gonorrhea. The infection may spread more rapidly if an intrauterine device (IUD) is used. In some women, particularly those infected with HIV, there may be resistance to therapy and recurrent episodes of inflammation and pain.
- **Cervical Cancer** This disorder may take a more aggressive course in women with HIV infection.

### **Evaluation of HIV Infection in Children**

Another recent development in Social Security's efforts to improve the way we evaluate disability claims involving HIV is the addition of special childhood disability guidelines for HIV infection. These guidelines recognize the fact that younger children with HIV infection can differ from adults, or even older children (age 13 or older), in the method of infection and in the course of the disease.

As with adults, some children may not appear to have the conditions specified in the guidelines, but they may have other signs and symptoms indicative of HIV infection that affect their ability to grow, develop, or engage in activities similar to those of children of the same age.

For more information about disability benefits for children, ask Social Security for a copy of the booklet *Social Security and SSI Benefits for Children with Disabilities* (Publication No. 05-10026).

## HOW DO YOU FILE FOR DISABILITY BENEFITS?

You apply for Social Security and SSI disability benefits by calling or visiting any Social Security office. (For your information: All Social Security files are kept strictly confidential.) It will help if you have certain documents with you when you apply. But don't delay filing because you don't have all the information you need. We'll help you get the rest of it after you sign up. The information you'll need may include:

- your Social Security number and birth certificate;
- the Social Security numbers and birth certificates for family members signing up on your record; and
- a copy of your most recent W-2 form (or your tax return if you're self-employed).

If you're signing up for SSI, you will need to provide records that show that your income and assets are below the SSI limits. This might include such things as bank statements, rent receipts, car registration, etc.

You'll also need to give us information about how your condition affects your daily activities, the names and addresses of your doctors and clinics where you've received treatment, and a summary of the kind of work you've done in the last 15 years.

If you have medical evidence such as reports of blood tests, laboratory work, or a physical, it would be helpful if you brought them with you. Beginning on this page, we give you some guidelines for providing us with medical and vocational information that will help speed up your claim. But first, we want you to know what Social Security does to make the process work as smoothly as possible.

### What Steps Has Social Security Taken to Ensure Prompt Processing and Payment of Disability Benefits?

This section includes information about when and how to apply for disability, what steps we take to ensure that your claim is processed quickly and accurately, and, most important, what things you can do to help the process along. Also included is information about situations when we can presume a person is disabled and make immediate payments.

All HIV infection claims are given prompt attention and priority handling. For many people applying for SSI with a medical diagnosis of symptomatic HIV infection, the law allows us to presume they are disabled. This permits us to pay up to six months of benefits pending a final decision on the claim. You will qualify for this immediate payment if:

- a licensed physician confirms that the HIV infection is severe enough to meet the Social Security Administration's criteria;
- you meet the other SSI nonmedical eligibility requirements; and
- you are not doing "substantial" work.

If you have symptomatic HIV infection and our field office cannot provide immediate payment, a disability evaluation specialist at the DDS may still make a "presumptive" disability decision at any point in the process where the evidence suggests a high likelihood that your claim will be approved. (If we later decide that you are not disabled, you will not have to pay back the money you received.)

Special arrangements have been made with a number of AIDS service organizations, advocacy groups, and medical facilities to help us get the evidence we need to streamline the claims process. And many DDSs have medical/professional relations officers who work directly with these organizations to facilitate this process.

### **What You Can Do to Expedite the Processing of Your Claim**

You can play an active and important role in ensuring that your claim is processed accurately and quickly. The best advice we can give you is to keep thorough records that document the symptoms of your illness and how it affects your daily activities, and then to provide all of this information to Social Security when you file your claim. Here are some guidelines you can follow:

- Document the symptoms of your illness early and often. Use a calendar to jot down brief notes about how you feel each day. Record any of your usual activities you could not do on any given day. Be specific. And don't forget to include any psychological or mental problems.
- Help your doctor help you. Not all doctors may be aware of all the kinds of information we need to document your disability. Ask your doctor or other health care professional to track the course of your symptoms in detail over time and to keep a thorough record of any evidence of fatigue, depression, forgetfulness, dizziness, or other hard-to-document symptoms.
- Keep records of how your illness affected you on the job. If you were working but lost your job because of your illness, make notes that describe what it is about your condition that forced you to stop working.
- Give us copies of all these records when you file. In addition to these records, be sure to list the names, addresses, and phone numbers of all the doctors, clinics, and hospitals you have been to since your illness began. Include your patient or treatment identification number if you know it. Also include the names, addresses, and phone numbers of any other people who have information about your illness.

This section provides an overview of special rules designed to help you return to work.

## **HELPING YOU RETURN TO WORK**

If you return to work, Social Security has a number of special rules, called “work incentives,” that provide cash benefits and continued Medicare or Medicaid coverage while you work. They are particularly important to people with HIV disease who, because of the recurrent nature of HIV-related illnesses, may be able to return to work following periods of disability.

The rules are different for Social Security and SSI beneficiaries. For people getting Social Security disability benefits, they include a nine-month “trial work period” during which earnings, no matter how much, will not affect benefit payments; and a three-year guarantee that, if benefits have stopped because a person remains employed after the trial work period, a Social Security check will be paid for any month’s earnings below the “substantial” level (generally \$500). In addition, Medicare coverage extends through the three-year time frame after the trial work period, even if your earnings are substantial.

SSI work incentives include continuation of Medicaid coverage even if earnings are too high for SSI payments to be made, help with setting up a “plan to achieve self-support” (PASS), and special consideration for pay received in a sheltered workshop so that SSI benefits may continue even though the earnings might normally prevent payment.

These and other work incentives are explained in detail in the publication *Working While Disabled. . .How Social Security Can Help* (Publication No. 05-10095). For a free copy, just call or visit your nearest Social Security office.

## WHAT YOU NEED TO KNOW ABOUT MEDICAID AND MEDICARE

This section includes a brief overview of the kinds of benefits available from the Medicaid and Medicare programs.

Medicaid and Medicare are our country's two major government-run health insurance programs. Generally, people on SSI and other people with low incomes qualify for Medicaid, while Medicare coverage is earned by working in jobs covered by Social Security, for a railroad, or for the Federal Government.

### Medicaid Coverage

In most States, Social Security decides whether you are eligible for Medicaid coverage. (Check with your local Social Security or Medicaid office to verify the requirements in your State.)

State Medicaid programs are required to cover certain services, including inpatient and outpatient hospital care and physician services. States have the option to include other services, such as intermediate care, hospice care, private duty nursing, and prescribed drugs.

For more information about Medicaid, contact your local Medicaid agency.

### Medicare Coverage

If you get Social Security disability, you will qualify for Medicare coverage 24 months after the month you became entitled to those benefits. Medicare helps pay for:

- inpatient and outpatient hospital care;
- doctor's services;
- diagnostic tests;
- skilled nursing care;
- home health visits;
- hospice care; and
- other medical services.

For more information about Medicare, call or visit your local Social Security office to ask for the booklet *Medicare* (Publication No. 05-10043).

These materials were developed in partnership with the Social Security Administration.

The information in this publication is solely for general information and for educational purposes and is not intended to be legal advice. Businesses and individuals should consult an attorney for specific legal advice.