



DECEMBER 2021

How to Access and Maintain Social Security Benefits



About Global Genes®

Global Genes is a 501(c)(3) non-profit organization dedicated to eliminating the burdens and challenges of rare diseases for patients and families globally. In pursuit of our mission we connect, empower, and inspire the rare disease community to stand up, stand out, and become more effective on their own behalf—helping to spur innovation, meet essential needs, build capacity and knowledge, and drive progress within and across rare diseases. We serve the more than 400 million people around the globe and nearly 1 in 10 Americans affected by rare diseases. If you or someone you love has a rare disease or are searching for a diagnosis, contact Global Genes at 949-248-RARE or visit our resource hub at www.globalgenes.org.

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Acknowledgments

Lauren Alford

Senior Marketing Communications
Director
[*Global Genes*](#)

Nikki Berry

Senior Brand Manager
[*Global Genes*](#)

Alex Cameron

Digital Marketing Manager
[*Global Genes*](#)

Hira Chowdhary, MPH, MS

Senior Program Manager,
Engagement Programs
[*Global Genes*](#)

Marie Daghlia

Copy Editor
[*Global Genes*](#)

Craig Martin

Chief Executive Officer
[*Global Genes*](#)

Pam Rattananont, MPH

Vice President, Development and
Marketing
[*Global Genes*](#)

Christian Rubio

Vice President, Strategic
Advancement
[*Global Genes*](#)

Contributors

Amy Corbin

Indiana ABLE Authority
in.gov/tos/able

Mindy Cameron

Patient Advocacy Consultant,
AdvocacyWorks

Cory Lewis

Sickle Cell Patient Ambassador,
Founder, RedMoon Project, Inc.
redmoonpro.org

N. Leah Fink

Attorney, Social Security Disability
and SSI
nleahfink.com

Sage Graves

Senior Associate Attorney at
Hickman Menashe
hickmanmenashe.com

Amy Aikins

Director, Government and
Social Programs, Little Hercules
Foundation
littleherculesfoundation.org

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Introduction

What Is Social Security?

Social Security is a federal program that provides retirement benefits and Medicare health insurance to senior citizens. However, Social Security is not just for elderly Americans. **Social Security Disability Insurance (SSDI)** provides a monthly benefit to adults with a disability that prevents them from working. Some children also receive SSDI. Social Security retirement benefits can be made available to spouses or children of people who paid Social Security taxes but who have died. Some working-age adults who have been disabled are eligible for Medicare.

The goal of this toolkit is to provide information and resources to help you prepare for receiving Social Security benefits, including retirement, disability, and Medicare. It is intended to help older Americans as well as those who have significant disabilities to learn about the federal benefits.

This toolkit focuses on the following topics:

1. Social Security requirements and application
2. Supplemental income for low-income seniors and people with disabilities
3. SSDI rules, review, and appeals
4. Medicare plans and assistance plans
5. Planning for retirement
6. Special money management resources for people with disabilities

Social Security Overview

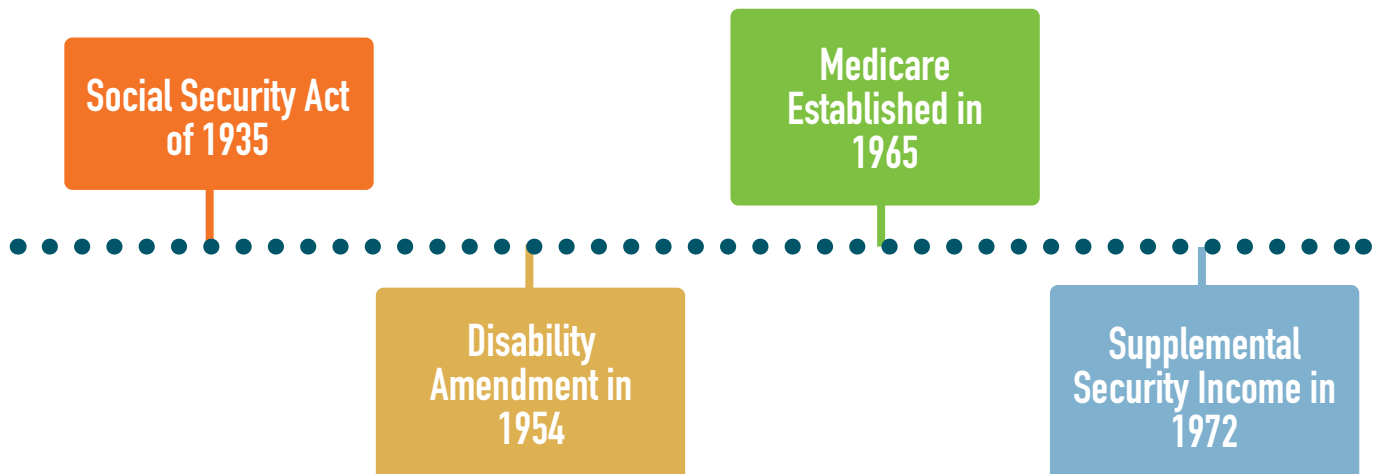
The Social Security Act of 1935 created Social Security, which provides retirement benefits to senior citizens. Over time, other benefits have been added, including disability payments, basic health insurance for older Americans (Medicare), and supplemental income for low-income retired people or working-age adults who have a disability.¹

For any of these benefits, you need a social security number (SSN). Most people get their SSN when they are infants, as paperwork often is filled out at the time of birth. SSNs are used when parents fill out annual income tax forms and list their children as dependents. An

SSN is needed to apply for a job, open a bank account, and complete a credit application, among others. Your SSN is your unique identifier for payroll, credit, taxes, and federal benefits.

Because your SSN is your unique identifier, keep your Social Security card in a safe place. Your Social Security card can be replaced 3 times each year and up to 10 times during your lifetime, not including new cards for changes to your (legal) name. To get a new Social Security card, you will be asked to provide proof of citizenship or immigration status, identity, and age.² You can request a [replacement card](#) online.

Figure 1. Timeline for Introduction of Social Security Benefits



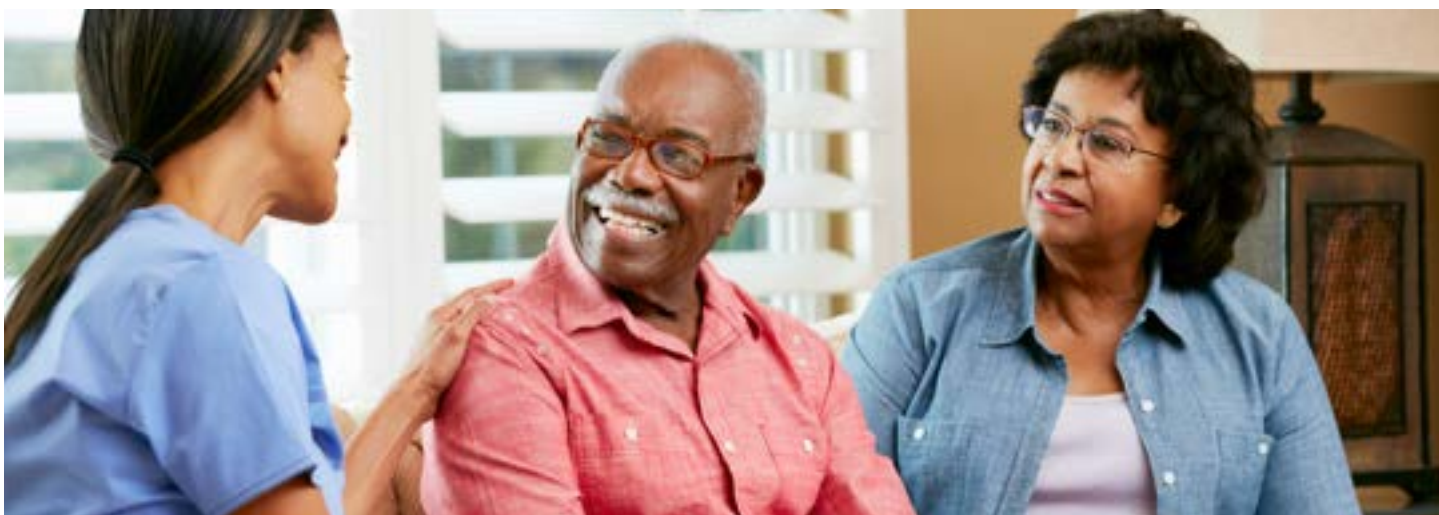
Social Security Retirement Benefits

Social Security retirement benefits, disability, and Medicare are funded through taxes taken from employee paychecks. If you work for a company, your employer pays half of your Social Security taxes. People who are self-employed pay the full Social Security tax through self-employment taxes. About 85 percent of Social Security taxes collected in 2021 go directly to retirees, and 15 percent is used for disability benefits.² **Supplemental Security Income**, which is available to some low-income retirees and people with disabilities, is funded by the federal income taxes paid by people and corporations.

Social security retirement and disability benefits as well as Supplemental Security Income are administered by the *Social Security Administration (SSA)*. Medicare is managed by the *Centers for Medicare and Medicaid Services (CMS)*.

Social Security Retirement Benefits

Most employees pay Social Security taxes, which are used to fund retirement benefits for older Americans. The Social Security benefit is about 40 percent, on average, of someone's pre-retirement earnings.³ Many people have other sources of money (savings, investments, etc.) to augment their Social Security benefit during retirement.



Who Is Eligible?

Any adult worker who is at least 62 years old and has collected 40 credits of work can begin to collect Social Security retirement benefits. Social Security assigns one credit for each \$1,470 in earnings. A person can be awarded a maximum of four credits each year. To qualify for Social Security retirement benefits, most people need 40 credits, or 10 years' worth of work to be eligible. Your spouse and children under the age of 16 years may also be entitled to receive a monthly benefit that can be up to half of your retirement benefit. The total amount paid to a family is capped at 150 to 180 percent of your retirement benefit.²

In addition to adult workers, Social Security retirement benefits are available to:²

- The surviving spouse of a worker who has died and who had met Social Security work requirements
- The divorced spouse of a worker who has died and who had met Social Security work requirements
- Children of a worker who has died and who had met Social Security work requirements

Surviving spouses. If you are widow or widower, you may be able to receive Social Security benefits earned by your deceased spouse. Typically, widows or widowers receive 75 to 100 percent of the deceased spouse's Social Security benefit. You must be at least 60 years old or at least 50 years old and have a disability in order to begin receiving Social Security benefits. If you are

What If a Spouse or Parent Dies Young?

If your spouse has died prematurely, Social Security does not apply the same work credit requirements (40 credits) for survivor and child benefits as it does for retirement benefits. Contact your local Social Security office to find out your monthly benefits. If your spouse had earned enough credits, you also may be eligible for a one-time payment of \$255.²

caring for your spouse's child who is younger than 16 years, you can receive Social Security benefits regardless of your age. If you are divorced, you may be entitled to your ex-spouse's Social Security benefits when your ex-spouse dies. You need to be at least 62 years of age, have been married for at least 10 years, and be unmarried. There are other requirements for ex-spouses. You should speak to your [*local Social Security office*](#) to see if you qualify for benefits.²

Children. Children younger than 18 years can receive a Social Security benefit. Children aged 18-19 years old who are full-time high school students also can receive a benefit. Children cannot be married. In addition, children aged 18 or older who have a disability can receive the Social Security benefit of a deceased worker. The disability must have started before the child reached the age of 22. In general, children receive 75 to 100 percent of the deceased parent's Social Security benefit. To determine the amount that a child can receive, contact your local [*Social Security office*](#).²

Retirement Benefits for Employees of State and Local Governments

Some people employed by state and local governments, such as teachers and police officers, may not be covered under Social Security. These workers don't have Social Security taxes taken out of their paychecks and do not receive benefits from this program. These workers typically are covered by a public retirement plan from their employer. If you don't know whether your retirement benefits are from Social Security or another source (public retirement plan, pension plan, etc.), contact the Human Resources department at your employer.

Section 218 Agreements made between some state and local governments with the SSA makes it possible for some people who are employed by a state or local government to be eligible for Social Security and/or Medicare. These workers do pay Social Security and/or **Medicare** taxes.⁴

Each state has a State Social Security Administrator that is responsible for Section 218 agreements that state and local governments have with the SSA. The State Social Security Administrator can help you understand your benefits in the Section 218 agreement that your state or local government employer has with the SSA.⁵ The National Conference of State Social Security Administrators lets you [search by state](#) to find the appropriate people to contact in your area.⁵

If you're eligible for both Social Security and a pension from a state or local government or federal service, your monthly Social Security benefit may be reduced.³



How It Works

As mentioned earlier, Social Security taxes deducted from your paycheck fund the majority of Social Security benefits, which are paid monthly. How much you receive is determined by:²

- How much you earned while working
- Your age at retirement

Higher earnings during your working life means you paid a higher amount of Social Security taxes. You receive a higher monthly benefit than people who had lower earnings during their working life. The average monthly Social Security benefit is \$1,543 in 2021.²

You can choose the start date for your retirement. Full retirement age is 67 for most people. If you were born before 1960, your full retirement age will be a few months before your 67th birthday. Early retirement for anyone who met Social Security's work requirements can begin at the age of 62. If you choose to retire early, your monthly benefit will be lower than if you retire at the full retirement age.³

Some people choose to work beyond retirement age. If you choose to continue working after the full retirement age, the amount you receive in your monthly benefit will continue to increase until you decide to retire (and receive benefits) or until you reach the age of 70.²

To help you decide when to retire, you can get an estimate of your Social Security benefit based on different

retirement ages. To do this, you need to create a [mySocialSecurity account](#) on the Social Security website. You'll need to provide a mobile number or email address so that Social Security can send you an activation code. After doing this, you should confirm that Social Security has the correct information regarding your work experience on file. You can also calculate the estimate for your Social Security benefit. This will help you decide at what age it's best for you to retire as well as plan other sources of post-retirement resources (savings, investments, etc.) that you will need during retirement.³

In calculating your monthly benefit, Social Security averages your highest monthly earnings over 35 years, if applicable. Added to this base benefit, Social Security adds a cost-of-living increase once you turn 62, even if you aren't receiving Social Security benefits. Each year, your benefit is increased for cost of living, which is based on the Consumer Price Index. The benefit for people who are eligible for Social Security and another government retirement program or pension is calculated using the [Windfall Elimination Provision](#).⁶

Quick Tips for Social Security

- Complete your Social Security application four months before you would like to receive your benefits
- Apply online, on the phone, or at your local Social Security office
- Organize the documents that Social Security requires
- It's helpful to have your recent W-2 forms or tax returns handy
- Have your bank information ready
- Give Social Security your mobile number so that you can receive texts or emails

Applying for Social Security

Once you've determined at what age you'd like to retire, you can fill out an application for Social Security online, on the phone, or at your [*local Social Security office*](#). You should apply for Social Security four months before you would like to begin receiving benefits.³

To complete the application, you will need to provide the SSA with:³

- Your birth certificate
- Your Social Security card
- Permanent Resident card (if you are not a U.S. citizen)
- Birth certificate of current spouse if your spouse is also applying for benefits based on your work credits
 - » Your marriage certificate
 - » If divorced, the name of your previous spouse and dates of

the marriage if it lasted for at least 10 years

- Birth certificates of children younger than 18 years, 18 to 19 years old and still in high school
 - » Birth certificates of children with a disability that was identified before they reached the age of 22
- The most recent W-2 you have from your employer or your tax return if you are self-employed
- Discharge papers if you served in the U.S. military
- Bank account information

For some documents, such as a birth certificate, the SSA requires the original document, not a photocopy. A certified copy for birth certificates is acceptable. Photocopies of other documents, such as W-2 forms and self-employment tax returns, are acceptable.³

Social Security will need the name of your employers and start and end dates of employment for the previous two years. For self-employed people, Social Security needs to know the kind of business and the business's net income for the past two years. If you've served in the U.S. military, Social Security will want to know the branch of military (Army, Navy, etc.), type of duty, and dates of service.³

Social Security does not send monthly benefit checks to people. Instead, it directly deposits funds into your bank account so you will need to provide your bank's routing number, the

account type (checking or savings), and the account number. If you do not have a bank account, Social Security will send you a debit card onto which your monthly benefit will be loaded.²

You can receive your Social Security benefit in most countries if you live outside the United States. However, benefit payments cannot be sent to Cuba or North Korea.³

Working and Receiving Social Security

You can also decide to continue working while receiving Social Security benefits. However, your Social Security benefits may be reduced if your earnings exceed the annual limit. If you begin receiving Social Security benefits at the age of 62 but continuing working, the 2021 annual limit for earnings is \$18,960. For every \$2 you earn above the annual limit, you will lose \$1 in monthly Social Security benefit. In the year of your full retirement age, the annual limit is higher at \$50,520 in 2021. In the year of your full retirement, your Social Security monthly benefit is reduced by \$1 for every \$3 you earn. After you reach your full retirement age, Social Security won't reduce your benefits if you keep working.³

You are allowed to receive your full Social Security benefit for one month in a single year during which you are receiving benefits and continue to work. This special rule is usually applied in the first year of retirement when someone may have worked for some of the year, and thus, exceeds the annual limit on

earnings. To receive your full benefit in a given month, you have to earn less during the month than a limit set by Social Security.³

Income Taxes on Your Social Security Benefit³

Most people don't have to pay income taxes on their Social Security benefits. However, about 40 percent of retirees do pay taxes on these benefits. You will be sent a Social Security Benefits Statement at the end of every year. You should use this form to complete a federal income tax return.

- If you're filing a federal income tax return as an individual, you may have to pay up to 50 percent in taxes on your Social Security benefits if your income is \$25,000-\$34,000. You may have to pay up to 85 percent of your Social Security benefits if your income exceeds \$34,000.
- If you're married and filing a joint return with your spouse, you may have to pay up to 50 percent in taxes on your Social Security benefits if your joint income is \$32,000-\$44,000. You may have to pay up to 85 percent of your Social Security benefits if your joint income exceeds \$44,000.
- People who are married but filing separate returns will likely have to pay taxes on Social Security benefits.

Supplemental Security Income (SSI)

Who Is Eligible for SSI?

To be eligible for SSI, you must be a U.S. citizen living in the United States or the Northern Mariana Islands, which is a protectorate of the U.S., and meet one of the following categories:^{10,12}

- Aged 65 years or older with low income and limited resources
- Working-age adult who is blind or has a disability that prevents employment and has limited resources
- Child who is blind or has a disability

(If you are an immigrant with permanent residence in the United States, you may also be eligible for SSI.)

You cannot receive SSI if you live in a U.S. protectorate or territory other than the Northern Mariana Islands. That means that people living in Puerto Rico, Guam, the U.S. Virgin Islands, and American Samoa cannot receive SSI. You also are not eligible for SSI if you live in a government-funded facility, such as a hospital or a prison. There are some exceptions, such as living at a vocational or educational public institution.^{8,12}

Federal Definition of Disability¹⁰

The federal government has different definitions for disability for adults and children.

For adults, disability is defined as a medically confirmed physical or mental impairment that results in “an inability to do any substantial gainful activity,” and that will last for at least 12 months or may result in death.

For children, disability is defined as a medically confirmed physical or mental impairment that results in “marked and severe functional limitations,” and that will last for at least 12 months or may result in death.

Income and Resource Thresholds

You also must meet income and resource requirements in order to receive SSI. Income includes wages or earnings from self-employment,

Federal Definition of Blindness¹⁰

The federal definition for blindness is the same for both adults and children. Blindness is defined as 1 of 2 scenarios:

1. Even with corrective lenses (glasses), your distance vision is <20/200 in your dominant eye, or
2. The visual field in your dominant eye is <20 degrees with the aid of glasses.

Even if you don't meet the definition for blindness, you may be eligible to receive SSI depending on your vision's impact on your ability to participate in "substantial gainful activity."

benefits from Social Security and other social programs, and food and shelter. There are different thresholds for unearned income and earned income. The maximum amount of 2021 income for adults is:^{8,10,12}

- Monthly unearned income, which comes from Social Security or other social programs, cannot exceed \$814 for an individual and \$1,211 for a couple
- Monthly earned income, which comes from wages or self-employment, cannot exceed \$1,673 for one person or \$2,467 for a couple
- Monthly earned income for a student younger than 22 years who is attending school full time cannot exceed \$1,930

For children with disabilities, the SSA doesn't distinguish between unearned and earned income. However, the SSA considers food and shelter to be income and may reduce an SSI payment based on a child living with a parent. The maximum amount of 2021 income for children with disabilities is:¹¹

- A child with a disability and who is not blind cannot exceed \$1,310 in monthly earnings
- A child who is blind cannot exceed \$2,190 in monthly earnings

The SSA will also consider the family's income when determining a child's eligibility for SSI. This is known as "deemed income," and the process for assessing the family's income is called "**deeming**."¹¹ The SSA takes into consideration whether the household is one- or two-parent, the number of children without disabilities also residing the household, and the amount of earned and unearned income when performing deeming.¹¹



RARE TIP

"Make sure you get some counseling on how to get the maximum amount for SSI. When my son first qualified, we only got paid \$525 a month."

ABLE accounts are under-utilized in the rare disease community. There is this idea that you can only use an ABLE account for costs directly associated with your disease or disability, but ABLE accounts are more inclusive on what you can use the funds for than many people realize."

– MINDY CAMERON, RARE DISEASE ADVOCACY CONSULTANT



PRO TIP 1

If Your Child Has a Rare Disease, Apply for SSI

Most parents with a child with a rare disease are grateful if their child is deemed eligible for Medicaid, as Medicaid can help offset deductibles and uncovered expenses of private health insurance (see Global Genes' toolkit, *Understanding and Navigating Medicaid*, for a full discussion of Medicaid's benefits). In most states, a child who receives SSI benefits will automatically be placed in his or her state's Medicaid program. Applying for SSI may be a faster route to obtaining Medicaid coverage for your child. Even if your child is denied SSI benefits, your state's Medicaid program may provide health coverage.¹¹

SSI also has a resource threshold. Resources include cash, bank accounts, investments, land, life insurance, and personal property (such as cars). Individuals cannot have more than \$2,000 in resources and couples cannot have more than \$3,000 in available resources.¹² If a child with disabilities is living with a parent, the family resources may be considered as being available to the child.¹¹

Fortunately, the SSA doesn't include some possessions in its assessment of

your resources. If you own a house or apartment, the SSA will not consider your home as part of your available resources. In general, the SSA will typically omit one car from the resource consideration.

The SSA provides a complete list of *income inclusions and exclusions* and *resource inclusions and exclusions* that are used in the evaluation of SSI eligibility. You can also contact your *local Social Security office* for further details. Make sure that you ask to speak with the person who handles SSI calculations for the local office.



Applying for SSI

You can apply online for SSI after you have created a mySocialSecurity account. You can also call or make an appointment at your *local Social Security office* to complete the application process. You will need to provide the following information:¹³

- SSN or Social Security card
- Proof of U.S. citizenship (birth certificate, U.S. passport, certificate of citizenship or naturalization)
- Proof of income (W-2s, self-employment tax returns, records demonstrating unearned income)
- Work expenses, if any
- Proof of resources (bank statements, investment portfolios, proof of ownership for secondary homes, etc)
- Proof of living arrangements (e.g., lease agreements, deed or property tax statement, SSNs for all people living in the residence, and household costs for rent or mortgage, food, and utilities)
- Work history for previous 15 years (if applicable)
- Medical information (contact information for doctors, medical records if you have them).

You will also need to give the SSA permission to contact your bank and medical providers.

You may be able to get an emergency advance payment from Social Security. If the SSA decides that you're not

eligible for SSI, you will have to pay back Social Security.¹²



RARE TIP

"I get less SSI because I live with my mom. That's why we're working on a renter's agreement so I can show Social Security that I am indeed paying rent."

– AUSTIN LECLAIRE, PATIENT ADVOCATE

Who Decides If You're Approved for SSI?

The SSA decides if a retired person or someone already receiving Social Security Disability Insurance (SSDI) can receive SSI. If you are already receiving SSDI, you may not need an additional medical evaluation to obtain approval for SSI. If you don't receive SSDI, a disability agency in your state makes the decision whether you qualify for SSI. You will need to give permission for your state's disability agency to access and review your medical charts. If they cannot determine whether you meet the criteria for disability, you (or your child) may have to be evaluated by a doctor or take some tests. The SSA will pay for the doctor's visit and/or tests.^{11,12}

It can take 3 to 5 months to find out if you are approved for SSI. If you have a severe disability, you may be considered to be "presumptively disabled" or blind. In this case, you may receive quick preliminary approval for SSI and can receive SSI payments for up to six months. If it is later determined that you don't meet SSI qualifications,

you will have to pay back the advance payment.¹²

State-Based Supplements to Federal Social Security

All states with the exception of Arizona, Mississippi, North Dakota, and West Virginia, supplement the federal SSI. State supplements may vary by group (elderly vs child with disability). In addition, several states have an arrangement with the SSA so that the state's supplement is added to the federal government's monthly SSI payment.¹²

Maintaining SSI

You have to report changes in your circumstances to the SSA in order to continue receiving SSI benefits. Changes that you are required to report include:¹²

- Income or resources
 - » Changes to a spouse's income or resources if married
 - » Changes to parent's income or resources for a child receiving SSI
- Living arrangement and/or address
- Marital status
- Employment status, including becoming self-employed
- Student status for children receiving SSI
- Child receiving SSI reaches the age of 18
- Child receiving SSI who is attending school reaches the age of 22

- Leaving the United States, Washington, D.C., or Northern Mariana Islands
- Arrest or felony warrant



RARE TIP

"I was working at an internship and Social Security sent me a letter saying that I owed money. They said that I was overpaid because of what I earned during the internship. The internship was temporary. I no longer have that income. I had to call Social Security. I had read the paperwork on the SSI. I was within my right of how much I was legally allowed to make. It's important to know your rights and stand your ground. I know it's not easy for people to do that but Social Security is there to serve us. That's why they exist."

– AUSTIN LECLAIRE, PATIENT ADVOCATE

If you live in the U.S. territories, such as Puerto Rico or Guam, you are not eligible for SSI. With the exception the Northern Mariana Islands, people receiving SSI cannot be outside the United States for more than 30 days and continue to receive SSI. An exception is made for children with a disability who have a parent serving in the military stationed outside the United States.¹²

You have to report any changes in income or circumstance within 10 days. If not, penalties of \$25 to \$100 can be deducted from your monthly SSI payment.¹²



PRO TIP 2

What to Do If Your Income May Increase

- Talk to Social Security and let them know your income may increase
- Don't call the 800 phone number on Social Security's website.
- Call your *local Social Security office*. When you get the automated service, press the option to speak to a live person.
- Ask to speak to the person who does the SSI calculations. He or she should be able to tell you whether your increased income will affect your SSI.

Ticket to Work

If you're aged 18 to 64 years of age, you can choose to participate in the SSA's Ticket to Work program when you are receiving SSI or disability benefits. The program allows you to receive free training or vocational rehabilitation. You have to choose from a list of SSA-approved programs.^{11,12} The SSA's *Ticket to Work* website offers career counseling, job placement, vocational training, vehicle modification, and legal support for employment-related issues. The website also offers information on how to report your wages in order to retain your SSI or disability benefits and how to access a benefits counselor for information on other programs, such as housing assistance.

SSI Redetermination

If you receive SSI, you may get periodic reviews from the SSA in order to maintain your status. This is called redetermination. Income and resources (e.g., savings in a bank) often need to be verified so keep your bank statements to show the SSA. Redetermination can take place over the phone or by mail. Sometimes, SSA may ask you to come to your local Social Security office.¹²

If you receive SSI because of a disability, you may also have to undergo a periodic review of your medical condition. The frequency of the review depends on the severity of the disability as well as whether it's possible for the condition to improve.¹²

Disability

Social Security Disability Insurance (SSDI) uses the same definition for disability as that used by SSI: an inability to do any substantial gainful activity that will last for at least 12 months or may result in death. However, SSDI differs from SSI in a fundamental way in that the person must have worked prior to the disability in order to be eligible.

Who Is Eligible for SSDI?

If you work at a company, you probably pay into SSDI through a payroll tax. If so, you'll be eligible for disability after earning a certain number of work credits. You are awarded one credit for each \$1,470 you earn through wages or self-employment. Up to four credits can be awarded each year. You need 40 credits, with half of the credits earned in the 10 years prior to your disability, in order to qualify for SSDI.¹⁴ Younger workers who become disabled have *lower work credit requirements*.

Family members can receive SSDI based on your work history. Eligible family members include:¹⁴

- Your spouse (must be 62 years or older)

- Your spouse (no age restrictions) who is caring for your child who is younger than 16 years or disabled
- Your unmarried child up to the age of 19 if still in high school
- Your unmarried child older than 18 years with a disability occurring before he or she turned 22

If you are applying for your child with a disability, he or she will be evaluated

SSDI Monthly Payments

If approved for SSDI, your monthly payment will reflect your average earnings up until the time of your disability. Your first SSDI monthly benefit will be on the 6th month after your disability began.¹⁴

The average SSDI monthly payment was \$1,279.71 in March 2021 for disabled workers. Spouses of disabled workers received an average of \$360.06 per month, with children receiving \$401.43 per month.¹⁵

under the adult definition of disability for SSDI purposes, not the child disability definition used for SSI.¹⁴

Applying for SSDI

You cannot receive disability benefits until five months after you became disabled. However, the SSA recommends that you apply for disability when you become disabled.¹⁴ You can apply online after you have created a mySocialSecurity account or make an appointment to file a disability claim with your *local Social Security office*.



RARE TIP

“Some people view disability as a brick road. A lot of people are hesitant to file for benefits. I view disability as a bridge to recovery. It helps you recover, get the treatment you need, and hopefully re-enter the workforce.”

– N. LEAH FINK, ATTORNEY

A benefit to applying for SSDI online is that you will be given a “re-entry” number for your application. If you need to find information or want someone to help you, you can finish the application later.

You will need to provide a lot of information to complete the application, including:¹⁴

- Your SSN or Social Security card
- Your birth certificate
- Contact information for all doctors, therapists, caseworkers, hospitals, and clinics that you have visited in the previous 12 months
- All medication and dosages
- Medical records for the past 12 months if you have them
- Results of laboratory (blood) work and other tests
- A summary of your work experience
- Your most recent W-2 or self-employment tax return

You will also have to complete a form indicating how your disability affects your work and sign a form giving permission to access your medical records.¹⁴

Review of Your SSDI Application

It usually takes 3 to 5 months to process the application. Similar to SSI, you may be considered “presumptively disabled or blind” and may be able to receive SSDI payments for up to six months as your application is processed. If it’s



later determined that you don't qualify for SSDI, you don't have to pay back the advanced money.¹⁴ If your disability is listed as a *Compassionate Allowance*, your application for SSDI could be expedited.

The SSA confirms that you have the requisite number of credits to receive SSDI. If so, the SSA sends your application to the disability agency in your state which will review your application. Your state disability agency will contact your doctors and facilities where you received treatment about your condition. Doctors and specialists at the agency will ask your doctor about your ability to work.¹⁴

The state disability agency may decide that you need to be examined by another doctor or undergo additional tests in order to decide whether you qualify for SSDI. The SSA will pay for the cost of the doctor's visit as well as any tests that you have to take. If you don't complete a recommended doctor visit or tests, your SSDI application may be denied.¹⁴

When reviewing your file, your state agency will consider five questions to determine whether to approve your SSDI application (see Figure 2). It's a tiered process in that the reviewer has to be satisfied that you meet the criteria for each question. For instance, if you are currently working and making more than is permitted by the SSA, your SSDI application will likely be denied.

Figure 2. Social Security's Considerations for Evaluating a Disability¹⁴

Are you currently working?

Is your medical condition "severe"?

Does your condition meet or medically equal an SSDI listing?

Can you do the work you did before the disability?

Can you do any other type of work?

Notification of SSA's Decision

The SSA will notify you of its decision regarding your SSDI application. You will receive a letter stating approval or denial. If you have been approved for SSDI, the letter will include your monthly benefit and the date for when the first payment will be made. If you have been denied for SSDI, the letter will explain why your application has been denied and the steps you can take to appeal the decision.¹⁴

Appealing a Decision

Don't be discouraged if your initial application is denied. This is not uncommon.

You need to appeal the decision within 60 days of the denial letter. Your request for an appeal must be made in writing. You can make an [online request](#) for a medical reconsideration of your case. You can also request a medical or nonmedical hearing with an administrative judge. You have the right to have an attorney to represent you in the appeals process and you can have witnesses, such as doctors, speak at the hearing. Hearings are normally within 75 miles of your home. Hearings conducted by video are also performed.

If you disagree with the administrative judge's decision, you can also appeal to an Appeals Council.¹⁷

Continuing to Work

The SSA allows you to try to return to work if possible. In addition to the Ticket to Work program, SSA permits you to "trial" working and receiving SSDI benefits.¹⁴

The SSA puts limitations on how much you can earn and still receive SSDI. For 2021, the maximum monthly amount that can be earned during a trial work period is \$940.¹⁶

N. Leah Fink, an attorney located in Pennsylvania who specializes in SSI and SSDI, shared her thoughts on the SSDI application and appeals process:

"When someone applies for SSDI, they need to let Social Security know everything about themselves: from the top of their head to the bottoms of their feet. If they have a rare disease, they're concentrating on that. They're forgetting to tell Social Security, I don't have clear vision. They need to list all doctors' names and addresses for visits over the past 12 months. All medications. Emergency room visits should be noted. Urgent care visits should be noted. Mental health should be listed, too, as well as physical and occupational therapy. It's important to tell them [Social Security] what your bad days are like.

Don't be discouraged if you get rejected. Most folks get a denial off the bat, so don't get upset. That's pretty normal. Appealing the decision is key. You will need to be heard by an administrative law judge. That's really important. That's where we'll win the case for your disability benefit. We look at a rejection as a hurdle that we jump over to get to the judge. That's another reason why it's important to talk about your mental health in your SSDI application. That can be helpful when explaining to the judge that you can't do any type of work whatsoever on a full-time basis because of your limitations, physically and mentally."

Medicare

Medicare is a federally funded plan that provides health coverage to people aged 65 and older. If you have end-stage renal disease or amyotrophic lateral sclerosis (ALS), you also are eligible for Medicare even if you're younger than 65 years of age. Alternatively, if you have been receiving SSDI for at least two years, you can have Medicare as your health insurance. You have to be a U.S. citizen or have a Permanent Resident Card to be eligible for Medicare.¹⁸

You get to choose the type of Medicare plan that is best for you. Medicare's basic plan consists of Part A (hospital insurance) and Part B (medical insurance). The federal government pays for most of the costs of these plans. If you want additional benefits and are willing to pay a higher monthly premium, you may want to choose a **Medicare Advantage** plan, which is sold by private companies. Prescription drug benefits, which are called Part D, are offered by private insurance companies that have been approved by Medicare.¹⁸

Quick Tips for Medicare

- You need to be at least 65 years old to qualify for Medicare
- If you're younger than 65 years but have end-stage renal disease, ALS (Lou Gehrig's disease), or have been on SSDI for at least 2 years, you are eligible for Medicare
- Complete your Medicare application 3 months before you would like receive benefits
- You can apply for Medicare even if you are not ready to retire
- Apply online, on the phone, or at your local Social Security office
- It takes 10 to 30 minutes to complete the application online

Medicare Basic Plan: Hospital and Medical (Parts A and B)

Medicare's basic insurance, sometimes called "Original Medicare" is segmented into two parts: Hospital insurance (Part A) and medical insurance (Part B). You

can choose to only have Medicare Part B (not receive Part A).

Hospital Insurance (Part A)

Medicare Part A covers hospital stays, care in skilled nursing facilities (SNFs), hospice care, and some home healthcare. Most people don't have to pay a monthly premium for Medicare Part A. If you or your spouse have worked less than 10 years, you may have to pay a premium for Medicare Part A.

You will be responsible for a *hospital deductible*, which is \$1,484 in 2021. If your hospital stay is more than 60 days, you will also be responsible for a coinsurance amount.¹⁹ There is no annual limit for what you may have to pay in out-of-pocket expenses.²⁰

Medical Coverage (Part B)

Medicare Part B helps pay for visits to doctors and other healthcare providers (HCPs), outpatient care, durable medical equipment (DME), and home healthcare. You can see any doctor or HCP who accepts Medicare. However, you should check with your doctor to make sure he or she agrees to accept Medicare payment rates. This is called assignment and means your doctor will bill Medicare for your visit. Some doctors do not accept assignment and may require you to pay for the cost of visit or they may charge more than the Medicare-approved rate.²⁰

For most people, the federal government pays 75 percent of the cost of Medicare Part B. Most people pay \$148.50 each month for Medicare

Part B.¹⁹ However, you may have to pay a *higher premium* depending on your income. The Internal Revenue Service (IRS) provides Medicare with your most recent tax return to determine your monthly premium.²¹

Medicare in Puerto Rico

If you live in Puerto Rico and already are receiving Social Security benefits, you will automatically be enrolled in Medicare Part A on the first day of the month of your 65th birthday. However, you will not be automatically enrolled in Medicare Part B. You will need to sign up for Medicare Part B if you would like Medicare's medical coverage.²⁰

Medicare Advantage (Part C)

Medicare Advantage plans are private insurance that combines Medicare Part A and Part B. Prescription drug benefits, as well some dental, hearing, and vision, also are included in Medicare Advantage plans. Medicare Advantage plans have more coverage than Medicare, such as additional covered days in the hospital. A Medicare Advantage plan also may reduce your out-of-pocket expenses. If you choose to have a Medicare Advantage plan, you can't have supplemental (Medigap) insurance.²⁰

With Medicare Advantage, you can choose the type of plan that works best for you:²⁰

- **Health Maintenance Organization (HMO)** – You can only see doctors and other HCPs who are part of the HMO network and typically need to have a referral from your primary care physician (PCP) to see a specialist. Most HMO plans cover prescription drug benefits.
- **Preferred Provider Organization (PPO)** – Like HMOs, PPOs have a network of doctors and other HCPs who participate in the PPO. However, you typically are permitted to see doctors who don't belong to the PPO's network. A higher copayment is usually required for out-of-network HCPs. PPOs usually cover prescription drug benefits.
- **Private Fee-for-Service (PFFS) plan** – You can visit any Medicare-approved doctor or other HCPs that accepts the PFFS plan. Some PFFS plans have a network of HCPs. A PFFS plan sets how much you will pay for each type of service. Some PFFS plans offer prescription drug coverage.
- **Special Needs Plans (SNPs)** – These are tailored for people with certain health conditions, such as ERSD or heart failure, or people with limited income.

Prescription Drugs (Part D)

You can purchase a plan for prescription drugs (**Medicare Part D**) if you already have Medicare Part A and Part B. (Prescription drug coverage is already part of most Medicare

Advantage plans.) You are not required to purchase Medicare Part D; it's entirely your choice. However, if you don't choose Part D when you first enroll in Medicare, you may have to pay a higher fee later.²⁰

Premiums for Medicare Part D vary based on your income. There are many plans for you to consider. Each plan has its own requirements for deductibles and copayments. Some plans require prior authorization for certain medications. Where and how you get medication refills differ by plan.²⁰

Supplemental Insurance (Medigap)

Supplemental Insurance, also known as **Medigap**, is sold by private insurance companies. You must have (or choose) Medicare Part A and Part B to purchase a Medigap policy. Medigap can help cover the cost of copayments, coinsurance, and deductibles for Medicare Part A. If you're just applying for Medicare, a Medigap plan cannot cover your deductible for Medicare Part B.²⁰

There are several Medigap plans available. All are required to offer certain benefits related to covering copayments, coinsurance, and deductibles. However, some plans only pay your coinsurance amount after you have met Medicare Part A's deductible.²⁰ Therefore, it is important to carefully look at the additional coverage that a Medigap plan offers to determine whether it is worth the additional investment.

Medicare provides a *comparison of Medigap policies* to help you make that determination. In addition, you can also contact your *State Health Assistance Program (SHIP)* to receive free counseling on the available options.²⁰ If you have a Medicare Advantage plan, supplemental coverage should not be purchased because it duplicates coverage provided by your Medicare Advantage Plan.

Applying for Medicare

It's important for you to apply for Medicare three months before you turn 65 years old. If you apply for Medicare three months after your 65th birthday, you may have to pay higher premiums for Medicare Part B and Part D plans. This is called your initial enrollment period.²⁰

You can apply *online*, over the phone, or at your *local Social Security office*. You will need your SSN or Permanent Resident Card.

Enrollment Periods

After your initial enrollment period, you can only change your Medicare coverage at certain times of the year. General enrollment is January 1-March 31 every year. If you sign up during general enrollment, your coverage will begin on July 1. If you would like to add, change, or drop a Medicare Advantage plan after your initial enrollment, the open enrollment period for Medicare Advantage plans is October 15-December 7 each year. Your Medicare Advantage coverage will begin on January 1 of the next year.²⁰



Money Management

If you're retired, you are likely living on a fixed income. If you have a significant disability, you may not be able to work or find that your income is limited. In both cases, being adept at managing your money is crucial.

Choosing a Medicare Plan and Help with Payments

You have many options for your Medicare health insurance. Medicare offers resources to help you choose which plan is best for you. You can compare [Medicare Advantage and Part D plans](#) on Medicare's website. You can also get free counseling from your [local SHIP](#) office to help you choose your Medicare plan. SHIP can also help you understand your rights and protections under Medicare.²⁰

If you are concerned about paying for deductibles or coinsurance, you may be eligible for assistance:

- **Extra Help** – A Medicare program that assists with prescription drug costs. If you are a dual Medicare/Medicaid **beneficiary**, you are automatically enrolled in Extra Help.
- **Medicare Savings Programs** – Your state may help you pay for Medicare premiums, deductibles, and coinsurance. There are four programs that help people with low income and limited resources. You should contact [your state's Medicaid program](#) to see if you qualify for assistance.
- **Medicaid** – Each state oversees its own Medicaid program, which offers health insurance to low-income residents. Eligibility varies by state, however, if you are already receiving SSI, you should be able to receive Medicaid. You may need to enroll in Medicare before you can enroll in Medicaid. If you are a dual beneficiary, Medicaid may pay for some healthcare costs not covered or only partially covered by Medicare.²⁰

Older People

The *Financial Literacy and Education Commission* provides online resources and education to help you *prepare for retirement* and other life events. The nonprofit *AARP* also can provide you information to help you plan for the future. It costs less than \$20 a year to become a member. AARP also makes some resources and news articles available to nonmembers. For instance, it has *downloadable worksheets* for budgeting and saving. Depending on your circumstances, you might want to consult with a financial advisor who is knowledgeable about Social Security. The *National Social Security Association* may help you find a financial advisor near you.

People with Disabilities

There are two notable money management vehicles for people with disabilities: *Achieving a Better Life Experience (ABLE) accounts* and Special Needs Trusts.

ABLE Accounts

ABLE accounts are tax-advantaged savings accounts that permit you to protect (and grow) your financial resources while maintaining your eligibility for Medicaid or SSI, both of which have resource limitations, i.e., how much money you can have in savings or investments.²² If you are a minor or living with your parents, ABLE accounts cannot shelter income that you or your parents earn (both Medicaid and SSI also look at your income when determining eligibility).

ABLE accounts were created by federal legislation in 2014 and are not available in all U.S. states as some states have not launched programs. Presently 43 states have active ABLE programs, but many programs offer enrollment to non-residents of that state. Here is a state-by-state glance of what which have active programs: <https://www.ablenrc.org/select-a-state-program/>. If you have a disability or blindness that occurred before you became 26 years old and

Quick Facts on ABLE Accounts²²

- Tax-advantaged savings accounts for people with a disability that started before age 26
- Protects your financial resources while maintaining your eligibility for Medicaid or SSI
- Not available in all states but many states offer programs to non-residents
- You can contribute up to \$15,000/year
- First \$100,000 in ABLE account is not counted for SSI purposes
- You are the account holder and control use of funds

are receiving SSI or SSDI, you can start an ABLE account. If you're not receiving SSI or SSDI, you may still be able to have an ABLE account if you have functional limitations and a certified disability letter from a doctor.²²

The federal law allows you to contribute up to \$16,000 to your ABLE account each year. The first \$100,000 in your ABLE account is not counted by Social Security when evaluating whether you can receive (or maintain) SSI. If you are working and don't participate in your employer's retirement plan, you are allowed to contribute an additional amount, up to the federal poverty level, which is \$12,760 in 2021. You can only have one ABLE account but people other than you can contribute to your ABLE account. The maximum limit on all ABLE account contributions remains \$16,000 even if more than one person contributes.²² The maximum total amount permitted in an ABLE account varies by state, and ranges from \$235,000 to \$529,000.²³

Your ABLE account can be used to pay for "qualified disability expenses," which can include your education, transportation, housing, personal support services, and assistive technologies, among others.²⁴ Funds in your ABLE account can also be used for financial management services and fees. In addition, federal law specifies

that ABLE accounts can be used to improve your health, independence, and quality of life, which significantly broadens the type of expenses that would be considered qualified. The federal penalty for using funds for a nonqualified distribution is 10 percent.

Opening an ABLE Account

ABLE accounts are opened online. Each state runs its own ABLE program and has set up its own website. To find the ABLE program in your state, search:

"Open ABLE Account + Your State."

This is just a suggestion. Double check with the administering state of the program you are considering. Check with your home state to learn if it offers tax or other benefits for investing in its own ABLE plan.

Each state that offers an ABLE program has its own state-specific rules and terms that can vary throughout the country. Each state has its own website that describes the rules in the state and lets you open an ABLE account. There is usually a minimum contribution you need to make to open the account; for most states, you need to contribute \$25 to start an account. There is often a low annual fee for maintaining your ABLE account. Some states have a gifting portal so that others can contribute to your ABLE account.²³

Most states offer at least four different



RARE TIP

"ABLE accounts are underutilized in the rare disease community. There is this idea that you can only use an ABLE account for costs associated with your disease or disability, but ABLE accounts are extremely lenient on what you can use the funds for."

– MINDY CAMERON, CONSULTANT

investment options for ABLE accounts. You can choose to put some of your funds in a more aggressive fund and some in a more conservative investment. In this way, you can grow your money. You can change your investment funds two times each year.²³

ABLE accounts also usually offer a cash-based option. If you choose this, you typically get a debit card and can use your ABLE account similar to a checking account.²³

Federal law gives state Medicaid programs the right to recoup any funds from ABLE accounts upon the death of the account holder.²³ Medicaid can only recoup funds from an ABLE account after all outstanding qualified expenses are paid for.



PRO TIP 3

Shop Around for ABLE

You might find that another state has more benefits than the state where you currently reside. The [ABLE National Resource Center](#) has an online tool that lets you see the features of ABLE accounts in your state. There is also a tool that allows you to compare ABLE account features in different states. For instance, California and Kansas are two states that allow out-of-state residents to enroll in their ABLE programs but Tennessee does not.

However, it is up to your state whether funds in your ABLE account will be given to your state's Medicaid program when you die. Some states allow you to designate a beneficiary for your ABLE account. You should check your state's ABLE program website for what your state does.

Special Needs Trusts

Special needs trusts are another way to protect assets without jeopardizing resource limitations for Medicaid and SSI. There are two primary types of Special Needs Trusts:²⁵

- **First-party trusts.** These are trusts set up by the beneficiary of the trust. This often happens if you were to receive an inheritance from a family member, such as a grandparent. You have to be younger than 65 years old and have a disability to do a first-party special needs trust.
- **Third-party trusts.** These are set up by someone other than the beneficiary. If your child has a rare disease, you may want to establish a special needs trust for him or her.

You need to keep in mind a few features of special needs trusts:²⁵

- Property, savings and investment accounts, and other assets can be included in the trust
- You need to name a **trustee** who will have authority to make decisions for disbursement of assets in the trust
- There's no minimum amount to establish a trust

Special needs trusts must be set up by an attorney. While many attorneys are familiar with trusts, it's important to use an attorney who is experienced with special needs trusts, which have very specific rules, and can advise you on who to select as a trustee, terms, and other things you should know. The [Special Needs Alliance](#) may help you find an attorney in your area. You can also

look for an attorney who specializes in disability law or elder care.

Pooled Special Needs Trusts, which are managed by a non-profit organization, are available in some states. A separate account is kept for you but your funds are combined with others for investment.²⁵

Sage Graves, who is an attorney in Washington, offered some thoughts on Special Needs Trusts:

"The big picture behind a special needs trust is setting money aside that will be available for the person with the disability without jeopardizing the person's eligibility for certain government benefits. If you have a properly drafted special needs trust, you can have an unlimited amount of money in it.

In a special needs trust, the trustee is 100 percent in charge of managing the money and making distributions to the beneficiary. The trustee has a broad amount of discretion in deciding what to use it for. The trust can be used for housing assistance, medical assistance, or things that are not covered by benefits. You can even use it to pay for a plane ticket for the beneficiary to go visit family or go on a vacation, use it for outings, or use it for trips to the hair salon.

A third-party special needs trust is commonly set up for a child with a disability by the parents. If you're doing a will, it's pretty inexpensive to set up a third-party special needs trust. These trusts can be worth their weight in gold because they allow the child to stay on benefits and also allow someone else to manage the money."



Glossary

ABLE Account: A tax-advantaged savings account for people with disabilities. It protects (and can help to grow) financial resources.

Assignment: The term used to describe when a doctor or other HCP agrees to Medicare's billing rates.

Beneficiary: The person who receives funds ("benefits") from a trust. Beneficiary can also refer to the person who participates in a social program, such as Medicare.

"Deeming": The name of the process when Social Security assesses a family's income and resources when considering someone for a Social Security benefit.

Medicaid: A joint federal-state program that provides healthcare coverage for low-income people. Medicaid programs vary by state.

Medicare: The federally funded plan that provides health coverage to people aged 65 years or older. Some people younger than 65 years are also eligible for Medicare.

Medicare Advantage: A type of Medicare plan sold by a private insurer. Medicare Advantage plans combine hospital, medical, and, in most cases, prescription drug benefits. Medicare Advantage plans may also be referred to as Medicare Part C.

Medicare Part A: Hospital insurance that is available for free for most people who are aged 65 years or older.

Medicare Part B: A plan that can be purchased by a Medicare beneficiary to cover medical expenses, such as doctor visits. For most people, the federal government pays for 75 percent of the cost of Part B.

Medicare Part C: See Medicare Advantage.

Medicare Part D: A plan that can be purchased by a Medicare beneficiary to cover prescription drug expenses.

Medigap Plan: A plan sold by a private insurance company that can be purchased by a Medicare beneficiary to help pay for Medicare copayments, coinsurance, and deductibles.

Redetermination: A periodic review performed by from the Social Security Administration to verify a recipient of Supplemental Security Income continues to fulfill eligibility requirements.

Section 218 Agreement: An agreement between Social Security and state or local governments that permits employees of the state/local government to participate in Social Security.

Special Needs Trust: A trust established for the benefit of a disabled individual that is designed to allow him or her to be eligible for government financial aid by limiting the use of trust assets for purposes other than the beneficiary's basic care.

Social Security: Social Security is a federal program that provides retirement benefits to senior citizens who have met work requirements and some families of deceased workers who had met work requirements.

Social Security Administration: The federal agency that oversees Social Security retirement benefits, Supplemental Security Income, and Social Security Disability Insurance.

Social Security Disability Insurance: A program within Social Security that provides monthly payments to people who meet a length of work history and the federal definition of disability.

Supplemental Security Income:

A federal program that provides additional financial support for low-income retired people with limited resources and low-income working-age adults who are disabled or blind and have limited resources. Children with significant functional disabilities may also be eligible for Supplemental Security Income.

Trust: A legal instrument comprised of a variety of assets intended to provide financial security benefits to an individual (usually a child or grandchild) or a nonprofit organization (charity). A trust fund gives the benefactor "control from the grave," regarding when, how, and to whom the fund is distributed.

Trustee: The person(s) who is designated to oversee a revocable living trust. When ownership of some or all money and property has been transferred to a trust, the person named as a trustee has the power to make decisions about the contents and disbursement of the trust.

Resources

Government Websites

www.Benefits.gov
www.medicare.gov
www.mymoney.gov
www.ssa.gov
www.ssa.gov/myaccount
www.ssa.gov/work

Nonprofits and Foundations

AARP

www.aarp.org

Kaiser Family Foundation

www.kff.org/about-program-on-medicaid-and-the-uninsured

National Disability Institute

www.nationaldisabilityinstitute.org/about

Other Organizations

ABLE National Resource Center

www.ablenrc.org

Academy of Special Needs Planners

specialneedsanswers.com

National Conference of State Social Security Administrators

ncsssa.org/index.html

SHIP State Health Insurance Assistance Program

www.shiphelp.org

Special Needs Alliance

www.specialneedsalliance.org

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28 Argonaut, Suite 150
Aliso Viejo, CA 92656

+1-949-248-RARE (7273)

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