

# Social Security

## What federal and state benefits can support a person with SMI?

When a person has a severe and disabling mental illness, finances and financial planning can be confusing. Learning about public benefits and options to support daily living and protect assets into the future can offer direct help, empowerment, and reassurance.

From start to finish, a full package of state and federal benefits might take up to two years to establish, so the application process may feel like a full-time job at times. Staying patient and persistent—and filing appeals as needed—pays off when benefits can last a lifetime. It's never too soon to begin, and some benefits backdate to the time of application.

**Pro tip:** *Whenever possible, schedule in-person meetings with professional agents. Some of what you need to learn isn't written down and will be revealed through questions and answers shared in real time. These meetings can be hours long: Bring water, snacks, and wear comfortable clothing.*

**Federal benefits** from the Social Security Administration can provide regular income to support housing, utilities, and living essentials. Social Security benefits link to Medicare, which automatically begin two years after a person is found to be medically disabled or sometimes sooner if the impact is determined to be severe. If a person's disability is proven to begin before age 22, they may be eligible for lifelong payments after their parents begin drawing Social Security at retirement. See section below: What is unique about a person who became disabled before age 22?

**State benefits** are a separate application process that can be done before, during, or after a Social Security benefits application. Much of the required paperwork will be similar. Medicaid (public health insurance), food assistance, and personal assistance with a caseworker assigned through a Medicaid "waiver program" are possible supports for someone living with a disability.

Once state and federal benefits are established, they can work together for an enhanced benefit. If the person is determined to be a Qualified Medicare Beneficiary ([QMB](#)), Medicaid might cover the Medicare deductible. An [Extra Help](#) program might cover non-reimbursed expenses for prescriptions for those who meet income criteria. If all eligibility criteria are met, a person's medical care could be entirely covered with this blending of benefits.

**Pro tip:** *After benefits begin, various Medicare Advantage companies might market their plans, which*

are private but reimbursed through Medicare. Beware that traditional Medicare might have lower premiums and a better prescription benefit.

## What if someone with SMI cannot work full time?

According to [research](#), only about 12 percent of people with schizophrenia are gainfully employed. Almost one in four of individuals who receive disability benefits from Social Security receive this financial assistance due to the impairments of a mental illness.

Although vocational support protected by the Rehabilitation Act of 1973 and accommodations protected by the Americans with Disabilities Act (ADA) can improve a person's opportunities, the reality for many is that public benefits are critically important to maintain housing and basic needs.

Finding the right balance between encouragement and toxic positivity can be difficult for some families, especially when there are societal pressures to live and work independently. Ableism refers to a range of ways that people with disabilities experience stigma and discrimination. One form of ableism is to assume that someone can "overcome" their disability to become a high achiever. Realistic expectations are helpful when seeking public benefits.

One option for people in recovery with SMI is [Clubhouse International](#), which accredits locations that provide vocational help and other support within a "work-ordered day" that encourages scheduled, purposeful activities.

## Does a documented SMI make sure someone is eligible for Social Security?

Usually, yes. It helps to speak the language, so here are some key terms to know first.

Whether a person might be eligible for Social Security Disability Insurance (**SSDI**), or Supplemental Security Income (**SSI**) depends on work history. The [application](#) is the same.

**SSDI** pays benefits to individuals and certain [family members](#) if the "insured" beneficiary worked long enough — and recently enough — and paid social security taxes on earnings.

**SSI** is for disabled adults and children who have not worked at all or enough to be eligible for SSDI. They must have a qualifying disability and meet income and asset criteria.

Schizophrenia spectrum and bipolar disorders are listed in the **Social Security Blue Book** as conditions that qualify a person for disability benefits if diagnostic criteria are met with adequate documentation about the diagnosis and the person's inability to work.

According to a website called [Disability Secrets](#), a **Blue Book listing** speeds up Social Security decision-making. "The Blue Book is a listing of impairments that the SSA considers serious enough to potentially keep someone from working....If you match the requirements of a listed impairment (called a "listing"), you'll automatically qualify as disabled, regardless of whether you could actually work an undemanding job or not."

The Blue Book lists a range of criteria for schizophrenia spectrum ([12.00B2](#)), including symptoms of psychosis: delusions or hallucinations, disorganized thoughts and speech, and/or grossly disorganized behavior or catatonia. Criteria for bipolar and related disorders ([12.00B3](#)) require evidence of five or more of the following: depressed mood, diminished interest in almost all activities, appetite disturbance with change in weight, sleep disturbance, observable psychomotor agitation or retardation, decreased energy, feelings of guilt or worthlessness, difficulty concentrating or thinking, or thoughts of death or suicide. Impacts must be significant and persistent.

## What documents will we need for the application?

Think like an investigator when gathering documents for a Social Security application. What evidence would you expect them to want, and what will make it easiest for them to verify the disability? For example, try to include multiple documents that define and describe the diagnosis and its impacts. If there is a doctor's note or letter that describes the level of disability as severe or "grave," that document will be helpful.

### Here is a starter list of other documents to build and gather:

- List every hospitalization, with the dates, addresses, and the names and phone numbers for all doctors who provided care.
- List all outpatient providers, with names of their agencies, addresses, phone numbers, and any available notes about diagnoses and treatment.
- History of homelessness or illness-related incarcerations with dates, addresses, and phone numbers for any relevant contacts.
- Work history with locations, dates, addresses, names of supervisors, phone numbers, and descriptions of how the illness has impacted work. If the person was working full-time before a psychotic break and has been unemployed less than 12 months, you might wait until a full year of unemployment to apply.
- School records, if there was early evidence of an illness or if there were behaviors that indicated earlier problems.

***Pro tip: If applying on behalf of a loved one, talk to the agent about your loved one's condition to find out how involved they might need to be to complete the application. If there is severe decompensation, psychosis, and/or paranoia, point out how difficult it may be for them to participate in an interview. Social Security might require only a short phone call to confirm their identity after the application has been verified.***

## What if we don't have patient records?

If you don't have official patient records, that is not a problem. There's a place on the application to sign for a release of records so that Social Security can contact the facilities and doctors directly. You must agree to this release of records for the application to be considered for approval.

Social Security investigators will verify all information provided and can subpoena the records they need. Providing the most comprehensive information possible—with details about *who*, *what*,

when, and where—supports this process and increases the chances for an approval on first application. If an appeal is needed, adding facts and details supports another chance for approval.

## **What is unique about a person who became disabled before age 22?**

A [disabled adult child](#) (DAC) is a person who experienced a disabling condition before their 22<sup>nd</sup> birthday. Childhood medical and school records might demonstrate early onset of a disability. For example, school staff or a provider might have documented signs and symptoms of a psychotic episode, even if a formal diagnosis wasn't made at the time.

If Social Security finds that a person was disabled before age 22, they can receive lifetime benefits based on a parent's work record as soon as the parent begins to claim their retirement benefits. The DAC's benefit does not diminish the parent's benefit, and the DAC may receive an enhanced benefit after parents die.

***Pro tip:** Do not expect a Social Security agent to volunteer this information; you must provide relevant documents and ask for this consideration.*

## **How can a person save money, given the income limits of their benefit?**

People with disability benefits through Social Security or other benefits programs often have resource limits or might be subject to fines or taxes if they accumulate wealth beyond what they need to meet very basic living expenses.

The Achieving a Better Life Experience (ABLE) Act of 2014 allows states to create savings programs for eligible people with disabilities. [ABLE](#) accounts have specific rules about how funds can be used, and distributions are tax-free only if used for qualified disability expenses. Establishment of an ABLE account can be part of regular estate planning for families who want to plan for the long-term financial needs of a loved one with disabilities.

## **What can be done to make sure someone uses their benefits wisely?**

Social Security benefits should be kept in their own bank account, so all payments and eligible withdrawals for basic living expenses are easy to track and document. If the person's benefit is through SSI, the bank account balance cannot exceed \$2,000.

A [representative payee \(sometimes called rep payee\)](#) is an adult appointed by the Social Security Administration to handle the funds of a social security recipient. The recipient's doctor must notify social security if they believe the individual isn't able to manage their own finances. The beneficiary can appoint someone or use an agency to handle the funds.

Use of a representative payee can ensure that basic living expenses, such as rent, are reliably paid and can assist with savings and asset management. Family members or loved ones sometimes act as representative payee for a social security recipient. This is the lowest-cost option since agencies charge a small fee for the service. Before agreeing to be representative payee for a loved one, be sure to consider the potential strain it could place on your relationship.

**Pro tip:** *Having financial management handled by a professional third party can promote independence and eliminate stress for aging caregivers who want to make sure their loved one's needs will be met in the long-term.*

## **What if my loved one lives with me: Do I have to charge rent?**

To maximize SSI benefits, a person with a disability who lives with friends or family must pay their “fair share” of rent and utilities. The same is true for food costs to maximize benefits through the Supplemental Nutrition Assistance Program (SNAP). The charges need to be documented, and bank withdrawals must match receipts.

If you support a loved one with a disability, figure out what to reasonably charge for rent by researching what it costs for someone to rent a room in your community. Draw up a simple rental agreement to demonstrate validity and be sure to share the same information with all state and federal agencies. Withdrawals from the person's bank account need to match the rental agreement exactly.

If you claim a disabled person in your home as a dependent on your taxes, your support is considered “in kind,” and benefits may be denied.

## **What state benefits should I know about?**

While applying for Social Security, ask about state benefits too: Your agent might know what's available and provide tips for applying. A community mental health agency or an inpatient facility might help with a Medicaid application, which can be done before, during, or after applying for Social Security.

Note that there is no centrally located place to research all these benefits and options—it's still a word-of-mouth learning process.

### **Here are three state benefits to consider:**

- SNAP (Supplemental Nutrition Assistance Program)
- Medicaid (public health insurance)
- Medicaid waiver programs

## **What is a Medicaid waiver program?**

Waiver programs provide a range of home and community services, paid caregiving, and a caseworker to support individuals with disabilities who need assistance with activities of daily living.

Having a responsible caseworker can alleviate stress for caregivers and provide comfort to aging parents who want to make sure their loved one with a disability will be looked after when they die. Sometimes a waiver benefit will pay for specialty equipment, such as a life alert emergency button that might support a medical instead of law enforcement response to a crisis, for example.

Waiver program eligibility is based on disability needs and age. The services available can vary widely state to state.

## **How can I plan for my loved one's long-term financial stability?**

A [special needs trust/pooled trust](#) is an option for people who want to plan for their loved one's long-term financial independence. A qualified family law attorney can help with these legal documents. The [Special Needs Alliance](#) is an organization of attorneys who focus on the practice of disability and public benefits law, and the website includes a button to find an attorney. For a referral to a qualified estate planning, elder law, or special needs attorney, contact your state bar association. TAC provides general guidance about [legal resources](#) but does not offer individual legal counsel.