

Navigating SSI Benefits: What You Need to Know When Your Loved One with Down Syndrome Turns 18

September 13, 2023



About the National Down Syndrome Society

Mission

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The National Down Syndrome Society's (NDSS) mission is to empower individuals with Down syndrome and their families by driving policy change, providing resources, engaging with local communities, and shifting public perceptions.

Vision

NDSS strives to ensure all individuals with Down syndrome are assured their human rights and valued by a more inclusive society.

NDSS Core Programs

NDSS supports and advocates for the Down syndrome community by focusing on three key areas of programming:

Resources & Support

- 1-800 Helpline (800-221-4602)
- Resource and information from birth to end of life
- Education, employment, health and wellness, aging, caregiving, and more

Advocacy & Policy

- Federal, State, and Local Advocacy
- Develop and improve laws and policies for individuals with Down syndrome, their families and caregivers
- Legislative agenda spans the life experience of individuals with Down syndrome

Community Engagement

- Scholarships, grants, and awards
- National Buddy Walk®
- Times Square Video
- Athlete Ambassadors
- Run for 3.21 Event
- Virtual Racing for 3/21 for WDSO
- Gala, golf, and more!

Employment Program



- Employment Policy and Advocacy
- Resource Development
- Entrepreneurship and Self-Employment
- Private-Sector Engagement
- Affiliate Support
- Highlighting Success
 - [Share your loved one's success story!](#)

Navigating SSI Benefits: What You Need to Know When Your Loved One with Down Syndrome Turns 18

Introductions



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Supplemental Security Income (SSI)

What is SSI?

SSI is a federal program that provides monthly payments to people with disabilities and older adults who have limited income and resources.

Who can get SSI?

Adults and children might be eligible for SSI if they have:

- Little or no income, and
- Little or no resources, and
- A disability, blindness, or are age 65 or older.

<https://www.ssa.gov/benefits/ssi/>

SSA Definition of Disability

Key Criteria for Adult Disability and Child Disability:

Adult:

- Must be severe - medical or physical impairment (or combination)
- Must have a duration of 12 months or more or result in death
- Impedes or prevent the person from engaging in substantial work activity

Children:

- Must be severe - medical or physical impairment (or combination)
- Must have a duration of 12 months or result in death
- Impedes or affects the child's growth and development or cognitive and physical functioning

What Changes When Your Loved One Turns 18

- When your loved one turns age 18, we will review their eligibility for continued SSI payments based on the disability rules for adults.
- These include non-medical eligibility rules pertaining to income, resources, residency, citizenship, etc.
- These rules are different than the rules that were applied when they were a child. We call this review an age-18 redetermination.
- We will make sure that you and your loved one are aware of this important change and the process for providing us with needed information.

What Changes When Your Loved One Turns 18 (Cont.)

SSI Determination for Children Turning 18

- We make a new disability determination using the adult rules.
- We no longer count the income and resources of parent(s) for eligibility.
- If the individual continues to live with their parent(s) but does not pay for food or shelter, a lower SSI payment may apply.
- An SSI application can be submitted as early as the day of the child's 18th birthday.

When Your Loved One Turns 18...

- SSA will usually contact your loved one prior to when they turn age 18.
- During this review, we will send you a letter to ask for the following information about your loved one's disability:
 - Names of any medicines.
 - Hospital stays and surgeries.
 - Visits to doctors and clinics.
 - Work activity.
 - Counseling and therapy.
 - Schools and special classes or tutoring.
 - Teachers and counselors who have knowledge of your loved one's condition.

Requirements for Getting SSI

Income

Earned	Unearned
Wages	SSA benefits
Net earnings from self-employment	Veterans' benefits
Payment for services in sheltered workshop	Unemployment benefits
	Interests
	Pensions
	Cash from family/friends

Requirements for Getting SSI

Resources

Included Resources	Excluded Resources
Bank Accounts (CDs, IRAs)	Home in which you live
Stocks, Bonds, 401Ks (Liquid Assets)	First car
Second Car	Burial plots for self & family
Life Insurance	Some resources set aside for burial
Property other than where you live	

Requirements for Getting SSI

Living Arrangements

Living arrangements are another factor to determine how much SSI a person can get. Benefits may vary depending on where you live:

- Living with parents
- In someone else's household (ex. grandparents, uncles, or relatives, etc.)
- In an institution – generally \$30/month maximum
- In a group care or board and care facility
- Own apartment
- Housing/Section 8, etc.

SSA Disability Programs

SSDI vs. SSI

Social Security Disability Insurance	Supplemental Security Income
Payments come from the Social Security trust funds and are based on a person's earnings.	Payments come from the general treasury fund, NOT the Social Security trust funds. SSI payments are not based on a person's earnings.
An insurance that workers earn by paying Social Security taxes on their wages.	A needs-based public assistance program that does not require a person to have work history.
Pays benefits to disabled individuals who are unable to work, regardless of their income and resources.	Pays disabled individuals who are unable to work AND have limited income and resources.
Benefits for workers and for adults disabled since childhood. Must meet insured status requirements.	Benefits for children and adults in financial need. Must have limited income and limited resources.

Medicaid

Medicaid – State health program for people with low income and limited resources.

In most states, children who get SSI qualify for Medicaid.

- If the eligible child gets \$1 or more of SSI benefits, he/she will be automatically eligible for Medicaid

In many states, Medicaid comes automatically with SSI eligibility.

- Some states will issue Medicaid before you apply for SSI.
- Some other states may require the individual to file or provide proof of his/her intent to file for SSI before they can get Medicaid.

[SSA - POMS: SI 01715.005 - Medicaid Groups - 11/23/2011](#)

Medicare

Medicare – Federal health insurance program for people 65 or older and people who have been getting disability benefits for 24 consecutive months.

When a parent(s) retires or applies for disability, there is a potential eligibility for the disabled adult child (DAC) to become eligible for cash benefits under their parents' record. ***This will not affect the parent's primary insurance amount (PIA) or monthly benefit amount (MBA).***

A disabled adult child could be potentially eligible for Medicare under the parents' record;

If the adult disabled child works, and becomes insured, he/she can also be eligible for Medicare under his/her own record. ***If so, the state can help pay for the Medicare Premiums (State-Buy-In)***

When to Apply for SSI

- Your loved one can apply as early as the day of their 18th birthday.
- Since processing an application for disability benefits can take several months, SSA advises to apply as soon as possible or as soon as a person develops a disability.
- Parents can assist with this process by getting other information we may need such as:
 - Completing Function Reports
 - Completing 3rd Party Reports
 - Obtaining school records (IEPs/School Evaluations, etc.)
 - Applying online

[EN-05-10519 - Checklist for Online Adult Disability Application_\(December 2021\) \(ssa.gov\)](#)

How to Apply for SSI

If you are under Age 18 or if you are Age 18

For children under Age 18:

- Schedule an appointment with Social Security. Call 1-800-722-1213 (TTY 1-800-325-0778) from 7 a.m. to 7 p.m., Monday through Friday or contact your local Social Security office; and
- Complete the online Child Disability Report at www.socialsecurity.gov/childdisabilityreport.

For Age 18 and older:

- The entire process can be completed online except for the **full SSI application**. SSA will call you to complete the application, or **you can mail the SSA-8000**.

How to Apply for SSI (Adult)

You may be eligible to complete your application online if you:

- are between the ages of 18 and 65;
- are a U.S. citizen;
- haven't applied for or received SSI benefits in the past; and
- are applying for Social Security Disability Insurance at the same time as your SSI claim.

SSI Application: What Happens Next?

- Your loved one's SSI application will be forwarded to the state Disability Determination Services (DDS) agency.
 - SSA transfers the medical report electronically to DDS.
- DDS is a state agency that completes the initial disability determination decision for us.
- Doctors and disability specialists in the state agency ask their doctors for information about their condition(s). They'll consider all the facts in their case.
- They'll use the medical evidence from their doctors, hospitals, clinics, or institutions where they've been treated.
- The DDS will contact medical providers to obtain medical records.
 - Ensure to provide all medical sources and school records such as IEPs/Psychological Evaluations, etc.
 - Very important to obtain such information and to establish an **onset date** at age 18 and prior age 22.

SSI Application: What Happens Next? (Cont.)

DDS may ask for additional information about how your loved one's condition(s) affect daily activities.

- It is highly recommended to provide SSA during the initial interview a medical record or letter providing with the diagnosis since **Down Syndrome is under our Presumptive category**, and the case will be flagged for an expedited decision.
- If we have the proof showing a presumptive diagnosis, the child can start receiving cash benefits while DDS continues to develop the final medical decision.

Your loved one may be eligible to receive SSI benefits right away based on a PD or PB determination if you have one or more of the following medical conditions:

- **Allegation of Down syndrome**

[Understanding SSI - Expedited Payments \(ssa.gov\)](https://www.ssa.gov/understanding-ssi-expedited-payments)

How is a Disability Determination Made?

Five-step process:

1. Is the applicant working?
2. Is the applicant's medical condition "severe"?
3. Does the applicant's impairment(s) meet or medically equal a listing?
4. Can the applicant do the work they did before?
5. Can the applicant do any other type of work?

[Blue Book](#)

Appeals Process

If you disagree with the decision...

- Initial Determination
- Reconsideration
- Administrative Law Judge
- Appeals Council
- Federal Court

SSI Application Tips

Here are a few helpful tips for an individual age 18 and older!

- For Age 18 and older, please open a [mysocialsecurity account](#)
- Schedule an appointment as soon as possible
- Please complete the adult disability report (**SSA-3368**), the SSDI (**SSA-16**), attest to the **SSA-827** online
- Complete and mail the **SSA-8000** to SSA (review the SSI application before scheduling an appointment)
- Have a letter or medical report showing the child's diagnosis

SSI Application Tips (Cont.)

Here are a few helpful tips for an individual age 18 and older!

- Complete and return any additional forms that will be mailed to you by DDS such as **Function Report or 3rd Party Report**;
- Always check the box "**Yes**" given permission to SSA to get your **financial reports**
- Do not confuse a **technical denial notice (SSDI)** issued to all adults with no work history, since this is a technical action that SSA must complete, and it is not a denial for SSI
- Report any changes immediately and **keep** records, copies and receipts of any documentation faxed or mailed to SSA

SSI Application Tips (Cont.)

Here are a few helpful tips for an individual age 18 and older!

- If you have funds set aside for the applicant (adult/child), please investigate setting aside the funds into a **Trust Fund** or **ABLE Account**
- If the Age 18 child is approved for SSI, please ensure that him/her continues all and any **Vocational Services (VR)** to receive protection from medical reviews in the future
- If your loved one wants to work (summer school, etc.), please contact an EN via www.choosework.ssa.gov

What to Report Under SSI

What Things Must You Report To Social Security?

Your loved one must report any changes in their status because it may affect their eligibility for SSI and their benefit amount. If they work and get SSI, then they must report their earnings.

When Do You Need To Report?

Report any changes that may affect their SSI as soon as possible and no later than 10 days after the end of the month in which the change occurred.

How Do I Report Wages?

Social Security offers a toll-free automated wage reporting telephone system and a mobile wage reporting application. You can also report wages through their personal [my Social Security account](#).

Resources

Recommended resources are denoted in **YELLOW**.

- [Supplemental Security Income \(SSI\) | SSA](#)
- [More Details about SSI and How It Works](#)
- [Income](#)
- [Resources](#)
- [Additional information about SSI](#)
- [I'm Ready to Request an Appointment Online](#)
- [Start the SSI Application \(if age 18-64\)](#)
- [For Children - Visit the Child SSI Page](#)
- [SSI Spotlight on Deeming Parental Income and Resources \(ssa.gov\)](#)
- [Youth Toolkit 2023 - Turning 18 \(ssa.gov\)](#)

Additional Resources

- [Supplemental Security Income \(SSI\)](#)
- [All available SSI Publications](#)
- [Understanding SSI](#)
- [What you must report to us](#)
- [Ways to Report Your Income for SSI](#)
- [Other SSI topics](#)
- [Achieving a Better Life Experience \(ABLE\)](#)
- [Nutrition Assistance Programs](#)
- [Health Information from Department of Health and Human Services](#)
- [Mortgage and Housing Assistance](#)
- [Discounted Internet Service if You Get SSI](#)
- [Welcome to Benefits.gov | Benefits.Gov](#)
- [Frequently Asked SSI Questions](#)

The Ticket to Work Program

- Social Security and Supplemental Security Income disability beneficiaries can get help with training and other services they need to go to work **at no cost to them**.
- Most disability beneficiaries are eligible to participate in the Ticket to Work program and can select an approved provider of their choice who can offer the kind of services they need.

choosework.ssa.gov

[Red Book](#)

Questions?



Upcoming Webinar



national down syndrome society
ndss.

join our
WEBINAR

with Dr. Jonathan Santoro, Pediatric Neurologist

**Updates on Down Syndrome
Regression Disorder:
What You Need to Know**

 September 19, 2023
7:00 PM ET

[Register Today!](#)

Upcoming Webinar



Understanding SSI and SSDI Work Incentives
October 4
1 p.m. ET

[Register Today!](#)

NDSS Engagement Opportunity

Don't forget to register for our 2023 Adult Summit!

national down syndrome society

ADULT
SUMMIT

CINCINNATI • 2023

November 9 - 11

Post-Webinar Survey



Thank you for attending!

Questions? Send an email to employment@ndss.org