

Understanding SSI: Saving, Working, and Keeping Benefits



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Jeremiah Foster

"Chef Jeremiah"



Opal Foster

President, Parents of Children with Down
syndrome (PODS) or Prince George's County MD

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Jeremiah Foster – Self-Advocate, Maryland

Opal Foster – President, PODS of PGC
Parents of Children with Down Syndrome of
Prince George's County, Maryland

The Big Ask

**Please cosponsor and support the SSI Savings Penalty
Elimination Act (S. 1234/H.R. 2540)
to raise SSI's asset limits to \$10,000/\$20,000 and
permanently index them to inflation.**

Why?

**Let people with disabilities WORK,
SAVE & BUILD
A FUTURE.**



My Name is Jeremiah Foster

AKA “Chef Jeremiah”

- **I want to be a chef one day**
- **I love cooking**
- **I am part of the CCC Program**
- **I love bowling, music and art**
- **I enjoy hanging out with my friends**



My Name is Jeremiah Foster

AKA “Chef Jeremiah”

I’m a part of :

- **Best Buddies**
- **Camp PALS**
- **Camp Accomplish**
- **KEEN Kids**
- **PODS of PGC**
- **DSNMC**
- **and other organizations**



**My name is Jeremiah Foster.
AKA “Chef Jeremiah”**

I receive \$667 in SSI each month.

That money helps me:

- **Contribute to my family’s mortgage**
- **Help with our food budget**
- **Build savings for my future in my MD ABLE Account**



But saving can create a problem.

- **Today, SSI's federal resource limit is only \$2,000 for an individual — a limit that has remained unchanged since 1989.**
- **I have an MD ABLE account, where I am currently setting aside \$100 each month.**

WHY IT MATTERS

I want to work.

I want to contribute.

I want to save.

I want to build my future.

**Saving for my future should not
put my SSI at risk.**



LET ME SAVE FOR MY FUTURE.

I'm not asking for a handout.

I'm asking for a chance to build a life.

My name is Jeremiah Foster.

AKA "Chef Jeremiah."



**“I want to save for my future.
I shouldn't have to choose between
saving money and keeping the
support I need.”**



Chef Jeremiah on Social Media

YouTube Channel:
@opalfoster6021

TikTok:
@opalfoster395



My Name is Opal Foster

(Proud Mom of Chef Jeremiah)

- **Presidents of PODS of Prince George's County, MD**
- **Parent-Advocate**
- **Part time Educator**
- **Freelancer Graphic Designer**
- **Involved in DSNMC and other organizations in the DS Community**



My Name is Opal Foster (Proud Mom of Chef Jeremiah)

- **Jeremiah's (PSP) Personal Supports Provider**
- **I use this income to pay our mortgage, utilities, food, travel to Jeremiah's activities and other expenses**

About me

- 25 years working on Social Security
- Worked at Social Security Administration HQ
- Mom of two sons



October 4, 2026

Background on SSI and Social Security for People with Down Syndrome

What is SSI & who qualifies?

- Supplemental Security Income (SSI) provides monthly cash assistance to disabled or older people who have little income and few assets.
- SSI helps people of **all ages**:
 - Children with disabilities (only federal income support program for kids)
 - Adults with disabilities
 - Older people (65+)
- SSI is for people with little to no income or savings

SSI is important for people with Down Syndrome

- **Income support**

- Up to \$994/month plus possible state supplement
- People with IDD, including Down Syndrome, make up more than half of SSI kids and more than a quarter of SSI adults

- **Pathway to Medicaid**

- In most states, SSI beneficiaries are automatically eligible for Medicaid.
- Some children who don't meet SSI's financial criteria can get Medicaid with a disability determination from SSA (e.g., Katie Beckett waiver)
- Medicaid supports home- and community-based services, such as personal and attendant care services.
- Medicaid also covers wheelchairs, lifts, and supportive housing services.

Social Security provides benefits to adults with Down Syndrome, too

- **Social Security Disability Insurance (SSDI)**
 - Provides disabled worker benefits for *adults* with disabilities.
 - Eligibility is based on past work: Must have had at least 10 years of work (fewer for younger applicants).
- **Children of Social Security beneficiaries can also get benefits if they are disabled adults (or minors).**
 - They can qualify if their parents are retired, deceased, or disabled.
 - Called “childhood disability benefits” or “disabled adult child” benefits.

Social Security Disability Insurance (SSDI) & SSI: Similarities

- **The same medical eligibility rules:**
Must have serious physical/mental health condition, expected to last over a year or result in death
- **The same work eligibility rules:**
Cannot earn more than \$1,690 per month
- **A similar process for applying:**
Contact SSA, fill out application, provide medical records
- **Similar (long!) wait times for a decision:** Over 6 months for initial decision, typically at least another year for an appeal
- **Some people receive both SSDI & SSI**

How SSI Affects Choices About Saving and Working

SSI has very low limits on savings

- **SSI has very low limits on savings:** up to \$2,000 for individuals or \$3,000 for couples/married parents, including savings, checking, investments, retirement, etc.
- **The savings and income of parents and spouses count, too:** For minor children and married people, SSA counts their resources against the limits. Once a child turns 18, they stop. Many families apply at age 18.

SSI has low limits on income, too

- **SSI has low limits on income:**
- The exact amount varies, but typically a person cannot earn more than about \$2,000 per month at maximum.
- most beneficiaries have little to no other income.
- **A small amount of income is exempted:**
- The first \$65 of earnings, and half after that
- The first \$20 of other income (including Social Security)

How work affects SSI benefits

- **SSI benefits are reduced if you earn more than \$65 per month.** After that, benefits are reduced by 50 cents for every dollar you earn until you lose eligibility.
- **SSDI beneficiaries face an earnings “cliff”:** If they earn more than \$1,690 per month, they lose eligibility.
- **It’s important to report any changes in earnings promptly.** Otherwise your benefit amount will be wrong, and you might lose your benefits or owe SSA money.
- **Overpayments are very common for working disability beneficiaries.** Waivers and payment plans are available if you ask.

SSI has complex rules for marriage & living, too

- In SSI, your spouse's income and resources count against you
- SSI recipients who marry each other face **penalties**: lower benefits and lower savings limits.
- Disabled people who marry can't get Social Security "childhood disability benefits" (CDB) if their parents die, become disabled, or retire.
- SSI beneficiaries who receive support with shelter (including living with parents) face complex rules, which can reduce their benefits by 1/3. Often drafting a rental agreement can help.

Tips for SSI/Social Security Beneficiaries

Tips for accessing SSA service

- **Set up a mySocialSecurity account online** and use it when possible.
Waits for phone and in-person service can be long.
- **If you call, do it early in the day and later in the week/month**, when wait times are shortest. Lines open at 8 am.
- **Book an appointment.** Call ahead to make an in-person and telephone appointment. Do it early because the wait is often a month or two.
- **Seek help from an attorney or representative** for disability appeals and navigating complex rules. Free assistance is available.

Tips for saving more on SSI

- **Open an ABLE account:**
 - Up to \$100,000 is exempt from SSI and Medicaid savings limits
 - Can be spent on: Housing, food, transportation, education, health care, employment support, assistive technology, and more
 - Tax-advantaged
 - Can be rolled over from 529 college savings accounts
- **Set up a Special Needs Trust**
 - Exempt from SSI and Medicaid savings limits
 - Spending more restrictive (e.g., cannot be used for housing and food)
 - Many variations (individual or pooled, first-party or third-party, for estate planning or during life)
 - Should arrange with a lawyer

Tips for protecting benefits

- **Set up a rental agreement.** If an SSI recipient lives with family or others rent-free or below standard costs, SSA reduces their benefits by up to 1/3. Setting up a formal agreement to pay rent can avoid these cuts. A lawyer can help.
- **Consider SNAP benefits to help pay for groceries.** If a person meets income and resource requirements, they qualify for SNAP. And if a person purchases and prepares food separately from their roommates or family members, only their own income counts. Work requirements don't apply to disability beneficiaries.

Advocacy Opportunity: Raise SSI Savings Limits

The SSI Savings Penalty Elimination Act

- **Would update savings limits for SSI:**
 - Raise them to \$10,000 (or \$20,000 for a couple)
 - Index to inflation
 - Eliminate marriage penalty in limit
- **Would make a real difference:**
 - Can save more for living expenses, emergencies, future needs
 - More people would qualify; fewer would be suspended/terminated; fewer overpayments
- **Bipartisan bill with a real chance:**
 - Led by outgoing Senator Bill Cassidy (R-LA), pushing to pass by year's end

Thank You

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