

# Self-Employment and Benefits: What Aspiring Entrepreneurs with Down Syndrome Need to Know (Part 1)

**December 9, 2025**

# NDSS Mission

*To create a world where individuals  
with Down syndrome thrive*

# NDSS Employment Program

**NDSS' Employment Program seeks to increase access to the workforce for all people with Down syndrome by focusing on:**

- Employment Policy and Advocacy
- Resource Development
- Private Sector Engagement
- Local Affiliate Support
- Raising Awareness
- Entrepreneurship and Self-Employment



# **SOCIAL SECURITY BENEFITS AND SELF-EMPLOYMENT**

By Lisa Linder

# Agenda

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& Work Incentives

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# Hello!



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## About Me:

- Navigating Adult Services
- Community Partner Work Incentive Counselor (CPWIC)
- 2x APSE Excellence in Benefits Planning Recipient
- Formerly with the CO SSA WIPA Program
  - Work Incentive Planning and Assistance
  - Served CO, NV, WY

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# My Story





# SSA Insight

- How can I keep my benefits?
- How much can I make with my benefits?

## **Social Security Benefits:**

75% Retired

25% Disabled

- About 20% - life derailed them before Full Retirement Age (FRA)
- About 5% - born with disability – some have an HCBS waiver
  - Our adult kids dropped into the 20% system

Retired workers and their dependents accounted for 78.5% of total benefits paid in 2024.

Disabled workers and their dependents accounted for 10.5% of total benefits paid in 2024.

Survivors of deceased workers accounted for 11.0% of total benefits paid in 2024.

- <https://www.ssa.gov/news/press/factsheets/basicfact-alt.pdf>



# SSA's WIPA Program

## 1. WIPA (Work Incentives Planning and Assistance)

- Free Benefits Counseling by certified experts called CWICs (Community Work Incentive Coordinator)
- CWICs – provide individualized, in-depth counseling about working, earning more money, and how working may affect your Social Security, health care, and other public benefits.

## 2. SSA Ticket-To-Work

- 866-968-7842
- <https://choosework.ssa.gov/Assets/cw/files/Library/Fact-Sheets/Fact-Sheet-Benefits-Counseling-and-the-Path-to-Employment.pdf>

# Work Incentives = Bridge

- Special rules make it possible for people with disabilities receiving Social Security (SSDI) or Supplemental Security Income (SSI) to work and still receive monthly payments and Medicare or Medicaid.
- System was designed for the those who became disabled before reaching FRA
- Basically, a bridge to getting back to self-sufficiency





# Key SSA Definitions

## Social Security's Definition of Disability:

The inability to engage in **ANY** substantial gainful activity (SGA) because of a medically determinable physical or mental impairment(s):

- That can be expected to result in death, or
- That has lasted or that can be expected to last for a continuous period of not less than 12 months

SSA Red Book, pg 7: <https://www.ssa.gov/pubs/EN-64-030.pdf>

# Key SSA Definitions

## Substantial Gainful Activity (SGA):

SGA is used to describe a level of work activity and earnings a person can have while still qualifying for benefits.

- 2025 - \$1,620/month non-blind individuals;
  - \$2,700 statutory blind individuals
- 2026 - \$1,690/month non-blind individuals;
  - \$2,830 statutory blind individuals

SSA Red Book, pg 7: <https://www.ssa.gov/pubs/EN-64-030.pdf>

SSA definition of Blindness: <https://secure.ssa.gov/poms.nsf/lnx/0426001001>



# SSA Reviews

SSA has 2 types of reviews:

1. Medical Review called Continued Disability Review (CDR)

- Social Security periodically reviews your medical impairment(s) to determine if you continue to have a disabling condition. If we determine that you are no longer [disabled or blind](#), your benefits will stop. The law requires us to perform a medical CDR at least once every three years, however, if you have a medical condition that is not expected to improve, we will still review your case, once every five to seven years.

2. Work Review SSDI – SSA-821 (& SSA-820 for SE)

- SSI – Redeterminations are conducted every 1-6 years or if something changes that can affect eligibility

<https://secure.ssa.gov/poms.NSF/lnx/0428001001>

<https://www.ssa.gov/ssi/text-cdrs-ussi.htm>

<https://www.ssa.gov/ssi/text-redets-ussi.htm>

# What benefit are you receiving?

The Social Security Administration administers TWO benefits for people with disabilities:

**SSDI**

Social Security Disability Insurance

- Title II
- All or nothing

**SSI**

Supplemental Security Income

- Title XVI
- Gradual Reduction

These programs are very different from each other!



# What is SSDI?

- Social Security Disability “Insurance”
- “Insured” by worker’s contributions to the Social Security Trust Fund – FICA tax
- Must pay a minimum in to get anything out
- Must have paid in “recently” to get SSDI
- Payment amount based on lifetime average earnings

SSA Red Book, pg 7: <https://www.ssa.gov/pubs/EN-64-030.pdf>

# Types of Title II Benefits

## **Social Security Disability Insurance (SSDI)**

### **Childhood Disability Benefits (CDB)**

- Previously called disabled adult child (DAC)
- Paid to a disabled adult child of an insured worker who has retired or become disabled, or has died.
- Individual must have had a disabling condition prior to turning age 22.

### **Disabled Widow Benefits (DWB)**



# SSDI Work Incentives

SSDI/CBD has 3 phases of work rules each with work incentives that support efforts to work:

## **1. Trial Work Period (TWP) –**

- 9 TWP months in a rolling 60 months (\$1,160/month in 2025)

## **2. Extended Period of Eligibility (EPE) –**

- 36 months after TWP (SGA - \$1,620/month in 2025)

## **3. Expedited Reinstatement (EXR) –**

- 60 months if benefits are terminated due to earnings after EPE

# SSDI Work Incentives

## Wage Employee

vs

## Self-Employment

- Impairment Related Work Expenses (IRWE)
- Subsidies & Special Conditions
- Unsuccessful Work Attempt (UWA)

- Impairment Related Work Expenses (IRWE)
- Unincurred Business Expenses
- Unpaid Help

**Medicare**



# What is SSI?

## *Supplemental Security Income*

Focus on “Supplemental....”

- Can SUPPLEMENT those that haven’t “paid in” or “paid in recently.”
- Can SUPPLEMENT a low SSDI payment.

Payment of Last Resort

- The program is paid for **by general tax revenues** -- not from the Social Security trust funds.

Meant to Pay for Basic Needs (housing, utilities, etc.)

- Can be affected by Living Situation, Spousal Income, Parental Income under age 18, Unearned Income

# SSI Income and Resource Limits

Must have limited income and resources:

- **Resource limit for single individuals less than \$2000**
- **Resource limit for couples less than \$3000**

Full payment amount based on Federal Benefit Rate:

**2025:**

- **\$967 per single individual**
- **\$1,450 per couple**

**2026:**

- **\$994 per single individual**
- **\$1,491 per couple**

# SSI Work Incentives

- Social Security uses a basic calculation to determine how the SSI payment is affected.
- General Income Exclusion
  - If no unearned income, \$20 of gross work income not counted
- Earned Income Exclusion
  - \$65 of gross work income not counted
- The “One For Two” Reduction
  - **The 1/2 earnings exclusion or the “one-for-two offset”**



# Examples

Gross Monthly Work Income	→	\$1,085
<u>-General Income Exclusion</u>	→	<u>-\$20</u>
<i>Remainder</i>	→	\$1,065
 <u>-Earned Income Exclusion</u>	→	 <u>-\$65</u>
<i>Remainder</i>	→	\$1,000
<i>Remainder / 2</i>	→	\$500

Countable Income = Amount your  
SSI Check will decrease

\$500

Old Monthly SSI Payment	→	\$967
<u>Subtract Countable Income</u>	→	<u>-\$500</u>
<b>New Monthly SSI Payment</b>	→	<b>\$467</b>
 New Monthly SSI Payment	→	 \$467
<u>PLUS Gross Work Income</u>	→	<u>+1,085</u>
<b>New Monthly Gross Income</b>	→	<b>\$1,552</b>

Total = \$1,552

# SSI Work Incentives

## Wage Employee

vs

## Self-Employment

- Impairment Related Work Expenses (IRWE) or
  - Blind Work Expenses (BWE)
- Student Earned Income Exclusion (SEIE)

- Impairment Related Work Expenses (IRWE) or
  - Blind Work Expenses (BWE)
- Student Earned Income Exclusion (SEIE)
- PESS
- PASS

**Medicaid**



# Basic Business Concepts

**Congratulations, you decided to start a self-employment business!**

Key Considerations to keep in mind:

- Business Plan - Roadmap
- Business Structure – Legal organization of a business
- Budget – Detailed plan to manage finances
- Profit & Loss – Assesses financial performance
- Self-Employment or Hobby – Business or fun?
- Accounting Methods – Reporting income & expenses
- NESE – Net Earnings from Self-Employment

Consult:

- CPA or Tax Specialist
- DVR – Division of Vocational Rehabilitation
- SSA's WIPA (Work Incentive Planning & Assistance) Program

# Net Earnings from Self-Employment

- Net Profit is what the IRS uses to determine how much you owe in self-employment taxes.
- SSA is concerned with NESE & uses the following formula:  
$$\text{Gross Income} - \text{Business expenses} = \text{Net Profit}$$
$$\times .9235 = \text{NESE}$$
- SSA deducts  $\frac{1}{2}$  of the self-employment tax that you pay to the IRS.
- <https://secure.ssa.gov/apps10/poms.nsf/lnx/0301803002>
- <https://secure.ssa.gov/apps10/poms.nsf/lnx/0500820200>

# Self-Employment or Hobby?

## Criteria for Determining Self-Employment

- Is there the intent to make a profit or generate income?
- Is the person engaging in these activities regularly (even if the work is seasonal)? Do the activities occur across years?
- Could this be considered a regular occupation?
- Is the person “holding himself out to others” as being engaged in the selling of goods or services?
- POMS: RS 01802.002 Factors Indicating the Existence of a Trade or Business
- <https://secure.ssa.gov/poms.nsf/lnx/030180200>

Self-Employment: Net Earnings from Self-Employment (NESE) – earned income  
Wage: gross wages – earned income

## Hobby per IRS

- A hobby is any activity that a person pursues because they enjoy it and with no intention of making a profit. People operate a business with the intention of making a profit. Many people engage in hobby activities that turn into a source of income. However, determining if that hobby has grown into a business can be confusing.
- To help simplify things, the IRS has established factors taxpayers must consider when determining whether their activity is a business or hobby.
- <https://www.irs.gov/newsroom/heres-how-to-tell-the-difference-between-a-hobby-and-a-business-for-tax-purposes>

Hobby: gross income – unearned income



# Two Business Types:

## Unincorporated:

- Sole Proprietorships
- Partnerships
- Limited Liability Companies (LLC)
- LLCs can assume different forms and can look like a sole proprietorship, partnership, or corporation
- Pays owner's draw, NESE, (not wages or salary) unless the LLC is structured as a corporation
- Liability protection as if a corporation without having to become incorporated

## Incorporated:

- S-Corporations
- C-Corporations
- Count as resources & SSI has limited resources
- Cannot use Property Essential to Self-Support (PESS)
  - Business structure affects whether resources can be excluded under PESS

# Sole-Proprietorship & Partnership

## Sole-Proprietorship:

- All NESE is attributed to owner
- Owner takes profit out via “owner’s draw” (no paycheck)
- Even if not all NESE drawn, ALL NESE:
  - Taxed by IRS
  - Counted by Social Security
- Owner personally liable for business

## Partnership:

- Percentage of NESE split between partners
- Owner takes profit out via “owner’s draw” (no paycheck)
- Even if not all NESE drawn, full percentage of NESE:
  - Taxed by IRS
  - Counted by Social Security
- Partners all personally liable for business

**Property Essential to Self-Support (PESS) applies!**

# Self-Employment and SSDI

SSA uses special rules for self-employed people on Title II disability benefits

- Trial Work Period (\$1,160/mo) or 80 hours month
- Work Incentives
  - Impairment Related Work Expenses (IRWE)
  - Unpaid Help
  - Unincurred Expenses
- Extended Period of Medicare Coverage (EPMC)

# Self-Employment and SSI

## Work Incentives

- Impairment Related Work Expenses (IRWE) – Non-Blind or
  - Blind Work Expenses (BWE)
- Student Earned Income Exclusion (SEIE)
  - Individuals under age 22 & regularly attending school
    - \$2,350/month & \$9,460/year in 2025
    - \$2,410/month & \$9,730/year in 2026
- PESS - Property Essential to Self-Support (PESS)
- PASS - Plan to Achieve Self-Support (PASS)

1619(b) Extended Medicaid Coverage

# Self-Employment

## PESS

- Property Essential to Self-Support (PESS)
- SSI
- SSDI – doesn't apply since resources aren't counted

## PASS

- Plan to Achieve Self-Support (PASS)
- SSI
  - Need other income
  - Possible with SSDI



# Setting up for Success

## 1. Stay Organized

- Keep copies of your records
  - Taxes
  - Don't shred; may need later

## 2. Report Earnings

- Report to SSA when you start earning money
  - State your expected monthly net profit
  - SSA-795 to document communication

## 3. Track Business Expenses & Taxes

- You have to file an income tax return if NESE is \$400+
- **DO NOT MIX YOUR MONEY**
  - Business/PASS
  - Personal
- Track Monthly Earning, Expenses & # hours
  - By April 15<sup>th</sup>, submit a copy of taxes, including Business Schedule C & SE
  - Keep every receipt (no matter how small)

# Health Insurance Options

**1. Medicare**

**2. Medicaid**

**3. Affordable Care Act (ACA) - Marketplace**

**4. Private Health Insurance Coverage**

**5. Small Business Coverage**

# Medicare

- SSDI – Medicare
  - <https://www.medicare.gov>
- Extended Period of Medicare Coverage (EMPC)
  - <https://www.ssa.gov/disabilityresearch/wi/extended.htm>
- Medicare Savings Program
  - <https://www.medicare.gov/basics/costs/help/medicare-savings-programs>

# Medicaid

- SSI – Medicaid
  - <https://www.medicaidplanningassistance.org/state-medicaid-resources/>
- Mandatory (1634 States)
  - <https://secure.ssa.gov/poms.nsf/lnx/0501715020>
  - Disabled Adult Child (DAC) Medicaid
    - <https://secure.ssa.gov/poms.nsf/lnx/0501715015>
- 1619b Protects SSI
  - <https://www.ssa.gov/disabilityresearch/wi/1619b.htm>
- Long-Term Care (LTC) & Medicaid Buy-In
  - Home & Community Based Services (HCBS) waivers
  - ABLE Accounts - <https://www.ablenrc.org>

# Other options

- Affordable Care Act (ACA) – Marketplace
  - [The Marketplace in your state | HealthCare.gov](#)
- Small Business Coverage
  - [Small Business Health Options Program \(SHOP\) | CMS](#)
- Private Health Insurance Coverage
  - *Parent/Spouse Employer Sponsored*



**THANK YOU!**