

The Social Security Administration (SSA) manages a program that can help developmentally disabled adults, including those who have PWS, receive monthly income to help pay for basic needs such as shelter and food. This program is called Supplemental Security Income (SSI). Starting at age 18, individuals with PWS may apply for the SSI benefits program and should qualify to receive SSI benefits.

A separate program, called Social Security Disability Insurance (SSDI), *is for adults who have worked in the past, paid Social Security taxes, and then become disabled.* Most individuals with PWS will *not* qualify for SSDI benefits since most individuals with PWS will *not* have a history of working 5 out of the last 10 years before becoming disabled and have not paid taxes into SSA. SSDI, SSI for a minor child, and other government benefits may be available to other family members but are not the focus of this article.

This article provides an overview of SSI benefits for the individual with PWS and is intended to help families better understand this complex federal benefits program.

What is SSI?

Supplemental Security Income (SSI) is intended to help disabled individuals pay for necessities like food and shelter. In order to be eligible, the individual must be disabled, have limited income and resources, be a United States citizen (or lawfully admitted permanent resident/lawfully admitted alien), and currently be a resident of the United States.

Does Prader-Willi syndrome count as a disability?

Yes. However, you'll need to "prove" your loved one meets eligibility criteria. Almost always, the fact that the adult with PWS must receive supervisory support or a job coach at the work site at all times to ensure their health and safety will help meet such "proof." You'll also need to prove that your loved one does not have income or assets greater than \$2,000. It is not uncommon for eligible candidates to be denied initially. Always appeal a denial.

What does SSI count as income or assets?

The Social Security Administration defines income for the SSI program as anything the individual receives in cash or in-kind (non-cash) during a calendar month that can be used to meet their basic needs for food or shelter. If countable income or assets are over the allowable limit – currently \$2,000 – then SSI benefits cannot be received until the assets are paid down to below \$2,000. This applies to only the income or assets *owned by or accessible to the disabled individual*, not the entire household.

SSI considers the following as income:

- **Earned Income** includes wages, net earnings from self-employment, and sheltered workshop payments.
- **Unearned Income** is all income that is not earned such as Social Security benefits received from parents, interest income, dividends, and cash from friends and relatives. Inheritances from relatives,
- **In-Kind Income** is food, shelter, or both that the individual gets for free or for less than its fair market value.
- **Deemed Income** is the part of the income parent(s) with whom the individual lives.

[Click here to learn more about what is considered SSI Income](#)

How can a Special Needs Trust protect SSI benefits?

Special Needs Trusts, also known as Supplemental Needs Trusts, are a legal framework designed to hold and manage assets for a person with a physical or mental disability without disrupting their eligibility for needs-based government benefits. SSI and Medi-Cal enforce strict income and asset thresholds. Placing assets into a Special Needs Trust ensures that the trust legally owns the funds, not the disabled individual, and therefore those funds do not count against the disabled individual's/beneficiary's personal resources limits.

If you haven't already, create your Special Needs Trust so that when you die – a long, long time from now – your loved one does not inherit monies or assets directly but can receive benefit of your hard-earned income through the Special Needs Trust. [Click here to learn more about Special Needs Trusts](#)

How can a CalABLE Account protect SSI benefits?

CalABLE is California's tax-advantaged savings and investment program designed for individuals with disabilities. It allows eligible individuals to have or save up to \$30,000+ per year (depending on employment status) and build up to \$100,000 in total savings without losing access to SSI and Medi-Cal benefits. If you haven't already, you may want to create a CalABLE account for your loved one so that they may receive monetary support and gifts without jeopardizing their federal and state entitlement benefits. [Click here to learn more about a CalABLE Account](#)

Inform family and friends to make their birthday or holiday gift checks payable to either the Special Needs Trust or the CalABLE account, *not in the name of your loved one*. Otherwise SSA will calculate these gifts as Unearned Income and reduce SSI benefits.

What if I don't yet have a Special Needs Trust or a CalABLE Account?

You will likely want to apply for SSI benefits when your loved one turns 18 even if you haven't yet written your Special Needs Trust or opened a CalABLE account. It will be quicker to establish a CalABLE account, so you may want to open this first until your Special Needs Trust is completed.

Is there a healthcare benefit to receiving SSI benefits?

Yes. In California, getting approved for SSI automatically qualifies for Medi-Cal, which provides free or low-cost health insurance coverage for persons with disabilities. Medi-Cal is funded equally by both the state and federal government.

How do I apply for SSI benefits for my loved one?

As soon as your loved one turns 18 years of age, you can apply for SSI benefits. Complete the application and answer all questions *as if you are the disabled individual*. This means the individual's household size is 1, only themselves; there is no income to report if the individual is not working for income, etc. [Click here to apply for SSI benefits for your loved one.](#)

What do I do when my loved one turns 18?

- Spend down assets or monies in your loved one's name or place those monies in a CalABLE Account *before* you apply for SSI benefits at or shortly after your loved one's 18th birthday.
- Create documentation that shows you will now charge your loved one their portion of the household rent (room, utilities, etc.), and you will charge them the "fair market value". Otherwise SSA will calculate the "discount" as In-Kind Income and reduce your loved one's SSI benefits.
- Create invoices or receipts documenting that you are in fact charging rent.
- When your loved one's SSI benefits are approved, you will be asked who will serve as their "Representative Payee" and manage SSI monies. Open a checking account into which SSA can deposit SSI funds each month.
- Use SSI funds to pay your loved one's rent and portion of the household expenses. Remember to pay all or most of the SSI benefits every month so that your loved one's total assets never exceed \$2,000.

More questions? Check the websites below or contact SSA

SSI Information Line: 800-772-1213

SSA Local Office Finder for in-person support <https://www.ssa.gov/locator>

Social Security Administration website <http://www.ssa.gov>

Understanding Supplemental Security Income Introduction - 2026 Edition
<https://www.ssa.gov/ssi/text-intro-ussi.htm>