



Qualifying For Social Security Disability with Prader-Willi Syndrome

Prader-Willi syndrome (PWS) is a rare and often misunderstood complex disability. People with PWS may experience an insatiable appetite, intellectual disabilities, and behavioral problems. If you have a child with PWS, he or she may be eligible for help. The Social Security Administration (SSA) offers monthly financial aid for people of all ages with severe disabilities. Many people with PWS are eligible for assistance.

Technical Approval For Disability Benefits

There are two forms of disability benefits available: Social Security Disability Insurance (<u>SSDI</u>) and Supplemental Security Income (<u>SSI</u>). If your child is a minor or has never worked before, he or she will be eligible for SSI benefits. For the most part, people with PWS will be eligible for SSI.

There are strict financial limitations for SSI applicants that you need to keep in mind before applying on behalf of a child. Adults with PWS will not be able to earn more than \$750 per month, nor can they have more than \$2,000 in available savings or assets (a home or one car do *not* count towards this asset limit, but a second car could).

Because children do not earn income, you and/or your spouses' income would be considered if you are applying on behalf of a child with PWS. The financial limitations are not as severe as they are for an adult, but if you or your partner earns a decent living, your child will not be eligible for SSI. Your specific limit will depend on how big your family is. For example, a single parent with one child who has PWS cannot earn more than \$39,000 per year in 2020, but a two-parent family of five with one child with PWS could earn up to \$57,000 per year and be eligible. The SSA has a <u>chart online</u> that outlines exactly how much your family could make per month and still be eligible for SSI benefits.

Unfortunately, income limitations are the top reason why parents of a minor child will be denied SSI benefits for PWS. The good news is once your child turns 18, your income will no longer count towards his or her SSI eligibility, even if your child still lives at home.

Medical Qualifications For People With PWS

The SSA uses its own medical guide, known colloquially as the Blue Book, when evaluating both children and adults for disability benefits. The Blue Book contains hundreds of listings for disability and the symptoms or test results your child needs to be approved.

There is currently not a listing for PWS, but that doesn't mean your child won't qualify! You can still be approved if you can prove that his or her symptoms "meet" another listing. For example, someone can qualify for SSI under the schizophrenia listing if he or she experiences "grossly disorganized behavior or catatonia" that extremely limits his or her ability to perform one of the following:

- Understanding, remembering, or applying information
- Interacting with others in a professional setting
- Concentrating or completing tasks
- "Adapting oneself," which means controlling emotions

While someone with PWS may not have a schizophrenia diagnosis, the food obsession that often comes with PWS often mirrors some of the same symptoms outlined in the schizophrenia listing of the Blue Book. By meeting a listing, your child may qualify. Other conditions outlined in the Blue Book that could be relevant for your child's eligibility, include, but are not limited to:

- Intellectual disabilities
- Behavioral problems
- Complications from obesity
- Hormonal issues

The entire Blue Book is <u>available online</u>, so you can review various listings with your child's doctor to determine where he or she may qualify.

Starting Your Application

If you are applying on behalf of a minor child, be sure to review the SSA's income limitation guideline first. If your income qualifies or if your child is 18 or older, the first step in the application process will be visiting your closest Social Security office and applying in person. SSI applications can be started online, but must be completed in person. You should review the SSA's <u>Child Disability Starter Kit</u> or <u>Adult Disability Starter Kit</u> before applying.

It should take three to five months to receive a decision on disability. If denied benefits, you can appeal the decision. More than 50% of applicants are approved during the <u>appeals process</u>. Once approved, you can focus on what's important: your child's health.

Helpful Links

SSDI:

https://www.disabilitybenefitscenter.org/social-security-disability-insurance/how-togualify SSI:

https://www.disabilitybenefitscenter.org/supplemental-security-income/how-to-qualify

SSI Income Limits For Families: https://www.ssa.gov/ssi/text-child-ussi.htm

SSA Blue Book: https://www.ssa.gov/disability/professionals/bluebook/AdultListings.htm

Social Security Hearing: <u>https://www.disabilitybenefitscenter.org/social-security-disability-application-process/hearing</u>

Child Disability Starter Kit: https://www.ssa.gov/disability/disability_starter_kits_child_eng.htm

Adult Disability Starter Kit: <u>https://www.ssa.gov/disability/disability_starter_kits_adult_eng.htm</u>