

USA

PRADER-WILLI SYNDROME ASSOCIATION
Still hungry for a cure.

Dear Parent/Guardian:

On this site, you will find documents we recommend you download and consider using in preparing an application for Supplemental Security Income (SSI). Some of these documents were prepared by PWSA (USA) following a public hearing of the Social Security Administration that focused on rare diseases including PWS.

SSI is a program of the Social Security Administration designed to provide cash assistance to people who have not worked, are unable to work, or can't work enough to meet basic living expenses. Those who receive SSI are automatically eligible for Medicaid as well.

Before they turn 18, many children with PWS are not eligible for SSI because the strict income eligibility criteria are based on the family's income. After turning 18, most people with PWS are eligible for SSI because eligibility is then based solely on his or her individual income and assets. So, even if an application was denied in the past, it is important to apply again. SSI approval provides a guaranteed monthly income for your child and automatic eligibility for Medicaid in every state.

When applying for SSI, you can complete a large part of the application by visiting www.ssa.gov. You also can call 1-800-772-1213 to ask for an appointment with a Social Security representative in your local office. The process to apply can be lengthy so it is important to start as soon as possible.

Even if you are denied initially, do not give up. According to the New York Times (12/8/07), two-thirds of initial applications are approved after a first denial. If you receive a denial, contact us immediately and we can help you with the appeal process.

Frequently Asked Questions

Should I hire a social security disability attorney?

Most parents do not hire an attorney unless they get to the third, and final, appeal stage. An attorney can be especially helpful at that stage. However, as we are not able to give legal advice, we encourage you to explore all options. In almost every part of the country you can find a social security attorney to consult with and he/she can explain to you their possible role so you can make an informed decision about retaining an attorney.

If approved for SSI benefits, does that mean my child cannot work?

Your child can work and still receive SSI benefits. The SSI program has built-in work incentives to allow people to work without losing benefits. We encourage people with SSI to explore work incentives available through the SSI program.

Our goal in this process is to provide you with as much support and encouragement as we can. In addition to our posted resource, we are available to write support letters, answer questions, and provide general guidance through the process.

The Crisis Team
PWSA (USA)
800-926-4797