

A Guidebook
to
Supplemental
Security
Income
(or SSI to those in the know)



Parents Reaching Out
Your One Stop Resource for a Stronger Family

Introduction

We know from experience that the Supplemental Security Income (SSI) system is not an easy one to get around. It is our hope that this guidebook answers some basic, but important questions such as:

Who is eligible?

How do you apply?

Is the application process complicated?

Where do you get help?

Is there an appeal process?

This booklet does NOT provide legal advice, but “just the facts” about the rights of children with disabilities. We have included a resource section that lists agencies, other print materials and websites that tell you more about SSI and the Social Security Administration.

If you have questions, please contact Parents Reaching Out at: 1-800-524-5176 or 505-247-0192 .

What is SSI?

Supplemental Security Income is, in short, extra monthly income. But not just anybody can get it. You must have the “right stuff,” which means you have to meet Social Security Administration (SSA) requirements. It is NOT an entitlement program (Check out the glossary to find out what entitlement means.). SSA also limits how much money an individual can receive. The basic SSI amount is the same, but is different from state to state. So, what you may get in New Mexico is probably different than if you lived in Hawaii. Benefits can also increase to keep up with the cost-of living.

It is not easy to qualify. The application process is not simple. But, the benefits may be just what your child and family need. Read this guidebook or talk to your caseworker, and then decide whether or not you should apply.

So, Who Can Get SSI?

Here’s the list. To qualify an individual must:

1. be a child who has a disability as defined by the Social Security Administration, AND have parents whose income and assets are within the limit set by SSA.
2. have limited income and assets (another one of those glossary words). Sorry, this means no condo in the Caribbean. SSA takes into account how many people live in the household, and if one or both parents work.
3. be a U.S. citizen or qualified alien. No, that doesn’t mean creatures from Roswell can get SSI. To find out who they are talking about, check out the glossary in the back.
4. be 65 or older, blind or disabled.

For SSI purposes, a child is someone under the age of 18, not married, and not the head of a household. Do you think your child might qualify? If you said yes, please read on.

How Can SSI Help?

The money from SSI can be used to buy services, equipment, or items you may need for your child.

SSI does not require that a child have a *permanent disability*. He or she must have a severe disability that is expected to last at least one year. If the disability lasts for more than a year, your son or daughter can qualify to receive the SSI benefits.

When an individual receives SSI, he or she can often also get Medicaid. Medicaid helps to pay doctor and hospital bills. More information about Medicaid is available at your local welfare or medical assistance office.

And finally, if your child qualifies and receives SSI, that information is confidential.

Getting Started

Take a deep breath. Just so you know, two processes (those Feds!) go on at the same time, **application and determination** (or decision, but check out the glossary for a complete definition) and application.

Let's start with the application.



The Application Process

1. Call 1-800-772-1213 to make an appointment to begin the process, which is a phone interview. If you have a hearing impairment or are hard of hearing, please call their TTY number, 1-800-325-0778. OR, you can go directly to your local Social Security Administration Office, pick up an application and make an appointment for an interview.
2. It doesn't matter which you do first. You will need to have a personal interview at the SSA office at some point in the process. If possible, it is a good idea to bring your child with you.
3. This seems like a no-brainer, but the child's parent or guardian must file an application with the local Social Security Office, not the child, even if he or she can read and write. **Your child is the applicant.**

Note: If you are a foster parent, the county welfare department or a private agency licensed by the department must file the application.

4. After the phone or in-person visit at the SSA office, you'll get an application packet in the mail. The application is called the "Questionnaire for Children Claiming SSI Benefits." Plan to set aside an hour or so to fill it out. You will also need to find and make copies of the following:
 - your child's medical records
 - his or her prescriptions
 - his or her Individualized Education Plan
 - Individualized Family Service Plan
 - proof of family members' income
 - proof of resources
 - proof of living arrangements
 - proof of guardianship or custody
 - proof of age for the child (Original Birth Certificate or a certified copy).

One of the things SSA will ask you to do is sign release forms for your providers (like doctors or therapists). This gives them permission to share any information that SSA will need to make a **disability determination**. You will read all about this process on page 6. Hurray! Something to look forward to.

TIP: Make a copy of your application before you send it off. You don't want to have to do it again if it gets lost!



FYI 1 SSA will always tell you where you need to send applications, forms and so on.

FYI 2 You will be asked to provide lots medical records, reports and evaluations and so on. If you do not have these records, SSA can obtain them at no cost to you.

5. After your application is reviewed to make sure it is done correctly and completely, the local SSA office will send it to the **Disability Determination Service (DDS)**. Then a disability adjudicator (what a job title!), better known as a claim evaluator, will collect all records they need about medical care and treatment . Next, he or she will meet with medical and mental health professionals to figure out if your child meets the SSA definition of disability (See page 7 to find out what they mean.).
6. If DDS does not get all the information it needs to make a decision, your child may need to be examined by one of their doctors or specialists. SSA pays for this evaluation. (You will read about this again in the part on determination.)

If the case is complicated, or DDS does not have all the information it needs, this step can take between 3-6 months. So, think about something fun or interesting to do while you are waiting.

7. Once the determination (decision) has been made, you will receive a letter telling you if your child has been approved or denied.
8. If your child is approved, (got the green light) SSA will let you know how much money your child will receive. If your child is turned down, the letter will explain why. It will also tell you that you have the right to appeal the decision and what to do next.

Enough about the application process.

Take a break.

*When you are ready to pick this guidebook up again, we're all set to talk about the second, fun-filled process we told you about a few pages back, **determination**.*

The Determination Process

Here's the big question they want answered: *How much money do you make?* The Social Security Administration is going to look at your income and assets if your child who has a disability is under the age of 18.

The bad news: If you are denied (that's the official word) or turned down because you make too much money, there is **NO** appeal process. But, if your income goes down for any reason, you can reapply. (We told you SSA was tough, but they know that life happens.)

There is hope though. When your child turns 18, SSA doesn't look at your income and assets to decide whether he or she is financially eligible for benefits. Just remember to apply **ONE MONTH BEFORE** your child turns 18.

What happens?

All documents (they love paper!) about your child's disability are sent to a state office called the **Disability Determination Service (DDS)** (sound familiar?). A disability evaluation specialist and a doctor review the case and decide whether your child meets the Social Security Administration definition of disability.

If there is not enough documentation (paper work) for the DDS team to make a decision, your child may need to have a special examination that Social Security will pay for. (That's only fair.) It is very important. *If you don't go to the appointment, you will be denied.* This can also happen if the results of the examination are not definite.



Definition of Disability

(by the Social Security Administration)

It's not easy or fun to read, but this is how Congress defines whether someone qualifies for SSI.

“an individual under age 18 shall be considered disabled...if that individual has a medically determinable physical or mental impairment which results in marked and severe functional limitations, and which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months...”

Here's more fun stuff (just kidding) from SSA. They have a three-step process to evaluate whether or not a child has a disability.

Step One asks whether the child can take part in a substantial gainful activity (SGA). They have decided that anyone who earns more than \$780.00 per month is taking part in a SGA, and is NOT disabled.

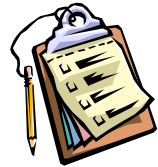
Step Two asks whether the child has a severe impairment (here's another one of those glossary words) or more than one impairment. This separates those who have only a slight abnormality or combination of abnormalities that cause no more than minimal limitations. Translated, that means a child will not qualify even if he or she has more than one impairment, and they do not limit much of what he or she can do.

Step Three asks whether the child's impairment or combination of impairments meets, or is medically equal to, or functionally equal to, a listed impairment. This means that SSA is trying to figure out how much the impairment or a combination of them fits into their definition of a medical or functional (what someone is able to do) impairment.

This process can take several months. But the folks at SSA know that some disabilities are severe enough that a child doesn't need to go through a determination. Here are some of those categories. If your child falls into one listed, the process will be shorter, but you will still need to prove that your child has the condition.

- HIV infection
- total blindness
- Down syndrome
- mental retardation
- amputation of two limbs
- total deafness (in some cases)
- cerebral palsy (in some cases)
- muscular dystrophy (in some cases)
- diabetes (with amputation of one foot)
- Amputation of the leg at the hip

SSA has come up with a long list of impairments that describe major categories of childhood disabilities. It includes physical, medical, mental and developmental impairments and limitations. That list is too long and detailed to include in this guidebook. You can get a copy by calling SSA at 1-800-772-1213 or download it from their website at www.socialsecurity.gov.



It is important to know that a newborn infant can meet disability standards. So can a very young child with failure to thrive (does not grow or gain weight when or in a way he or she is supposed to), or has other significant development delays (such as severe difficulty with speech, trouble with motor skills, or cerebral palsy).

If a child's impairment(s) does not meet, or is not medically equal to a listed impairment, the DDS team must decide if the limitation is functionally equal to a listed impairment. Confused yet? That pretty much means SSA is willing to use another way to figure out if a child can qualify for SSI.

To make this decision, the DDS team looks at how much the disability affects the child's ability to get around and do the things he or she needs to every day like dressing, bathing, feeding oneself, or walking. This functional assessment (figuring out how well and easily a child can get through a day) should include information from both medical and non medical sources—like parents, teachers, or anyone else who has regular contact with the child.

Here is some more SSA language to read carefully. A child's impairment is functionally equivalent if by itself, or in combination with impairments, causes either an extreme limitation in an area of functioning or a limitation in two areas of functioning. This means that if a child's impairment will not let him or her do one thing at all, or makes it pretty hard to do two of them the impairment may fall within the definition on their list (That's the one that is too long to put in this guidebook.).

Here is the list of SSA activity areas (functioning) or domains they use to figure out the functional equivalence we just talked about. They also figure in five age categories to help make their decision. Feel like you're in math class again?

- acquiring and using information (learning)
- attending and completing tasks (doing stuff)
- interacting and relating with others (okay being with people)
- moving about and manipulating objects (getting around and using things like the TV)
- caring for self (washing, getting dressed)
- health and physical well-being (this one is easy)

How Do They (SSA) Make a Disability Determination?

These folks want to be careful and thorough (plus they love paper), so they need all available medical records to make a decision, or disability determination. They are also interested in reading school records and reports from therapists and other caregivers. Anyone who has direct contact with a child like family members, caregivers, teachers, case workers, or child care providers should complete a report on the child's activities of daily living (ADL) such as feeding, dressing, toileting, mobility and bathing.

This ADL report should tell what your son or daughter can and cannot do. Anyone filling out an ADL report should be open, honest, and thorough. Parents or caregivers often give too few details, or try to make the child look good and include things that he or she really can't do, or do well. It's okay to want to be positive about what your child can do, ('cause just about everyone else is telling you what he or she can't do) but now is not a good time to do that. Everyone doing an ADL report should be honest about what your child can and cannot do.



The Appeal Process

So, you have been turned down. Now what? You can appeal IF the **determination letter** says that your child is not disabled or is no longer disabled. This is also called a denial letter. If you decide to appeal, you need to do it quickly. You have only 60 DAYS from the time you receive the determination letter to start the appeal process.

You still have sixty days to appeal a decision, at whatever appeal level you may be in. If you miss the deadline, you will have to begin the application process all over. You cannot appeal a denial because you make too much money or have too many assets (See page 2.).

Stage One is called reconsideration. You will need to call SSA at 1-800-772-1213 between 7 AM and 7 PM, EST, Monday - Friday, or go into your local office and ask for the “Request for Reconsideration” form. It will ask why you disagree with the decision.

After you have completed and returned this form, you will get ANOTHER one to fill out. It is called the “Reconsideration Disability Report” and is about 6 pages long. See, we told you this wouldn’t be easy. It will ask for any information you have about the evaluation or changes in your child’s condition. You need to complete these forms too, and return them to your SSA office.

When you ask a provider to prepare a report, remind him or her that it is for a **disability determination**. It is important that the provider include the details about the symptoms of the disability—not just notes about the diagnosis and treatment.

A new team (just to be fair) at DDS reviews the records and agrees or disagrees with the first determination (decision).

Just so you know, it will take 3-6 months for them to make a new determination. If you are denied again, you can go to Stage Two.

Now is when you will want legal representation (a lawyer) for your child. Call Parents Reaching Out at 505-247-0192 or 1-800-524-5176. We will try to connect you with a lawyer who will not charge a fee.

You will receive a determination letter whether you are approved or denied. If you decide to appeal, you need to do it quickly. You have only 60 DAYS from the time you receive the determination letter to start the appeal process.

Stage Two is a hearing before an administrative law judge. You will need to call SSA at 1-800-772-1213 between 7 AM and 7 PM EST, Monday-Friday, or go into your local SSA office and ask for a “Request for Hearing by an Administrative Law Judge” form. It will ask why you disagree with the ruling and whether you have any new information. Once again, you have only 60 DAYS to file a request for a hearing. If you miss the deadline, you will have to start the application process over.

After you complete and return the form to your SSA office, you will receive a “Claimant” statement. It is about 3 pages long and will ask about changes in your child’s condition (activity or health wise), and if you have any new information from your doctor (s). They will let you know your hearing date in about 6-8 months. So get out your calendar!

The judge will review the records and hear new evidence (sort of a legal word for information). At the hearing, you can tell the judge about your child’s disability and how it affects his or her life.

The judge will not make a decision at the hearing. You will get a written decision in several months. Boy, this whole process takes a long time, doesn't it?

If you are denied at the hearing level, it will be up to your lawyer to decide whether to continue with the appeal. Again, you have only 60 DAYS from the time you receive the letter to start the appeal process.

Stage Three is to the appeals council at SSA headquarters in Falls Church, Virginia. It reviews the file and decides if a mistake has been made. If the appeals council agrees that a mistake was made, the case is sent back to the hearing level. (sort of like Chutes and Ladders). A very small number of cases get a favorable decision at this level.

Final Stage is a judicial review in the federal courts (the really big guys). It's probably a good idea to have an experienced lawyer or advocate handle a long appeal. It can take several years. If the appeal decides that a child was disabled, benefits are given retroactively to the date of the original application. That means you can collect all the money that would have been sent for your child from the date of the first application.

As time goes on during the appeal process, families are often able to collect medical evidence (proof) that their child meets the disability severity standard for SSI eligibility. That means they have been able to build their case while waiting. The child passes!



Continuing Disability Review

(oh, it can go on and on) Congress wanted to be sure SSA would stay on top of things, and so it passed a requirement that SSA keep looking over the records of people getting SSI. They did this to move people off SSI who did not qualify any more (seems like a good idea). This process is called *continuing disability review* (CDR).

How Often Does It (CDR) Happen?

A CDR is scheduled for a child every three years. Depending on the case, a review could be done more often. If there is little chance for change or for things to get better, a CDR may not need to be done at all.

Seventeen Candles

A CDR **MUST** be done when a child turns 17 or 17 ½. That is when SSA decides whether he or she meets adult standards for a disability. Remember, this is also the time that a child can qualify on his or her own (no parent income to get in the way).



One step, two steps...

The CDR process is a lot like the application process. Thank goodness there is not another process to learn! The state DDS collects medical records, evaluations and other documents like school records and activity of daily living reports if they are needed. After looking everything over, the DDS makes a *disability determination*.

This time, DDS must show that improvement has taken place (things are better). SSA will apply adult disability standards to a 17 year-old's case and treat it as a new application. They do not have to prove medical improvement.

Show Me the Money

Every child under age 18 who receives SSI or Social Security benefits must have a representative payee appointed to receive benefits for them. This can be a parent, an adoptive parent, grandparent, or court appointed guardian.

No surprise, Congress and the SSA have lots of rules for the representative payee. He or she must:

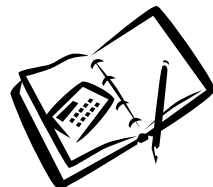
- be sure that benefits are spent for the current and future use of the child;
- complete an annual report explaining how benefits were used during the preceding year; and
- keep accurate records of how the benefit (money) was spent.

Certain large retroactive (the time before a decision was made) SSI payments that cover more than six months must be paid into a dedicated account in a financial institution (put into a special account at a bank). No other funds may be put in with these deposits. Money in a dedicated account must be used for only certain expenses for the child such as:

- medical treatment, education, or job skills training
- personal needs assistance, special equipment,
- housing modification, and therapy or rehabilitation
- any other item or service related to the child's
- disability that the SSA determines to be appropriate (says is okay)

Keeping Track

You must keep good records on how the benefit (money) is spent. If you use it for any thing other than what SSA has said is okay, they can stop your child's SSI payments until that money is put back into the dedicated (special) account. YES, they can check the dedicated account at anytime.



Other Social Security Benefits to Know About

Just when you thought we were done... Here are some other benefit programs you might want to know more about.

Social Security Survivors Benefits

SSA is also in charge of Social Security Disability Insurance (SSDI) program, or Social Security. SSDI benefits are based on a worker's work history. Most individuals get Social Security benefits after they retire or become disabled.

Children of eligible wage earners who retire, become disabled or die, can qualify for Social Security Survivor's benefits. The benefit amount is based on how long the parent worked and how much he or she earned.

Social Security Survivor benefits last until a child is 18 or 19, if he or she is a full-time high school student. It doesn't matter whether or not a child has a disability to get Social Security benefits. But, if the child has a severe disability that began before the age of 22, the parent dies, retires, or becomes severely disabled, and has an earning history, the child can still get Social Security benefits on the parent's earnings record for as long as he or she has the disability, unless the individual gets married.

At last, THE END

Whew! We hope that this guidebook gives you some idea of how SSA works and what you will need to do, besides have lots of patience, and a couple of new pens. Don't be afraid of the system! Although you may become frustrated and it may not seem like it, SSA is there to help provide support to your child

Glossary

Administrative Law Judge (ALJ): This person is an official of the Social Security Administration's Office of Hearings and Appeals and is specially qualified by education and experience to hold hearings and make independent decisions about eligibility for SSA programs based on all evidence and testimony. ALJs hold impartial (fair) hearings and make decisions to claimants who have appealed earlier determinations (decisions) by SSA.

Assets: All property such as cash, stock or land

Determination: This is a decision made by a two-person team made up of a medical or psychological consultant (a physician or psychologist) and a disability examiner. If the team finds that new or more evidence is still needed, the consultant or examiner may re-contact a medical source(s) and ask for more information.

Determination letter: This is the official letter that you will receive from SSA after reviewing your child's application for SSI. It will state if you have been approved or denied. If you are denied, it will tell why and what your rights are for appeal. You will receive one after each CDR (Continuing Disability Review).

Disability Determination Service (DDS): These are state agencies, fully funded by the federal government, and responsible for developing medical evidence and making the initial determination on whether the claimant is disabled or blind under the law.

Disability Determination: This is the determination (decision) made by the team at the DDS whether a child meets the SSA disability criteria.

Entitlement: A particular federal program that guarantees a certain level of benefits to those who meet requirements set by law, such as Social Security, farm price supports or unemployment benefits. It leaves no discretion (freedom of action) to Congress on how much money to appropriate (set aside). Some programs have permanent appropriations.

Functional Assessment: This review looks closely at how the child or adult functions in each of the six domains described on page 5.

Impairment: These are listed by major body systems in the SSA document we talked about on page 8. An impairment is a disability of some sort. SSA determines whether an impairment is severe enough to prevent an individual from doing any substantial gainful activity or, for a child to cause marked or severe functional limitations.

Qualified Alien: This is someone who falls under and has the income and resources of their immigration sponsors and sponsors' spouses available for their support for three years after the date of their lawful admission into the United States. The sponsor's income and resources are not considered if the alien becomes blind or disabled after the individual is admitted to the U.S. for permanent residence.

Resources

Social Security Administration (SSA). SSA has many publications about its benefit programs. They are free of charge. Call 1-800-772-1213 and ask for a copy. You can also go to their web site at www.socialsecurity.gov. It has all their publications and the “blue book” that lists all impairments by body systems.

Parents Reaching Out (PRO). Our organization provides information on all the healthcare systems free of charge. We will try to answer any question you have as you go through the SSI system. We will also help you find a lawyer when you are at the hearing level of the appeal process.

Contact us at 1-800-524-5176 or 505-247-0192. You can also e-mail us at info@parentsreachingout.org or visit our web site at www.parentsreachingout.org.

Healthy and Ready to Work Policy Briefs. There are five policy briefs written to help families with transition issues. We recommend “Youth with Disabilities in Transition: Health Insurance Options and Obstacles.” This has lots of information on what is out there for youth either in school or transitioning to work. You can find these briefs at www.mchbhrw.org OR you can call 1-888-433-1851 to ask them to be sent to you. We have copies available at Parents Reaching Out that we can mail to you. Give us a call!



References

A Guide to SSI and Social Security Benefits for Children and Youth in and out of Home Care. Developed for Casey Family Programs National Center for Resource Family Support, by Michael A. O'Connor, consultant.

To get a copy, write to:

Casey Family Programs National Center

1808 Eye Street NW 5th floor,
Washington, DC 2000. Phone: 1-888-295-6727

Website: www.casey.org/cnc

E-mail: cncinfo@casey.org

*Social Security. Benefits for Children with Disabilities SSA
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To a get a copy, call SSA office at 1-800-773-1213 or their website: www.socialsecurity.gov



Parents Reaching Out

Your One Stop Resource for a Stronger Family

As a statewide non-profit organization, we connect with parents, caregivers, educators and other professionals to promote healthy, positive and caring experiences for New Mexico families and children. We have served New Mexico families for over twenty five years. Our staff and Family Leadership Action Network volunteers reflect the unique diversity of the communities throughout our state.

Children do not come with instructions on how to deal with the difficult circumstances that many families experience. Parents Reaching Out believes that families' needs go beyond the bounds of formal services. *What we can offer to each other is uniquely ours.*

Our Mission

The mission of Parents Reaching Out is to enhance positive outcomes for families and children in New Mexico through informed decision making, advocacy, education, and resources. Parents Reaching Out provides the networking opportunities for families to connect with and support each other. This mission supports *all families* including those who have children with disabilities, and others who are disenfranchised. Parents Reaching Out achieves this by:

- ♦ Developing family leadership
- ♦ Connecting families to each other
- ♦ Building collaborative partnerships
- ♦ Providing families knowledge and tools to enhance their power

Our Beliefs

- ♦ Families need support where ever they are in their journey.
- ♦ All families care deeply about their children.
- ♦ Families may need tools and support to accomplish their dreams.
- ♦ All families are capable of making informed decisions that are right for their family.
- ♦ Families in the state benefit from our organization having the staff and materials that meet their diversity.
- ♦ Systems that listen carefully to the family perspective improve outcomes for our children.

Parents Reaching Out is the home of:

NM Parent Information and Resource Center (NMPIRC)

NM Parent Training and Information Center (NMPTIC)

NM Family to Family Health Information Center (NMF2FHIC)

1920 B Columbia Dr. SE, Albuquerque, NM 87106
1-505-247-0192 · 1-800-524-5176 (Toll free in NM)
www.parentsreachingout.org

