



NYS Kinship Navigator

FEDERAL BENEFITS FOR DISABLED GRANDCHILDREN

Supplemental Security Income (SSI) payments for children with disabilities

SSI makes monthly payments to people with low income and limited resources who are 65 or older, or blind or *disabled*. A child younger than age 18 can qualify if he or she meets Social Security's definition of *disability* for children, and if his or her income and resources fall within the eligibility limits.¹

To grasp the dimensions of this, at the beginning of 1995, about 892,000 of the 6.3 million SSI recipients, or 14%, were blind or disabled children.² While state public assistance financial benefits are certainly one means of assistance, federal sources may offer more benefits and should definitely not be overlooked, especially under these circumstances.

Definition of Disability

Disability is defined as the inability to perform any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to result in death or to last for a continuous period of not less than 12 months. Until early 1990, individuals under the age of 18 were considered disabled if they suffered from any medically determinable physical or mental impairments which were comparable in severity to disabling impairments for adults. However, as the result of the February 22, 1990, Supreme Court decision in *Sullivan v. Zebley*, 493 U.S. 521 (1990), the criteria for evaluating disabled children were revised to include assessment of the child's ability to engage in age-appropriate activities.³ Monthly SSI payments for disabling impairments are determined mainly by individual income and resources.⁴

¹ 20 CFR 416.202. Additionally, a qualified applicant must be a resident in the US, either be a US Citizen, be lawfully admitted for permanent residence in the territorial US, or be a child of armed forces personnel overseas (subs. (b)).

² Office of the Inspector General's Audit Report of the Social Security Administration's Low Birth Weight Baby Program - A-04-95-06015 - 7/29/97.

³ *Ibid.*

⁴ *Ibid.*

SSI rules about disability

A child must meet all of the following requirements to be considered disabled and therefore eligible for SSI:

- The child must not be working and earning more than \$980 a month in 2009. (This earnings amount changes every year.) If he or she is working and earning that much money, we will find that your child is not disabled.
- The child must have a physical or mental condition, or a combination of conditions, that results in “marked and severe functional limitations.” This means that the condition(s) must very seriously limit your child’s activities.
- The child’s condition(s) must have lasted, or be expected to last, at least 12 months; or must be expected to result in death.

If the child’s condition(s) results in “marked and severe functional limitations” for at least 12 continuous months, Social Security will find that he or she is disabled. But if it does not result in those limitations, or does not last for at least 12 months, Social Security will find that he or she is not disabled.

Representative Payees

Generally, Social Security requires a “representative payee”⁵ to accept and manage SSI payments for a child or other disabled person, and to file periodic reports, if they have determined that the qualifying individual is not able to manage or direct the management of benefit payments in his or her own interest, as is often true in cases where the child is disabled. This person could preferentially be a grandparent under relevant circumstances where the grandparent has custody and are in the best position to care for the child and there is no natural or adoptive parent or guardian with custody in the picture. If a grandparent becomes a child’s legal custodial guardian, however, this puts them at or near the top of the preference list for representative payees.⁶

Their policy is that every beneficiary has the right to manage his or her own benefits. However, some beneficiaries due to a mental or physical condition or due to their youth may be unable to do so.⁷ If the beneficiary is a legally incompetent individual, Social Security will appoint the legal guardian or some other person as a representative payee.⁸ They may pay current monthly benefits directly the disabled child while finding a suitable representative payee unless they determine that paying the child directly would cause substantial harm them,⁹ determined on a case-by-case basis.

⁵ 20 CFR §416.601(a)

⁶ 20 CFR §416.621(c)(1)

⁷ 20 CFR §416.601(b)(1)

⁸ 20 CFR §416.601(b)(2)

⁹ 20 CFR §416.611(a)

When is a representative payee necessary?

Social Security pays SSI benefits to a representative payee on behalf of a beneficiary 18 years old or older when it appears that this method of payment will be in the interest of the beneficiary. They do this if they have information that the beneficiary is¹⁰

- Legally incompetent or mentally incapable of managing benefit payments; or
- Physically incapable of managing or directing the management of his or her benefit payments; or
- Eligible for benefits solely on the basis of disability and drug addiction or alcoholism is a contributing factor material to the determination of disability.

When is a representative payee not necessary?

Generally, if a beneficiary is under age 18, Social Security will pay benefits to a representative payee. However, in certain situations, they will make direct payments to a beneficiary under age 18 who shows the ability to manage the benefits. For example, they make direct payment to a beneficiary under age 18 if the beneficiary is—¹¹

- A parent himself and files for himself or herself and/or his or her child and he or she has experience in handling his or her own finances; or
- Capable of using the benefits to provide for his or her current needs and no qualified payee is available; or
- Within 7 months of attaining age 18 and is initially filing an application for benefits.

Selection criteria

Before selecting a representative payee, Social Security will perform a background investigation, usually including a face-to-face interview.¹² In selecting a payee Social Security tries to select the person, agency, organization or institution that will best serve the interest of the beneficiary. In making their selection they consider—¹³

1. The relationship of the person to the beneficiary;
2. The amount of interest that the person shows in the beneficiary;
3. Any legal authority the person, agency, organization or institution has to act on behalf of the beneficiary;

¹⁰ 20 CFR §416.610(a)

¹¹ 20 CFR §416.610(b)

¹² 20 CFR §416.624

¹³ 20 CFR §416.620

4. Whether the potential payee has custody of the beneficiary; and
5. Whether the potential payee is in a position to know of and look after the needs of the beneficiary.

Who can be a representative payee for a minor child?

The order of preference for selecting a representative payee for a minor child is:¹⁴

1. A natural or adoptive parent who has custody of the beneficiary, *or a guardian*;
2. A natural or adoptive parent who does not have custody of the beneficiary, but is contributing toward the beneficiary's support and is demonstrating strong concern for the beneficiary's well being;
3. A natural or adoptive parent who does not have custody of the beneficiary and is not contributing toward his or her support but is demonstrating strong concern for the beneficiary's well being;
4. *A relative or stepparent who has custody of the beneficiary*;
5. A relative who does not have custody of the beneficiary but is contributing toward the beneficiary's support and is demonstrating concern for the beneficiary's well being;
6. A relative or close friend who does not have custody of the beneficiary but is demonstrating concern for the beneficiary's well being; and
7. An authorized social agency or custodial institution.

Representative payees for adult disabled persons

The order of preference for selecting a representative payee for a child *over 18* is:¹⁵

1. A legal guardian, spouse (or other relative) who has custody of the beneficiary or who demonstrates strong concern for the personal welfare of the beneficiary;
2. A friend who has custody of the beneficiary or demonstrates strong concern for the personal welfare of the beneficiary;
3. A public or nonprofit agency or institution having custody of the beneficiary;
4. A private institution operated for profit and licensed under State law, which has custody of the beneficiary; and
5. Persons other than above who are qualified to carry out the responsibilities of a payee and who are able and willing to serve as a payee for the beneficiary; e.g., members of community groups or organizations who volunteer to serve as payee for a beneficiary.

¹⁴ 20 CFR §416.621(c)

¹⁵ 20 CFR §416.621(a)

SSI rules about income and resources

A person is not eligible for SSI benefits if he or she does not apply for all other benefits for which they may be eligible, including veterans' compensation and pensions, workers' compensation payments, Social Security insurance benefits and unemployment insurance benefits, as a general rule.¹⁶

The amount of the SSI payment is different from one state to another because some states add to the SSI payment.¹⁷ Each local Social Security office give more details about its state's total SSI payment.

If there is an "essential person" in the household, additional benefits may be available for that person.¹⁸ A person such as a spouse is "essential" if they continuously lived in the same household with the qualifying individual since 1973, but were never qualified for SSI benefits in their own right.¹⁹ However, any additional income from an essential person may be used in decreasing benefits to the qualifying individual.²⁰

Social Security considers a child's income and resources in determining benefits. It also considers the income and resources of family members living in the child's household, under its "deeming rules."²¹ These rules apply if a child lives at home.²² They also apply for temporary absences from home²³, such as if he or she is away but intends to and does return in the same month or the month immediately following the absence,²⁴ in a medical treatment facility,²⁵ or at school but returns home from time to time and is subject to a parents' control,²⁶ or on active duty military assistance.²⁷ But the earned income of a student under 22 will not be considered.²⁸

If a beneficiary is receiving free food or shelter or other care by living in another person's household,²⁹ Social Security may reduce benefit up to one-third of the total

¹⁶ 20 CFR §416.210(a)

¹⁷ 20 CFR §416.503

¹⁸ 20 CFR §416.220

¹⁹ 20 CFR §§416.222(a), 416.223(a).

²⁰ 20 CFR §416.223(c)

²¹ 20 CFR §§416.410-416.414, 416.428, 416.430, 416.1160, 416.1168

²² 20 CFR §§416.1160, 416.1161

²³ 20 CFR §416.1149

²⁴ 20 CFR §416.1167(a)(1)

²⁵ 20 CFR §416.1167(a)(2)

²⁶ 20 CFR §416.1167(b)

²⁷ 20 CFR §416.1167(c)

²⁸ 20 CFR §416.1112(c)(3)

²⁹ 20 CFR §416.1132(b)

benefit for that,³⁰ but no more than a third.³¹ The one-third rule is either applied or not applied; there is no in-between.³² If the “one-third rule” is not applied, Social Security may still deduct according to a “presumed value rule,” a presumed maximum value that may be rebuttable by the applicant’s documenting of a lesser value.³³

If a child’s income and resources, or the income and resources of family members living in the child’s household, are more than the amount allowed, Social Security will deny the child’s application for SSI payments.³⁴ However, your home, your household goods, a car, essential business or trade property, life insurance, disaster relief assistance, housing assistance, tax refunds, gifts to children with life threatening conditions, and childrens’ college savings and other categories are all excluded from any resource calculations.³⁵ Other resources may have to be agreed to be disposed of within certain time limits in order to qualify for benefits.³⁶

SSI payments are limited to \$30 when a child is in a medical facility where health insurance pays for his or her care.

Applying for SSI

In applying for child’s SSI benefits, a grandparent must be prepared to give detailed information about the child’s medical condition and how it affects his or her ability to function on a daily basis. Social Security works with state agencies in reaching these determinations.³⁷ They will need permission for the doctors, teachers, therapists and other professionals who have information about the child’s condition to send the information to us. School records are also useful this way. All of the information is sent to the Disability Determination Services in each state. Doctors and other trained staff in that state agency will review the information, and will request the child’s medical and school records, and any other information needed to decide if the child is disabled.

If the state agency cannot make a disability decision using only the medical information, school records and other facts they have, they may ask to take the child for a medical examination or test, paid for by Social Security.

Social Security can make immediate SSI medical payments in some cases

It can take three to five months for the state agency to decide if a child is disabled. However, for *some particular medical conditions*, Social Security can make SSI

³⁰ “In Kind Support or Maintenance”, 20 CFR §§416.1130(a), 416.1131(b)

³¹ 20 CFR §416.1131(c)

³² 20 CFR §416.1131(b)

³³ 20 CFR §§416.1140, 416.1141

³⁴ 20 CFR §§416.1201-416.1204, 416.1205, 416.1208, 416.1104, 416.1110

³⁵ 20 CFR §§416.1210-416.1261.

³⁶ 20 CFR §416.1240

³⁷ 20 CFR §§416.1003-416.1033.

emergency “presumptive payments” right away and for up to six months while the state agency decides if the child is disabled.³⁸

Following are just some conditions that may qualify for presumptive disability: leg amputation at hip; HIV infection; total blindness; total deafness; stroke; cerebral palsy; ALS; down syndrome; Parkinson’s syndrome, muscular dystrophy; severe mental retardation (child age 7 or older); and low birth weight.³⁹

If the child has one of the qualifying conditions, he or she will get SSI payments right away. Other types of emergency, such as a financial emergency, to meet an immediate threat to health or safety, such as the lack of food, clothing, shelter, or medical care can also be paid right away.⁴⁰ However, the state agency assigned to make the disability determination on behalf of Social Security may finally decide that a child’s disability is not severe enough for SSI. If that happens, the interim SSI payments that the child got will not need to be paid back.

SSI disability reviews after approval

Once a child starts receiving SSI, the law requires that Social Security review the child’s medical condition from time to time to verify that he or she is still disabled. This review must be done at least every three years for children younger than age 18 whose conditions are expected to improve; and by age 1 for babies who are getting SSI payments because of their low birth weight, unless we determine their medical condition is not expected to improve by their first birthday and we schedule the review for a later date.⁴¹

Social Security will perform a disability review even if a child’s condition is not expected to improve. When they do a review, they will need to see evidence that the child is and has been receiving treatment that is considered medically necessary for your child’s medical condition.

Age 18 and over

For disability purposes in the SSI program, a child becomes an adult at age 18, requiring different medical and non-medical rules when deciding if an adult can get SSI disability payments. For example, Social Security does not count the income and resources of family members when deciding whether an adult meets the financial limits for SSI. They count only the adult’s income and resources. They also use the disability rules for adults when deciding whether an adult is disabled.

³⁸ 20 CFR §§416.931, 416.932

³⁹ 20 CFR §§416.933, 416.934, 416.990(b)(11), (under 4 pounds 6½ ounces)²

⁴⁰ 20 CFR §416.520,

⁴¹ 20 CFR §416.990(b)(11)

- If a child is already receiving SSI payments, Social Security must review the child's medical condition when he or she turns age 18. They usually do this review during the one-year period that begins on the child's 18th birthday. We will use the adult disability rules to decide whether your 18-year-old is disabled.
- If the child was not eligible for SSI before his or her 18th birthday because the parents, grandparents or other caregivers had too much income or resources, he or she may become eligible for SSI at age 18.

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