



A GUIDE TO SSI AND SOCIAL SECURITY BENEFITS FOR CHILDREN AND YOUTH IN OUT-OF-HOME CARE

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A Guide to SSI and Social Security Benefits for Children and Youth in Out-of-Home Care

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Introduction

This guide to Supplemental Security Income (SSI) and Social Security programs is intended to provide basic information about the rights of children or youth in out-of-home care to receive benefits under these two programs. Older youth in care, resource families—foster parents, adoptive parents, and kinship caregivers*—biological parents, and social workers may use this information. In addition, this Guide reviews the basic application requirements, eligibility rules, and appeal procedures for SSI and Social Security and offers practical tips for effective advocacy. The Guide also describes the unique roles and responsibilities of state and county child welfare departments regarding the management of SSI and Social Security benefits. Finally, special issues of interest to foster parents, adoptive parents, resource family relatives, and older youth in care are reviewed.

Children and youth who are or have been in out-of-home care face additional challenges: the incidence of severe disabilities is several times higher in this population compared to other children and youth. Children and youth who are or have been in out-of-home care are two to three times more likely than other students to have disabilities that affect their ability to learn (Calvin, et al., 2000), and children in care use Medicaid services at a rate two to four times higher than other children (Rosengach, 2001). Children and youth in care are three to six times more likely to have emotional, behavioral, or developmental problems (CWLA, 1998). It has been estimated that more than 10% of children and youth in care are eligible for SSI but do not receive it. The number of children and youth in care who are enrolled in the SSI program range from 4% in the lowest state to 20% or more in the highest ranking states (Benton & Associates, 1998).

This Guide is not intended to give specific legal advice on individual cases but rather is intended to provide general information about the rights of children with disabilities. It is important to remember that this guide is prepared for a national audience. Although the SSI and Social Security programs are national, many states have additional laws and regulations that may supplement the amount of SSI benefits or affect how benefits are managed for disabled children and youth in care. Caregivers should seek assistance in their respective communities from other foster or adoptive parents, advocacy organizations, child welfare agencies, disability groups, parent training information centers, and health professionals. The resource section of this Guide offers some suggestions for locating additional information.

SSI and Social Security programs

SSI. The SSI program provides cash assistance to persons who are elderly, blind, or disabled, and who have limited income and resources. SSI eligibility rules also require that a person be a U.S. citizen or a “qualified alien.” The SSI resource limit is \$2,000 for an individual. Children who meet the disability, income, and resource standards are eligible for monthly cash benefits up to \$545 per month during 2002. The maximum monthly benefit is adjusted annually based on inflation. In addition, some states supplement the SSI payment. SSI is administered by the federal government, through the Social Security Administration (SSA).

Social Security Survivors Benefits. The Old Age, Survivors, and Disability Insurance (OASDI) program, generally referred to as “Social Security,” is also administered by the SSA. Social Security benefits are based on a worker’s employment history. Most beneficiaries receive Social Security benefits after retirement or after becoming disabled. Children of eligible wage earners who retire, become disabled, or die can qualify for Social Security Survivor’s benefits. A child’s Social Security Survivor’s

* Kinship caregivers are individuals who have related children, such as a grandchild or a nephew, placed in their home by a child welfare agency. These caregivers may be licensed and receive the regular board payment, or they may be unlicensed and receive a payment that is less than the regular cost of care reimbursement. In some cases, kinship caregivers have no involvement with a child welfare agency and may receive child-only cash assistance (usually TANF) from the state or county welfare agency.

benefit is based on the length of employment and wages of the parent and can exceed \$800 per month. However, because most children and youth in care come from lower income families, Social Security Survivor's benefits are typically much lower. A child may qualify for Social Security benefits if a parent is retired, disabled, or deceased. The fact that a child is in foster care and even that parental rights have been terminated will not affect a child's eligibility for Social Security Survivor's benefits based on a biological parent's wage record.

Social Security Survivor's benefits continue until a child reaches age 18 or until age 19 if the child is a full-time student in high school. Disability is not a relevant factor for a child to receive Social Security Survivor's benefits. However, if a child has a severe disability with an onset prior to age 22 and the child's parent dies, retires, or becomes severely disabled, and the parent has sufficient earnings history, then the child continues to receive Social Security benefits on the parent's earnings record for as long as the disability continues.

A child with a severe disability may be eligible to receive both SSI and Social Security. If the Social Security benefit for a disabled child is less than \$545, the SSI payment will bring the total monthly benefit up to \$565, but no higher (SSI disregards the first \$20 in unearned income, for example, unearned income from Social Security benefits).

Why SSI is important for children and youth in care

Some resource families and even social workers avoid SSI because of concerns that a child may be stigmatized or labeled as "permanently disabled." Avoidance of SSI based on this concern is not warranted for several reasons. A child's status as an SSI beneficiary is confidential and should not have a negative impact on the child's relationships with peers, school teachers, or others in the community. Moreover, the SSI program does not require that a child be permanently disabled, rather that a child have a severe disability that is expected to last at least one year. Indeed, many children who have been found eligible for SSI later grow out of the disability with good care and medical treatment. Those children whose disability continues can qualify for special services and supports that will improve their lives and make them far more productive.

The box on page five outlines several specific benefits that occur when a child or youth in care applies for and begins receiving SSI benefits.

BENEFITS OF RECEIVING SSI

- Diagnostic evaluations completed during the application process will improve the likelihood that the child or youth will receive timely and appropriate treatment.
- SSI (and Social Security) benefits can increase the amount of funds available to meet a child's/youth's needs, although children with a foster care maintenance payment or adoption assistance subsidy above the benefit payment will see no immediate, practical effect in receiving SSI or Social Security benefits.
- SSI benefits follow a child or youth who is returned home to a lower income biological family.
- SSI benefits can be a critical source of cash assistance and Medicaid for a youth who ages out of care and cannot be self-supporting because of a severe disability.
- SSI benefits ensure eligibility for a federal adoption assistance subsidy if a child or youth cannot be returned to biological parents.

Representative Payees

Every child under age 18 who receives SSI or Social Security benefits must have a representative payee appointed to receive benefits on behalf of the child. Generally the representative payee is the biological parent, adoptive parent, or court-appointed guardian. Because most children and youth in foster care have guardianship placed in a state or county child welfare department, that agency usually requests the SSA to be appointed representative payee. Generally, resource families who are assisted guardians (also known as subsidized guardians) of a child or youth in care can expect to be appointed representative payee.

Congress and the SSA have established extensive rules governing responsibilities of representative payees. They must ensure that benefits are spent for the current and future use of the child, and if not used for current needs, the benefits should be saved and invested. Representative payees are required to complete an annual report explaining how benefits were used during the preceding year, and they must keep records so that an accurate accounting of benefits can be provided.

Certain large retroactive SSI payments covering more than six months of benefits must be paid into a “dedicated account” in a financial institution. No other funds may be combined with benefits deposited in a dedicated account. Money in a dedicated account must be used for only certain allowable expenses for the benefit of the child:

- Medical treatment and 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.

Representative payees must keep a log of all withdrawals from a dedicated account and also keep receipts for all expenditures for a period of at least two years.

Resource families should ask the child’s caseworker about whether the child is receiving SSI or Social Security and whether the child has a dedicated account. If the child or youth does have a dedicated account, the family should obtain information about the current balance, plans for expenditures, and procedures for proposing expenditures to meet the needs of the child that are not covered by current maintenance payments.

SSI disability standard

Congress established the following eligibility standard for SSI: “an individual under the age of 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...” SSA regulations describe a three-step process for evaluating a child’s disability.

Step One asks whether the child is engaged in “substantial gainful activity” (SGA). Anyone earning more than \$700 per month is engaged in “substantial gainful activity” and is presumed not to be disabled.

Step Two asks whether the child has a severe impairment or combination of impairments. This is a pre-screening process to separate applicants who have only a slight abnormality or combination of abnormalities that causes no more than minimal functional limitations.

Step Three asks whether the child’s impairment or combination of impairments meet or medically equal or functionally equal a listed impairment.

The SSA has published a “listing of impairments” that summarizes major categories of childhood disabilities and describes the degree of severity necessary to meet the SSI disability standard (see Resource Section for citation). The listing includes physical, medical, mental, and developmental impairments and limitations. It is important to note that even a newborn infant can meet the disability standard. For example, infants weighing fewer than 2 kg at birth (about 2.8 lbs.) are deemed to meet the disability standard. Also, very young children with failure to thrive or other significant developmental delays may also be found to meet the disability standard. There are many, many other examples of childhood impairments that are too numerous to be mentioned in this guide.

If a child’s impairment(s) does not meet or medically equal a listed impairment, the disability decision maker must determine if the limitation caused by the impairment functionally equals a listed impairment. This assessment requires review of the impact of the impairment(s) on the day-to-day functioning of a child, and then a determination is made whether the impaired functioning is equal in severity to a listed impairment. A functional assessment should include evidence from both medical and non-medical sources, including parents, teachers, and others who have contact with the child.

The SSA assesses children based on their ability to function and/or develop in up to six domains of activity using five age categories.

The first domain is acquiring and using information, which includes: learning through sight, sound, taste, touch, and smell; understanding names; acquiring and using concepts, symbols, and language to learn to read, write, do arithmetic, understand and use new information; applying information learned in thinking, perceiving, remembering; reasoning, making logical choices, solving problems; using language to think and talk about the world, e.g., following directions, asking questions, giving explanations.

The second domain is attending and completing tasks, which includes: regulating levels of alertness; initiating and maintaining concentration; filtering out distraction and remaining focused on activity or task at consistent level of performance; changing focus when needed; thinking and reflecting before starting or stopping activity, predicting possible outcomes of actions; determining time needed to finish task at appropriate pace, within appropriate timeframe.

The third domain is interacting and relating with others, which includes: initiating and responding to exchanges with other people, for practical or social purposes; using facial expressions, gestures, actions, words to interact with individuals or groups; forming and sustaining intimate relationships with family, friends; responding to emotional and behavioral cues; speaking intelligibly and fluently; participating in verbal turn-taking and nonverbal exchanges; considering others' feelings and points of view; following social rules for interaction and conversation; responding to others appropriately and meaningfully, including peers, family, persons in authority.

The fourth domain is moving about and manipulating objects, which includes: use of gross and fine motor skills in: Moving one’s body from one place to another, e.g., rising or pulling oneself from a sitting to a standing position, balancing weight on legs and feet, crawling, walking. Moving and manipulating things, e.g., engaging upper and lower body to push, pull, lift, or carry objects; coordination, dexterity, pace, physical ability to persist at task; sense of body in space; integration of sensory input and motor output; capacity to plan, remember, and execute controlled motor movements.

The fifth domain is caring for self, which includes: maintaining a healthy emotional and physical state; developing independence and competence in meeting physical and emotional wants and needs in appropriate ways; regulating oneself by responding to changes in emotions and daily demands of one’s environment; helping oneself and cooperating with others in taking care of personal needs, health, and safety; becoming increasingly independent in making and following own decisions; relying on own abilities and skills, and displaying consistent judgment about consequences of caring for oneself; recognizing when one is ill, following recommended treatment; taking medication as prescribed; following safety rules; responding to circumstances in safe, appropriate ways, making decisions that do not endanger oneself, knowing when to ask for help.

The sixth domain is health and physical well-being, which includes: cumulative physical effects of physical or mental impairments and of their associated treatments or therapies on a child's functioning (not already considered under Moving About and Manipulating Objects), e.g., generalized weakness, dizziness, shortness of breath, reduced stamina, fatigue, psychomotor retardation, allergic reactions, recurrent infection, poor growth, bladder or bowel incontinence, local or generalized pain; physical effects of medications (e.g., for asthma, depression); physical effects of chronic illness during periods of exacerbation, including how often and how long these periods occur; medical fragility and need for intensive medical care to maintain level of health and physical well being.

A child's impairment is functionally equivalent if the impairment or combination of impairments causes either an extreme limitation in one area of development or functioning or a marked limitation in two areas of development or functioning.

All available medical records should be reviewed in making a disability determination. In addition, school records and reports from therapists and other caregivers should be considered. Resource families, as well as others with direct contact with the child (teachers, caseworkers, child care providers), should be asked to complete a report on the child's activities of daily living (ADL). These ADL reports provide documentation concerning the functional limitations experienced by the child. Anyone filling out an ADL report should be candid and thorough. Too often caregivers provide fewer details in the mistaken belief that a full and candid report may reflect poorly on their parenting or resource family skills.

SSI application procedures

Generally, a child's parent or guardian must file the SSI application with the local Social Security Office. Accordingly, a state or county child welfare department or a private agency licensed by the department must file an application for a child in foster care. In addition to the application form, a separate medical history form should be completed. This form should include all medical or mental health providers that have evaluated or treated the child. If the child receives special education services at school or if the child has a 504 plan,* that information should be noted as well. The parent or guardian will be asked to sign releases for all providers, authorizing them to share information needed for the disability determination.

After initial processing of the application forms, the local Social Security office transfers the file to a state disability determination service (DDS), which is operated in a state agency under contract with the SSA. A disability adjudicator or evaluator will collect records concerning medical care and treatment. If a functional assessment is required, ADL forms will be sent out to appropriate caregivers. Foster parents and other caregivers should provide detailed, candid information regarding the actual level of functioning of the child. Other caregivers, such as child care providers, teachers, tutors, and others with direct contact, should also be asked to fill out an ADL form.

Medical and mental health professionals assist the disability adjudicator in evaluating the child's disability. If the record is incomplete, the DDS may schedule a consultative exam by one of its doctors or specialists. Depending on the completeness and complexity of the child's record, the disability determination may be made within two to three months; in other cases more than six months may pass before a final decision is made.

Continuing disability reviews

Not all disabilities are permanent. Some individuals can, over time, recover from a disabling condition; in other cases, a severe impairment can improve to the point where the impairment exists but no longer in a severe form. In recognition of these factors, Congress requires that the SSA conduct "continuing disability reviews" (CDR's) to determine whether an SSI recipient still meets the disability standard. For children, a CDR is generally scheduled every three years. In some cases, the CDR is

scheduled more often, and in other cases in which ¹likelihood of improvement is small or nil, the CDR may be waived. A CDR is also scheduled when a child is age 17 or 17 ½, and at that time the child is assessed for disability under the adult standard.

The CDR process is similar to the initial application. The state DDS collects medical records and evaluations and collects additional documents, such as school records and activity of daily living reports if relevant. The DDS then makes a disability determination. However, the burden is on the DDS to show that an improvement has occurred (note that for CDRs at age 17 ½, the SSA will apply the adult disability standard as though it's a new application. The SSA does not have the burden to show medical improvement in these cases).

Appeals

If an initial determination is made that a child is not disabled or is no longer disabled, that decision can be appealed. The decision whether to initiate the appeal generally rests with the child's legal guardian. The first step in the appeal process is called reconsideration. At that stage, a new team at the DDS reviews the record and makes a decision to either affirm or change the initial determination. Reconsideration offers an opportunity to supplement the medical records with any new information. Also, it may be useful to ask doctors, psychologists and other professional providers to update any written reports that have been provided. When asking a provider to prepare a report, remind the individual that the report is for a disability determination. Too often medical professionals prepare a report that notes diagnosis and treatment but lacks detail regarding the degree of severity of symptoms experienced by the child.

A second stage is a hearing before an administrative law judge, who reviews the records and hears new evidence. A third stage is an appeals council at SSA headquarters in Baltimore, MD, which reviews the file and determines whether an error has been made. The final stage in the appeal process is judicial review in the federal courts.

Generally, extended appeals should be handled by experienced advocates. The time required to complete an appeal can be several years; for those appeals that determine a child was disabled, benefits are awarded retroactively to the date of the original application. For many children who prevail in their appeals, the accumulation of medical evidence during the appeal helps the children meet the disability severity standard for SSI eligibility.

Tips for:

Foster parents

- If a child in your care is receiving SSI, ask your caseworker about dedicated account, trust fund account, and disposition of SSI benefits.
- If your foster child is not receiving SSI but has a significant disability, ask your caseworker about SSI application procedures. Also ask whether SSI advocacy help is available.
- If you learn that a biological parent of a child in your care has died, become disabled, or has retired, ask the caseworker to apply for Social Security Survivor's benefits for the foster child.
- If a young person in your care is in or about to start an Independent Living Program, see tips for older youth below.

* A 504 plan is developed under Section 504 of the Rehabilitation Act of 1973 and describes modifications and adaptations necessary for a student with a disability to participate in the school's programs.

Adoptive parents

- Income and assets of the adoptive family are taken into account in assessing the eligibility for SSI of a child who has been adopted.
- When a child who has been adopted reaches age 18, the parents' income and assets no longer affect eligibility; if the individual has a significant disability, he or she should apply for SSI.
- Generally, there is no "double dipping" with regard to SSI and the adoption assistance subsidy. Adoptive parents are required to report the adoption assistance subsidy to the SSA, and the SSI benefits will be reduced by the amount of the subsidy.
- A child who qualified for Social Security Survivor's benefits (based on a biological parent's earnings) prior to termination of parental rights continues to receive those benefits even after the adoption is finalized. However, the adoption assistance subsidy will generally be reduced by the amount of the Social Security benefit.

Kinship caregivers

- If you care for a child and legal guardianship is with a child welfare department, then the rules for foster parents apply.
- If you care for a child and also are the child's guardian, then you should be the representative payee for the child's SSI and/or Social Security benefits.
- Generally, income and assets of a kinship caregiver do not affect eligibility for SSI; however, in some cases, relatives may be deemed to contribute a portion of support, resulting in a partial reduction of SSI benefits.

Older youth

- If you receive SSI, you should expect a Continuing Disability Review (CDR) at around age 17-17 ½; this review will use the "adult" standard of disability. It will be important to get all medical evaluations and reports that are available to the Disability Adjudicator.
- If you receive Social Security Survivors benefits, they will cease at age 18, or at age 19 if you are still in high school. If you have a serious disability, apply for Social Security Survivors benefits as an "adult disabled child;" if you are found disabled, Social Security benefits will continue.
- If you are eligible for SSI and/or Social Security benefits, at age 18 you should become payee for benefits. However, if there is evidence that you may not manage your funds effectively, then a representative payee may be appointed. You can contest this decision, and you may appeal it if you are dissatisfied with the result.
- When you reach age 18, any funds in a dedicated account or trust account that consists of SSI or Social Security benefits should be turned over to you, unless a new representative payee is appointed.
- If you receive SSI and you receive other income that is currently reducing your SSI benefits or you have assets from a dedicated account or savings that exceed the \$2,000 asset limit, you should ask the Social Security Claims Representative about ways to create a Plan to Achieve Self Support (PASS). Upon approval by the Claims

Representative, a PASS allocates certain savings or other assets to a specific goal, which may be for vocational school or setting up a business. The assets listed in a PASS do not affect SSI eligibility or benefits.

Resources

Social Security Administration. The SSA web site has much useful information: <http://www.ssa.gov>. In addition, the SSA home page on SSI is also an important resource: <http://www.ssa.gov/notices/supplemental-security-income/>.

The SSA also offers the complete listing of impairments on its web site at: http://www.ssa.gov/OP_Home/cfr20/404/404-ap09.htm.

Advocacy Services. Advocacy services represent another critical resource for resource families as well as children and youth in care. Some states have created effective advocacy services for disabled children either through specialized staff or through contracts with private advocacy organizations. The child's caseworker or supervisor should have information about advocacy services. State or regional foster parent and adoptive parent groups can also offer valuable referral information (See child welfare contact below).

Local legal service programs and protection and advocacy programs can provide useful consultation and training resources. In addition, national disability organizations can be helpful in identifying diagnostic and treatment resources that may be critical for both an SSI application and for effective care of a child. The resource section of the companion Guide to Special Education Advocacy published on Casey Family Programs National Center for Resource Family Support's web site, at http://www.casey.org/cnc/support_retention/special_education_advocacy.htm should be checked for links to national advocacy and national disability groups.

Child Welfare Community. National Foster Parent Association (NFPA), <http://www.nfpainc.org>, is a national organization that brings together foster parents, agency representatives and community people who wish to work together to improve the foster care system and enhance the lives of all children and families. The NFPA web site offers extensive information about training events, resources, state and local foster parent associations, and many other contacts in the child welfare community.

North American Council on Adoptable Children (NACAC), <http://www.nacac.org/>, is a non-profit organization committed to meeting the needs of tens of thousands of children who cannot be reunited with their birth parents and are waiting for families to adopt them. Operating throughout the United States and Canada, NACAC offers education, parent support, and research and advocacy to promote changes in law and practice that better serve the interests of children. The NACAC web site provides information about publications, annual conference, and many links to sites concerning adoption, child welfare programs, special needs and disabilities, and advocacy.

Casey Family Programs National Center for Resource Family Support (CNC), <http://www.casey.org/cnc>, is part of Casey Family Programs, a national operating foundation that serves children, youth and families. The CNC's mission is to support the development and dissemination of information on best practices for the retention, support and recruitment of resource families.

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