Supplemental Security Income (SSI) for Children and Youth With Disabilities
Council on Children With Disabilities
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Policy Statement—Supplemental Security Income (SSI) for Children and Youth With Disabilities

abstract

The Supplemental Security Income (SSI) program remains an important source of financial support for low-income families of children with special health care needs and disabling conditions. In most states, SSI eligibility also qualifies children for the state Medicaid program, providing access to health care services. The Social Security Administration (SSA), which administers the SSI program, considers a child disabled under SSI if there is a medically determinable physical or mental impairment or combination of impairments that results in marked and severe functional limitations. The impairment(s) must be expected to result in death or have lasted or be expected to last for a continuous period of at least 12 months. The income and assets of families of children with disabilities are also considered when determining financial eligibility. When an individual with a disability becomes an adult at 18 years of age, the SSA considers only the individual’s income and assets. The SSA considers an adult to be disabled if there is a medically determinable impairment (or combination of impairments) that prevents substantial gainful activity for at least 12 continuous months. SSI benefits are important for youth with chronic conditions who are transitioning to adulthood. The purpose of this statement is to provide updated information about the SSI medical and financial eligibility criteria and the disability-determination process. This statement also discusses how pediatricians can help children and youth when they apply for SSI benefits. Pediatrics 2009;124:1702–1708

THE SUPPLEMENTAL SECURITY INCOME PROGRAM FOR CHILDREN

The Supplemental Security Income (SSI) program was established by the Social Security Amendments of 1972 (Pub L No. 92-603) and replaced several federal programs including Old-Age Assistance, Aid to the Blind, Aid to the Permanently and Totally Disabled, and other grants to the states. The SSI program makes monthly payments to people who have low income and limited resources (assets) and are 65 years or older, blind, or disabled. It was the first government program to provide cash payments for the benefit of children with disabilities. The first payments were made under SSI in January 1974. The number of child recipients of SSI has grown substantially since it was first introduced. As of December 2005, more than 1 million children younger than 18 years were eligible for SSI benefits.1 The SSI program continues to be administered by the Social Security Administration (SSA).
The SSI program remains an important program of the federal government for children and adolescents with disabilities/special needs. SSI is a nationwide program that:

- provides monthly cash payments based on family income and resources;
- qualifies a child for Medicaid health care benefits in most states; and
- ensures referral of children who receive SSI to state Title V children with special health care needs programs.

**SSI VERSUS SOCIAL SECURITY DISABILITY INSURANCE**

SSI is often confused with Social Security Disability Insurance (SSDI). The SSI program makes payments to children with disabilities/special needs who are younger than 18 years, and eligibility is based on family/individual income and assets. The definition of disability for children under SSI is different from the definition of disability for adults. SSI payments are funded through general revenues of the federal government but can be supplemented by the states. SSDI benefits are funded by Social Security (Federal Insurance Contributions Act [FICA]) taxes, which workers and self-employed people pay into the Social Security trust fund. Any child, disabled or not, can receive SSDI benefits if a parent is disabled or retired and is entitled to Social Security benefits, or if a parent dies, having worked long enough under Social Security. The child must be younger than 18 years (or 18–19 years of age and still in high school) and unmarried. For SSDI, there are no income or asset limits; however, SSDI is based on employment history and payment of Social Security taxes. An adult who was disabled before 22 years of age may be eligible for child’s benefits if a parent is deceased or receiving retirement or disability benefits. The SSA considers this a “child’s” benefit, because it is paid on a parent’s Social Security earnings record. The disability decision is made by using the disability rules for adults. An individual who is entitled to receive SSDI benefits becomes eligible for Medicare after a 2-year waiting period. There are different listings of medical impairments that may qualify for either SSI or SSDI, although both are based on an individual’s disability precluding them from gainful employment.

Approximately two thirds of US states and the District of Columbia provide Medicaid eligibility to people who are eligible for SSI benefits. In these states, the SSI application is also the Medicaid application, and eligibility for Medicaid starts the same month as that for SSI. A small number of states use the same rules to decide eligibility for Medicaid as the SSA uses for SSI but require the filing of a separate application, and others use their own eligibility rules for Medicaid, which are different from federal SSI rules, and a separate application for Medicaid must be filed.

The last major change to the SSI program was in 1996, when the Personal Responsibility and Work Opportunity Reconciliation Act (Pub L No. 104-193) changed the definition of disability for children to require a medically determinable impairment or combination of impairments that results in marked and severe functional limitations. This legislation also removed the individualized functional assessment step from the disability-determination process, which had been in place since February 1990.

*For more information about current related laws, please contact the American Academy of Pediatrics Division of State Government Affairs (www.aap.org/advocacy/stgov.htm).

**ELIGIBILITY**

**Disability Criteria**

Under current regulations, the SSA considers a child (birth to age of 18 years) to be disabled if:

- the child has a medically determinable physical or mental impairment (or combination of impairments) that results in marked and severe functional limitations; and
- the disability has lasted or is expected to last at least 1 year or is expected to result in death (within 1 year).

**Financial/Resource Eligibility Criteria**

The financial and resource eligibility criteria for SSI are complicated. Although there are general guidelines, there are many exceptions. Therefore, the information provided here should be used as a general guide. The upper income limits for eligibility for the SSI program (Table 1) are higher in most states than for other federal or state programs, such as Medicaid or a State Children’s Health Insurance Program (SCHIP). There are also limits on the amount of total assets (resources), such as jewelry, savings accounts, or checking accounts, that a family can have. In 2009, the limit on assets is $2000 if 1 parent lives in the household and $3000 if 2 parents live in the household.

**BENEFITS**

Children on SSI receive a monthly payment based on the income of the child and other family members in the household. The federal benefit rate in 2009 is $674 per month for an individual and $1011 for a couple. The total SSI payment varies according to state, because some states supplement the federal benefit rate with state funds. SSI eligibility also automatically qualifies a child for Medicaid in most states.
The income eligibility requirements for SSI continue to be more liberal, in general, than those for Medicaid. Therefore, the SSI program continues to provide children with disabilities access to the health care services that they might not otherwise be able to afford.\textsuperscript{3} In addition, the Deficit Reduction Act of 2005 included passage of the Family Opportunity Act, a long-sought program that gives states the opportunity to provide Medicaid coverage to children with special health care needs who would qualify for SSI if not for family income and/or resources. Under the Family Opportunity Act, states have the option to expand Medicaid coverage to children up to the age of 18 with family incomes up to 300\% of the federal poverty level who meet the SSI disability standard but whose family income exceeds current eligibility levels. The Family Opportunity Act includes provisions that require limits on cost-sharing and interaction with employer-sponsored insurance when families have access to insurance in which the employer provides at least 50\% of the costs of the annual premium.\textsuperscript{6} Several states also exempt SSI recipients from mandated enrollment in Medicaid managed-care arrangements. In addition, all state Title V children with special health care needs programs are mandated to assist children who receive SSI in accessing health and other supportive services.

APPLICATION PROCESS
If there is any possibility that a child is eligible for SSI, the parent or guardian should apply on behalf of the child. Some states require that families apply for SSI before they will consider the child’s eligibility for state programs. Table 2 provides detailed information about how families can apply for SSI benefits for a child with disabilities.

DETERMINATION OF ELIGIBILITY FOR SSI

Presumptive Disability
Presumptive disability allows payments to begin quickly when there is a very strong likelihood that the child will be found to be disabled once all the evidence is obtained. Children for whom 1 of the following conditions is alleged may meet the requirements for a presumptive-disability decision, which can be made at the local SSA office. These conditions are:

\begin{itemize}
  \item amputation of a leg at the hip;
  \item total blindness;
  \item total deafness;
  \item bed confinement or immobility without use of a wheelchair, walker, or crutches as a result of a recent change in a long-standing condition, excluding recent accident or recent surgery;
  \item stroke (cerebral vascular accident) that occurred more than 3 months ago, and the child has continued marked difficulty in walking or using a hand or arm;
  \item cerebral palsy, muscular dystrophy or muscular atrophy, and marked difficulty in walking, speaking, or coordinating the hands or arms;
  \item Down syndrome;
  \item severe mental deficiency (mental retardation) in a child aged 7 years and older;
  \item symptomatic HIV infection;
  \item birth weight of less than 1200 g and an age of 1 year or younger;
  \item birth weight between 1200 and 2000 g related to specific gestational ages and an age of 1 year or younger;
  \item HIV infection, confirmed by a medical source, and the file contains form SSA-4814 or SSA-4815;
  \item terminal cancer/illness with a life expectancy of 6 months or less, with confirmation by telephone or in a signed statement from a physician, or in hospice care, with confirmation from a physician or knowledgeable hospice official;
  \item allegation of spinal cord injury causing inability to ambulate without a walker or equivalent device 2 weeks after a spinal cord injury, with confirmation from an appropriate medical professional;
  \item end-stage renal disease with ongoing dialysis, and the file contains a completed form CMS-2728 (End-Stage Renal Disease Medical Evidence Report-Medicare Entitlement and/or Patient Registration); or
  \item allegation of amyotrophic lateral sclerosis (ALS or Lou Gehrig disease).
\end{itemize}
The field-office staff may base presumptive disability decisions on observations they make during interviews or on the documentation from medical or other health care professionals. Medical or psychological staff of the state disability-determination services (see next section) may make such decisions with respect to any impairment, not just those listed here.

A child who has been found to be disabled under a presumptive disability decision may receive SSI payments for up to 6 months while the formal evaluation of eligibility is conducted. For the determination of a presumptive disability, the pediatrician who treats a child with 1 of these conditions should provide the parents with a statement about the diagnosis and the severity of the child’s condition. Parents can request a presumptive disability decision for their child on the basis of this statement.

**Disability Determination**

Each state has an agency that makes disability determinations on behalf of the SSA. States use a variety of names for these agencies; however, they are generically known as disability-determination services (DDSs). State DDS offices operate under federal regulations and instructions issued by the SSA. Once the representative in the SSA office determines that the child is a US citizen and appears to qualify financially, he or she sends information about the child’s disability and a list of additional sources of information to the DDS office. (Additional information about citizen and residency requirements is included in Table 2.) The DDS agency uses a team that consists of a disability examiner and medical or psychological professionals to decide whether a child is eligible for SSI on the basis of the available medical and nonmedical evidence.

The decision-making team attempts to develop a complete medical and functional history for the child for at least the 12 months preceding the application for SSI. DDS staff members do not examine the child. Information is requested from physicians, hospitals, psychologists, schools, teachers, therapists, social workers, parents, friends, relatives, the child, and anyone else who may be able to provide relevant information about the child’s impairment(s) and functioning. The determination of disability by the DDS agency is based primarily on the written information submitted, especially the child’s medical records. It is essential, therefore, for pediatricians and other professionals to forward appropriate records or to provide a complete, detailed summary report.

**TABLE 2** What to Tell Families About SSI Application, Disability Determination, and Appeals Procedures: SSI Citizenship and Residency Eligibility Criteria

<table>
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<tr>
<th>How to apply</th>
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<td>To apply for SSI benefits for a disabled child, parents should call the toll-free number for the SSA (1-800-772-1213) to make an appointment for a telephone interview or visit a local Social Security office to complete an application.</td>
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| If parents make an appointment for a telephone interview, an SSA claims interviewer will contact them. The interviewer will provide general information to parents about the financial, medical, disability, and functional criteria used to determine SSI eligibility. This information is provided to help parents decide whether to proceed with the application process. The SSA prefers that parents use the telephone process because, according to the SSA, it is more efficient for both the parents and the SSA. |

<table>
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<th>What parents need to know</th>
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<tr>
<td>The telephone line is often busy, but they should keep trying. The SSA interviewer will gather information about family income, financial resources, and the child’s citizenship/residency status. On the basis of the above-listed information, the interviewer will indicate whether it appears that the child is financially eligible for SSI. Financial eligibility for adults (≥18 y) is based on what the young adult owns and/or earns, parental income/assets are not considered in the determination. The interviewer will ask the parents if they want to file an application for the child. They have a right to request and file an application even if it does not appear that the child qualifies financially. They will need to be prepared to provide the interviewer with information about all the medical sources who have treated or examined the child for the alleged conditions, including their complete names, addresses, telephone numbers, and dates of treatment. Application forms completed by telephone will be mailed to the parents’ home for signature. The telephone interviewer should not suggest that the child does (or does not) appear to meet the SSI disability criteria. The date of the telephone interview serves as the protective filing date, so there is no loss of payments. Parents should keep a record of all contacts with the SSA, including the name, date, and telephone number (including the extension) of the person with whom they spoke. The process of determining disability can take several months or more.</td>
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Applying at the SSA field office

| If parents choose to go to a local SSA field office, they should call either the local office or the toll-free number to make an appointment. This will ensure that an SSA staff person will be available to take the application and will reduce the amount of waiting time when filing an application. If parents cannot gather all of the required information by the time of the appointment, they should still go to the SSA field office at that time to begin the application process, thus establishing a protective filing date. When the SSA has the needed information about family income and financial resources, they will determine the financial eligibility for SSI. |

SII citizenship and residency eligibility criteria

| To be eligible for SSI, a child must be a US citizen or a naturalized citizen. For SSI disability purposes, a child is an individual who is younger than 18 y. Children who are authorized to remain in the United States by the Immigration and Naturalization Service may also qualify. The child must also reside in 1 of the 50 states, the District of Columbia, or the Northern Mariana Islands. Children who live in Puerto Rico, Guam, and the US Virgin Islands may be US citizens but do not meet the SSI requirements for residency. The exception is children of military personnel who are assigned to overseas duty. |

Each state has an agency that makes disability determinations on behalf of the SSA. States use a variety of names for these agencies; however, they are generically known as disability-determination services (DDSs). State DDS offices operate under federal regulations and instructions issued by the SSA.
Role of the Primary Care Physician

The primary care physician, as provider of the medical home, is uniquely positioned to act as both repository for this information and facilitator for submission of the summary report. However, the role of treating physicians is to provide accurate, timely, impartial information, not to decide whether an individual is disabled. The DDS team will make the disability decision by using information from the primary care physician and many other sources. A pediatrician’s medical report in support of a child’s application for SSI should:

- use specific terms and include results from specific clinical tests (if they have been obtained) mentioned in the childhood Listing of Impairments from the SSA;
- include at least a 12-month medical history of the child;
- provide complete, detailed clinical findings (including any results of physical, intelligence, developmental, and mental status examinations);
- include complete, detailed laboratory findings (eg, blood pressure, radiographic films, and chromosome test results);
- specify the diagnosis (statement of disease or injury on the basis of signs, symptoms, and laboratory findings);
- review treatments prescribed with response and prognosis;
- state the probable duration of the impairment;
- include an assessment of the child’s physical or mental abilities to function in an age-appropriate manner and to perform age-appropriate daily activities; and
- describe the nature and limiting effects of the impairment(s) on the child’s ability to function in an age-appropriate manner and to perform age-appropriate daily activities.

If the available information provided by those who treat the child is insufficient for determining disability, the DDS agency can arrange and pay for a consultative examination by a treating physician or, if a treating physician is unable or unwilling to conduct the examination, by an independent physician. On the basis of all the available information, the DDS agency follows a 3-step process11 (“sequential evaluation”) to make a determination. The steps of this process and the decision criteria are described in the next paragraph. The DDS agency then informs the SSA of the decision and sends a written notification of the decision to the parents (or other applicant). If the claim is denied, the decision notice includes the reasons and provides information about the right to appeal the decision.

THE 3-STEP EVALUATION PROCESS

At step 1, the examiner determines whether the child is engaging in substantial gainful activity (SGA)—that is, working and earning more than $980/month ($1640/month for a blind individual).† If the child is engaging in SGA, the claim is denied. If the child is not engaging in SGA, the examiner goes to step 2 of the evaluation process. At step 2, a medical or psychological consultant determines, on the basis of available documentation, whether the child has an impairment or combination of impairments that is severe. “Severe” is defined as more than a minimal or slight limitation in a child’s ability to function in an age-appropriate manner. If the child’s impairment is a slight abnormality or combination of slight abnormalities that causes no more than minimal functional limitations, the SSI claim is denied. If it is determined that the impairment is severe, the examiner proceeds to step 3.

At step 3, the medical or psychological consultant determines whether the child’s impairment is the same as (“meets”) or is medically equivalent in severity to (“equals”) 1 of the conditions on the Listing of Impairments from the SSA. The DDS team will find that a child’s impairment (or combination of impairments) meets a listed condition only when the symptoms, signs, and laboratory findings are the same as the findings included in the criteria in the SSI listings for that impairment. If a child’s impairment meets a listing, then that child is determined to be disabled and is eligible for SSI benefits. If the child’s impairment does not meet a listing, the medical consultant must determine if the child’s impairment is “medically equivalent in severity” to any listed impairment. If it is not, the medical consultant must determine if the child’s impairment functionally equals any listed impairment by considering how the child functions compared with children of the same age without impairments.

TRANSITIONING YOUTH

SSI can be an important source of financial support and health benefits (by linked Medicaid eligibility) for young adults with disabilities. Once an individual with a disability becomes an adult at 18 years of age, the DDS agency determines his or her eligibility for SSI by using the adult definition of disability—that is, inability to perform SGA. Approximately one third of children who receive SSI will lose their SSI eligibility because of the change in disability criteria effective at 18 years of age, based on disability and financial resources. However, children with severe impairments who were not eligible for SSI as children because the family did not meet financial eligibility criteria in the childhood Listings of Impairments...

†These represent 2008 income levels.
requirements often become eligible for SSI after their 18th birthday. The SSA regards individuals aged 18 years and older, even if they live with their parents, to be a household of 1 for purposes of determining financial eligibility. These individuals must meet the adult definition of disability to be found disabled. Adults on SSI are generally eligible for services through their state vocational rehabilitation agency as well as a variety of work incentives and supports, including the Medicaid Buy-In Program, which has been introduced in a number of states. Each state has at least 1 Benefits Planning and Outreach Assistance organization that can help individuals to understand SSI and SSDI benefits as well as work incentives.

RECOMMENDATIONS
Pediatricians, individually and through state chapters of the American Academy of Pediatrics, should continue efforts to make families aware of the SSI program and provide assistance with the SSI application process. Such efforts can ensure that program benefits intended for children and youth with medically eligible conditions will be received. These efforts should include:

- in conjunction with the medical home model, designating at least 1 member of the office staff to remain up-to-date on SSI policies and procedures;
- making up-to-date information about the SSI program available to families;
- obtaining a copy of the Listing of Impairments from the SSA and using this document as a basis for providing specific, detailed reports to the DDS agency in support of children’s applications for SSI benefits;
- promoting methods of increasing office efficiency for timely completion of reports provided to the DDS agency;
- following the Pediatric Consultative Examination Guidelines of the SSA when performing consultative examinations of children; the guidelines are available through the DDS agency (“The Green Book”);
- supporting and facilitating the ongoing distribution of SSA brochures to inform professionals and families about the SSI program; and
- inviting staff members from the SSA and DDS to participate in local and statewide educational meetings and workshops organized by American Academy of Pediatrics chapters.

WEB RESOURCES
Social Security Administration: www.ssa.gov
Benefit Eligibility Screening Tool: https://secure.ssa.gov/apps7/best/benefits
SSA disability programs: www.ssa.gov/disability/index.htm
SSA health and school professionals: www.ssa.gov/disability/professionals/index.htm
SSA employment support for people with disabilities: www.ssa.gov/work/index.html
SSA publications: www.ssa.gov/pubs/english.html

SELECTED PUBLICATIONS FROM THE SSA

COUNCIL ON CHILDREN WITH DISABILITIES EXECUTIVE COMMITTEE, 2008–2009
Nancy A. Murphy, MD, Chairperson
Robert Burke, MD
Larry W. Desch, MD
REFERENCES

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### Council on Children With Disabilities

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