

# AMERICAN ACADEMY OF PEDIATRICS

Committee on Children With Disabilities

## The Continued Importance of Supplemental Security Income (SSI) for Children and Adolescents With Disabilities

**ABSTRACT.** In 1996, as part of the Personal Responsibility and Work Opportunity Reconciliation (Welfare Reform) Act, Congress redefined the Supplemental Security Income (SSI) definition of disability for children and removed the individual functional assessment (IFA) step from the disability determination process. As a result, an estimated 100 000 SSI child beneficiaries have lost or will lose their SSI benefits. The publicity associated with this Congressionally mandated change might also have reduced the number of families applying for SSI benefits on behalf of their children because of a widely held belief that the eligibility criteria for disability benefits are now so restrictive that almost no children are determined to be eligible. The purpose of this statement is to provide updated information about the SSI Program's disability and financial eligibility criteria and disability determination process. This statement also discusses how pediatricians can help to ensure that all eligible children receive the SSI monies and associated benefits to which they are entitled.

**ABBREVIATIONS.** SSI, supplemental security income; SSA, Social Security Administration; CSHCN, Children With Special Health Care Needs; DDS, disability determination services; SGA, substantial gainful activity.

### THE SUPPLEMENTAL SECURITY INCOME (SSI) PROGRAM FOR CHILDREN

The SSI program for children remains an important part of the federal government's social benefits program for children with special needs.<sup>1-3</sup> The SSI program continues to be administered by the Social Security Administration (SSA) as a nationwide program that does the following:

- Provides monthly cash payments based on family income
- Qualifies a child for Medicaid health care services in many states
- Ensures referral of SSI child beneficiaries into the state Title V Children With Special Health Care Needs (CSHCN) program's system of care.
- Under current regulations, the SSA considers a child to be disabled if:
- The child has a medically determinable impairment (physical or mental) that results in marked and severe functional limitations
- The condition has lasted or is expected to last at least a year or is expected to cause death (within a year).<sup>4,5</sup>

The recommendations in this statement do not indicate an exclusive course of treatment or serve as a standard of medical care. Variations, taking into account individual circumstances, may be appropriate.

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The SSI eligibility automatically qualifies a child for Medicaid in most states.<sup>6</sup> The income eligibility requirements for SSI continue to be more liberal, in general, than those for Medicaid. Therefore, the SSI program continues to provide disabled children access to the health care services that they might not otherwise be able to afford.<sup>7</sup> Several states also exempt SSI beneficiaries from mandated enrollment in Medicaid managed care arrangements. In addition, all state Title V CSHCN programs assist SSI child beneficiaries' access to health and other supportive services.

### APPLYING FOR SSI

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 considering the child's eligibility for state programs.<sup>6</sup> Table 1 gives detailed information about how families can apply for SSI benefits for a disabled child.

### FINANCIAL/RESOURCE ELIGIBILITY CRITERIA

The financial and resource eligibility criteria for SSI are extremely complicated. Although there are general guidelines, there are many exceptions. Therefore, the information provided here should be used as a general guide. The income limits for the SSI program (Table 2) are more liberal in most states than for other federal or state programs, such as Medicaid or the 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. The limit on assets is \$2000 if 1 parent lives in the household and \$3000 if 2 parents live in the household.

### DETERMINATION OF ELIGIBILITY FOR SSI

*Presumptive Disability:* Presumptive disability allows payments to begin quickly, when there is a very high likelihood that the child will be found to be disabled once all the evidence is obtained.

If a child has 1 of 15 specific impairments, he or she may be found "presumptively eligible" for disability payments by the SSA field office staff. These 15 conditions are:

- amputation of 2 limbs
- amputation of a leg at the hip
- total blindness
- total deafness

**TABLE 1.** What to Tell Families About SSI Application, Disability Determination, and Appeals Procedures—SSI Citizenship and Residency Eligibility Criteria

*How to Apply*

To apply for SSI benefits for a disabled child, a parent should call the SSA's toll-free number (1-800-772-1213) to make an appointment for a telephone interview or visit an SSA office to complete an application.

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 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.

*Parents need to know the following:*

- 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.
- On the basis of the above information, the interviewer will indicate whether it appears that the child is financially eligible for SSI.
- The interviewer will ask whether 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.
- Application forms completed by phone will be sent by mail to their 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 protected filing date, so there is no loss of benefits. A record should be kept of all contacts with the SSA, including the date and phone number, with the extension, of the person with whom they spoke.
- The process of determining disability can take several months.
- Financial eligibility for young adults 18 years or older is based only on what the young adult owns and/or earns. Family income/assets are not considered.

*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 protected filing date. When the SSA has the needed information about family income and financial resources, financial eligibility for SSI will be determined.

*SSI 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 years. Children authorized to remain in the United States by the Immigration and Naturalization Service may also qualify. The child must also reside in one of the 50 states, the District of Columbia, or the northern Mariana Islands. Children living in Puerto Rico, Guam, and the United States' Virgin Islands may be US citizens but do not meet the SSI requirements for residency. The exception is children of military personnel assigned to overseas duty.

- bed confinement or immobility because of a long-standing condition
- stroke or cerebral vascular accident that occurred more than 3 months ago, with the child having continued marked difficulty in walking or using a hand or arm
- cerebral palsy, muscular dystrophy or muscular atrophy, and marked difficulty in walking, speaking, or coordinating the hands or arms

**TABLE 2.** SSI Income Eligibility

Parents' maximum monthly income for a child with disability to be eligible for SSI in states that do not supplement SSI payments (for the year 2000). Amounts are adjusted each year to reflect inflation. The maximum levels are higher in states that supplement SSI. The monthly limit for either type of income increases by \$257 for each additional child without a disability in the household.

Maximum Earned Monthly Income		
Number of Other Children Without a Disability in Household	One-Parent Household	Two-Parent Household
0	\$2173	\$2687
1	\$2430	\$2944
2	\$2687	\$3201
3	\$2944	\$3458

  

Maximum Unearned Monthly Income		
Number of Other Children Without a Disability in Household	One-Parent Household	Two-Parent Household
0	\$1064	\$1321
1	\$1321	\$1578
2	\$1578	\$1835
3	\$1835	\$2092

Rules related to "earned" and "unearned" income are complex. A chart cannot show a maximum when some of the family's monthly income is earned and some is unearned. If the family's total estimate is close to the limit for earned income, a child may still qualify for SSI.

- diabetes with amputation of a foot
- Down syndrome
- for a child 7 years and older, severe mental deficiency
- symptomatic human immunodeficiency virus infection
- birth weight less than 1200 g and younger than 6 months
- birth weight between 1200 g and 2000 g combined with specific gestational ages
- terminal cancer in hospice care
- inability to ambulate without a walker or equivalent device 2 weeks after a spinal cord injury.

The field office staff may base decisions on observations made during interviews or on documentation from medical or other health professionals. Medical or psychological staff of the state disability determination service (see next section) may make such decisions in any impairment, not just those listed above.

A child can be presumptively eligible and receive SSI benefits for up to 6 months while the formal evaluation of eligibility is conducted. For the determination of presumptive eligibility, the pediatrician who treats a child with 1 of these 15 conditions should provide the parents with a statement about the diagnosis and the severity of the child's disabling condition. Parents can request presumptive eligibility for their child based on this statement.

*Disability Determination:* The SSA does not make disability determinations directly.<sup>5,8</sup> The law establishing SSA provided that each state could establish an agency to make disability determinations. States

use a variety of names for these agencies. However, they are generically known as disability determination services (DDS). State DDS agencies operate under federal regulations and instructions issued by the SSA. Once the SSA determines that the child is a US citizen and appears to qualify financially, information about the child's disability and a list of additional sources of information are sent to the DDS unit. (Additional information about citizen and residency requirements is included in Table 1.) The DDS agency uses a team comprised of a disability examiner and a medical or psychological professional to decide whether the child is eligible, based on the available written information.

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. Information is requested from physicians, psychologists, schools, teachers, therapists, social workers, parents, friends, relatives, the child, and anyone else who may be able to provide useful information about the child's impairment(s) and functioning. DDS staff does not examine the child. Because the determination made by the state DDS unit is based on written information, it is important that pediatricians provide complete, detailed data. The primary care physician who provides the medical home is best qualified to submit this report. The role of the primary care physician is to provide accurate, timely, impartial information, not to decide whether or not the child is disabled. The DDS team will make the disability decision using information from the physician and from many other sources. The pediatrician's medical report in support of a child's application for SSI should do the following:

- Use specific terms and include results from specific clinical tests (if they have been obtained) mentioned in SSA's childhood *Listing of Impairments*<sup>2</sup>
- 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, chromosome test results)
- Specify the diagnosis (statement of disease or injury based on 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
- Include any school documents, reports, or information indicating the child's need for special education services and deviations from age-appropriate performance in the school setting
- 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 can arrange for a consultative examination at the SSA's expense by the child's treating physician, or, if the treating physician is unable or unwilling to conduct the examination, by an independent physician. On the basis of all the available information, the DDS follows a 3-step process ("sequential evaluation") to make a determination. The steps of this process and the decision criteria are described below. The DDS then informs the SSA of the decision, which is given to the parents in writing. The process of determining disability can take several months. If the application is rejected, the parents are sent a written notification that includes reasons why the application was turned down and information about the applicant's right to appeal the decision.

### THE THREE-STEP EVALUATION PROCESS

In Step 1, the examiner determines whether the child is engaged in substantial gainful activity (SGA), ie, work with income greater than \$700/month. If the applicant engages in SGA, the claim is rejected. If the child does not engage in such activity, Step 2 is begun.

In Step 2, the medical consultant determines, on the basis of available documentation, whether the applicant has a severe impairment or combination of impairments. 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 applicant has a minimal or slight limitation or impairment, the claim is rejected. If the team determines that the impairment is severe, or if there is doubt about the severity or the effect of the impairment on the child's functioning, step 3 begins.

In Step 3, the medical consultant determines whether the child's impairment is the same as ("meets") or is medically or functionally equivalent in severity to ("equals") one of the conditions on the SSA's *Listing of Impairments*. The DDS will find that a child meets a listing only when the symptoms, signs, and laboratory findings meet the findings included in the criteria in the SSI listings for that impairment. If a child meets a listing, then that child is determined to be disabled and is eligible for SSI benefits. If the child 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 impairment is "functionally equivalent in severity" to a listed impairment.

### REDETERMINATIONS

In the Welfare Reform Act, the SSA was required to redetermine the SSI eligibility of approximately 288 000 children who had been found eligible for SSI benefits through the individual functional assessment (IFA) process or because of functional limitations associated with maladaptive behavior. Through an ini-

tial screening process, SSA determined that more than 28 324 of the 288 000 redetermination cases should remain on the SSI roles. An additional 10 077 children were found not to be eligible for SSI because of family income or other factors not related to disability. Of the remaining 249 599 cases, a redetermination was completed on 245 737 cases by July 31, 1999. Of these, 101 048, or about 40%, were redetermined as eligible for SSI. Approximately 60% (44 689) were found to be not eligible for SSI on the basis of the new criteria and were sent a notice that the child's SSI benefits would be terminated. In this notice, SSA also provided information about how to appeal the determination and how to request that benefits continue during the appeals process. Of those who were sent a termination notice, 112 136 (72%) submitted an appeal. Children whose initial appeals are rejected have the right to request additional reviews of their cases. By July 31, 1999, 40 709 (34%) of these appeals were upheld (34 507 at the first level of appeal) and these children continued to receive SSI benefits. As of July 31, 1999, 170 081 children have been found to continue to be eligible for benefits. The SSA currently estimates that about 188 000 children of the 288 000 "redetermination cases" will ultimately be found eligible for SSI under the new criteria, while 100 000 of these children will lose their SSI and associated Medicaid benefits. Before the passage of SCHIP, it was estimated that about one third of the 100 000 who lost SSI as result of redetermination would have lost Medicaid. As a result of the SCHIP legislation, all children who are terminated from SSI through the reevaluation process but meet the financial eligibility criteria for SSI will continue to be eligible for Medicaid benefits until their 18th birthday.

### RECOMMENDATIONS

Pediatricians, individually and through state chapters of the Academy, should continue to help ensure that all eligible children receive the SSI monies and associated benefits to which they are entitled. These efforts should include:

- 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 SSA's *Listing of Impairments* and using this document as a basis for providing specific, detailed reports to the DDS in support of children's applications for SSI benefits
- Advocating for better reimbursement
- Promoting improved methods for providing reports to the DDS
- Supporting and facilitating the ongoing distribution of SSA brochures to inform professionals and families about the SSI program
- Inviting the staffs of the SSA and DDS to participate in local and state-wide educational meetings and workshops organized by AAP chapters.

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### REFERENCES

1. Reiss J, Wallace HM, McPherson M. The Supplemental Security Income Program for children. In: Wallace HM, Gordon G, Jaros KJ, Paine LL, Story M, eds. *Health and Welfare for Families in the 21st Century*. Sudbery, MA: Jones & Bartlett; 1998:281–298
2. Social Security Administration. *Disability Evaluation Under Social Security*. Baltimore, MD: Social Security Administration; 1999. Publ. No. 64-039. Ordering information available at: <http://www.ssa.gov/disability/professionals/publications.html>; Listings alone available at: [http://www.ssa.gov/op\\_Home/cfr20/404/404-ap09](http://www.ssa.gov/op_Home/cfr20/404/404-ap09); Automatic updates available at: <http://www.ssa.gov/enews>
3. *Sullivan v Zebley*, 493 US 521. 1990
4. Schulzinger R. *The Advocate's Guide to SSI for Children*. 3rd ed. Washington, DC: Judge David L. Bazelon Center for Mental Health Law; 1998
5. Judge David L. *How Your Child May Qualify for SSI*. Bazelon Center for Mental Health Law Web site. Available at: <http://www.bazelon.org/ssirevu.html>. Accessed April. 2000;6
6. Perrin JM, Ettner SL, McLaughlin TJ, Gortmaker SL, Bloom SR, Kuhlthau K. State variations in supplemental security income enrollment for children and adolescents. *Am J Public Health*. 1998;88:928–931
7. US Social Security Administration. *Disability Report—Child*. Baltimore, MD: US Social Security Administration; 1998. Publ. No. SSA-3820-BK
8. Perrin JM, Kuhlthau K, McLaughlin TJ, Ettner SL, Gortmaker SL. Changing patterns of conditions among children receiving Supplemental Security Income disability benefits. *Arch Pediatr Adolesc Med*. 1999; 153:80–84

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