Why Supplemental Security Income Is Important for Children and Adolescents

Committee on Children With Disabilities

The Supplemental Security Income (SSI) program for children is an important part of the federal government’s social benefits program for children with special needs. The SSI program is a nationwide program administered by the Social Security Administration (SSA) that does the following:

- provides monthly cash payments based on family income,
- qualifies the child for Medicaid health care services in many states, and
- assures referral of SSI child beneficiaries into the state Title V Children With Special Health Care Needs program’s system of care.

The SSA considers a child to be disabled if:

- the impairment—physical or mental, or chronic medical condition—is as severe as a condition that would keep an adult from working,
- the condition is expected to last a long time or is life threatening, and
- the child is unable to engage in the everyday activities that most children the same age can do.

Congress implemented the children’s component of the SSI program in 1974 in recognition that disabled children who live in low-income households are among the most disadvantaged of all Americans and therefore deserve special assistance. The cost of caring for a child with special needs is an especially heavy burden for families with limited resources. The intent of the SSI program is to reduce the additional deleterious environmental effects that a low family income can have on the growth and development of the disabled child and thereby help these children become self-supporting members of society.

The SSI program provides cash benefits. Therefore, parents can decide how best to use these flexible funds to meet the needs of their child, such as for respite care, special equipment, or transportation to the physician’s office. These benefits can also offset the potential income of a second working parent, thus allowing a mother or father to provide care for the child at home.

In addition, SSI eligibility automatically qualifies the child for Medicaid in many states. Because the income eligibility requirements for SSI are more liberal than those for Medicaid, the SSI program can provide disabled children access to the health care services that they might otherwise be able to afford. In addition, all state Title V Children With Special Health Care Needs programs assist SSI child beneficiaries to access health and other needed supportive services that may be available through public and private programs.

The SSI rules for determining financial eligibility and disability are very complex. In addition, significant changes have been made recently to the eligibility criteria. The SSI program has never been well understood by many parents, health care providers, and program administrators at the federal, state, and local levels. Although approximately 910,780 children (0 to 21 years of age) were receiving SSI benefits as of June 1994, many more children would receive SSI benefits if they applied. This statement provides basic information about the SSI program and describes the roles that pediatricians can play in the SSI outreach, application, and disability determination processes.

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 are more liberal than some other federal assistance programs, such as Medicaid. For example, in 1994 a family with two parents in the home and two children in addition to the disabled child can earn up to $2,800 per month and still be financially eligible for SSI; a family with one parent in the home and two children in addition to the disabled child can earn up to $2,354. There are also limits on the amount of total assets (resources), such as jewelry, a savings account, or a checking account, that a family can have. The limit on assets is $2,000 if one parent lives in the household and $3,000 if two parents live in the household. When the family’s assets are calculated, the following are not included: the family home (regardless of its value), household goods and personal effects up to $2,000, and, generally, the family car. Additional information about 1994 income limits is included in Appendix A. These income limits are updated periodically.

This statement has been approved by the Council on Child and Adolescent Health.

The recommendations in this policy 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 ZEBLEY DECISION

A significant change in the SSI program resulted from the February 1990 U.S. Supreme Court decision in the case of Sullivan, Secretary of HHS, v Zebley. In this decision, the Supreme Court ruled that the procedures used by the SSA to determine the eligibility of children for SSI were unconstitutional.

Before the Zebley decision, there was no assessment of a child applicant’s “functional status” as part of the disability determination process. It was this omission that the Supreme Court cited as unconstitutional, because it discriminated against children by requiring them to meet stricter standards than adults to qualify for SSI. Thus, the child’s functional status, in addition to diagnosis, became a critical factor in determining eligibility for SSI.

As a result of this ruling, the SSA has done the following:

- contacted and reevaluated children who had been denied benefits between January 1, 1980, and February 11, 1991, based on medical evidence alone (termed the “Zebley class”),
- developed new methods for gathering information about the medical condition and functional status of children,
- worked to improve the ways in which parents receive information about the program and apply for benefits, and
- developed methods for assessing the functional status of children.

The SSA methods for assessing functional status are now more applicable to children and take into consideration the child’s ability to perform expected, age-appropriate activities; the impact of multiple conditions; and the child’s need for support and assistance from others.

DETERMINATION OF ELIGIBILITY FOR SSI

Presumptive Eligibility

If a child has 1 of 13 specific impairments, he or she may be found “presumptively eligible” for disability payments by the SSA field office staff. These 13 conditions are as follows:

- amputation of two limbs;
- amputation of a leg at the hip;
- total blindness;
- total deafness;
- bed confinement or immobility because of a long-standing condition;
- stroke/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;
- diabetes with amputation of a foot;
- Down syndrome;
- for a child 7 years and older, severe mental deficiency;
- renal disease requiring dialysis on a regular basis;
- human immunodeficiency virus infection; and
- birth weight less than 1200 g and less than 1 year of age.

A child can be presumptively eligible and receive SSI benefits for up to 6 months while the formal evaluation of eligibility is conducted. The decision of whether the child is presumptively eligible is based in part on the family’s statements and on observations of the child by SSA staff members. The SSA staff cannot evaluate medical evidence. The pediatrician who treats a child with 1 of these 13 conditions should provide the parents with a statement about the diagnosis and the severity of the child’s disabling condition. Parents need to know that they can request presumptive eligibility for their child based on this statement.

Disability Determination

The SSA does not make disability determinations directly. Rather, it has a contract with a state Disability Determination Services (DDS) agency to perform this function. State DDS agencies operate under federal regulations and instructions issued by the SSA. Once the SSA determines that the child is a U.S. 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/residency requirements is included in Appendix B.) 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 disability examiner must develop a complete medical and functional history for the child for at least the 12 months preceding the application for SSI. Staff of the DDS do not examine the child or meet with the child or family. Because the determination made by the state DDS unit is based on written information, it is important that pediatricians provide complete, detailed data in response to requests for information from the DDS.

Therefore, the pediatrician’s medical report in support of a child’s application for SSI should do the following:

- Refer to the SSA’s childhood “Listing of Impairments” and use the specific terms and reference the specific clinical tests included in the listings. The listing contains criteria for evaluating the impairments of children (younger than 18 years), ie, mental and physical symptoms, signs, and/or laboratory findings, and includes 66 childhood diseases and disorders. These listings, however, have been criticized for omitting many disabling conditions. (A copy of the “Disability Evaluation Under Social Security” may be obtained from the SSA Office of Public Affairs, Public Information Distribution Center, P.O. Box 17743, Baltimore, MD 21235; telephone 410-965-0945, fax 410-965-0696).
- Include a medical history of the child (for at least
the previous 12 months).
- Provide complete, detailed clinical findings (eg, the results of physical, intelligence, developmental, and mental status examinations).
- Include complete, detailed laboratory findings (eg, blood pressure, radiographic films).
- Specify the diagnosis (statement of disease/injury based on signs and symptoms).
- Review treatment(s) 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 independently, appropriately, and effectively in an age-appropriate manner and to perform age-appropriate daily activities.
- Describe the nature and limiting effects of the impairment(s) on the child’s ability to function independently, appropriately, and effectively 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 four-step process (“sequential evaluation”) to make a determination. The steps of this process and the decision criteria are described in the Figure and given in detail 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 2 to 3 months. If the application is rejected, the parents have the right to appeal the decision.

THE FOUR-STEP EVALUATION PROCESS

In step 1, the examiner determines whether the child is engaged in Substantial Gainful Activity, ie, work. If the applicant engages in Substantial Gainful Activity, the claim is rejected. If the child does not engage in such activity, step 2 is begun.

In step 2, the examiner determines, based on the 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 independently, appropriately, and effectively in an age-appropriate manner. If the examiner 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. If the applicant has a minimal or slight limitation impairment, the claim is rejected.

In step 3, the examiner determines whether the child’s impairment is the same as (“meets”) or is either medically or functionally equivalent in severity to (“equals”) one of the conditions on the SSA’s “Listing of Impairments.”

An examiner will find that a child meets a listing only when the symptoms, signs, and laboratory findings meet the findings included in the criteria for that listed impairment. If an examiner finds that a child meets a listing, then the child is determined to be disabled and is eligible for SSI benefits. If the child does not meet a listing, the examiner must determine whether the child’s impairment is medically equivalent in severity to any listed impairment. If it is not, the examiner must determine whether the impairment is functionally equivalent in severity to a listed impairment.

An examiner must determine whether the available documentation indicates that a child’s impairment or combination of impairments exhibits signs, symptoms, and laboratory findings that are of equal medical significance or severity to the listed criteria. If the child’s impairment is judged to be medically equivalent to a listed impairment, he or she is classified as disabled. If the child’s impairment is not judged to be medically equivalent, the examiner must determine whether the impairment is functionally equivalent in severity to a listed impairment. For example, according to listing 106.02D, a child who has had a kidney transplantation should be considered disabled for at least 1 year after the transplantation. Although not specifically listed, a child with disability from a heart transplantation should be found “equivalent to a kidney transplant because it has a similar impact on a child’s ability to function in an age-appropriate manner” (Clark and Manes, 1992, chapter 12, page 6). The SSA rules and regulations (20 C.F.R. § 416.926a[d]) provide 15 examples of impairments that are functionally equivalent to those in the listings. If the child’s impairment is judged to be functionally equivalent to a listed impairment, he or
she is classified as disabled. If it is not, then the examiner must complete an Individualized Functional Assessment.

Step 4, the process of Individualized Functional Assessment, is the major modification to the SSI regulations by the SSA in response to the Zebley decision. The examiner must determine whether the impairments limit the child’s ability, as much as they would an adult’s ability, to function independently, appropriately, and effectively in an age-appropriate manner. The SSA’s definition of “comparable severity” was expanded to take into consideration that if the manifestations of impairments in children are age related, then the evidence needed to evaluate disability appropriately is age related. The new SSI regulations specify the following age groups:

- newborns and young infants (birth to age 1 year),
- older infants and toddlers (ages 1 to 3 years),
- preschool children (ages 3 to 6 years),
- school-age children (ages 6 to 12 years),
- young adolescents (ages 12 to 16 years), and
- older adolescents (ages 16 to 18 years).

When evaluating the functional status of children aged 0 to 16 years, DDS examiners focus on the following:

- cognition (the child’s ability to learn),
- communication skills (the child’s ability to receive, understand, and express messages; with respect to speech, audibility, intelligibility, and efficiency of speech production),
- motor skills (the child’s ability to use his or her body, hands, and feet in gross and fine motions),
- social skills (the child’s ability to form, develop, and sustain relationships with other people on a personal and social basis), and
- personal/behavioral patterns, which refer to activities and behaviors entailed in the following: self-help, such as feeding and dressing; self-regulation, such as maintaining proper nutrition and sleep; self-improvement, such as increasing self-help behavior through learning new skills; self-protection, such as taking necessary safety precautions; and self-control, such as adapting to changes in the environment or an activity, or controlling impulsive or aggressive behaviors that could result in self-harm.

For evaluation of the functional status of infants, information should be provided about the child’s physical and emotional responses to stimuli. For children older than 3 years, concentration, persistence, and pace in the completion of tasks should be evaluated. For older adolescents aged 16 and 17 years, school and work-like activities and the ability to function in a work setting are relevant factors.

As part of the Individualized Functional Assessment, the disability examiner must develop a complete medical and functional history for the child for at least the 12 months preceding the application for SSI. In determining the child’s functional capacity, the examiner must also consider the impact of the following:

Chronic Illness. Detailed descriptive information should be provided if hospitalizations are so extended or frequent that they interfere with overall functioning, or if the frequency and/or effects of outpatient care significantly interfere with the child’s daily activities.

Medication. Detailed descriptive information should be provided if medications and/or side effects cause or contribute to a child’s functional limitations.

Supportive and Structured Settings. Detailed descriptive information should be provided as to how a child’s symptoms are controlled or reduced by a highly structured or supportive environment, and whether the child can function independently, appropriately, and effectively in an age-appropriate manner outside of this environment.

Assistive Devices, Appliances, and Technology and Special Support Services. Detailed descriptive information should be provided if special devices or services provide some improvement without restoring adequate functioning, or if they themselves impose limitations.

Frequent and Ongoing Therapeutic Intervention. Detailed descriptive information should be provided if the multidisciplinary therapies that the child receives interrupt school or home activities and interfere with the child’s development and age-appropriate functioning.

Although the information provided to the DDS by pediatricians is critical to the efficient, accurate determination of disability, pediatricians and other professionals generally do not describe a child’s physical status and impairments using the criteria listed above. A physician’s declaration that a child is disabled is not sufficient evidence for the DDS to determine a child eligible for SSI benefits. The SSA regulations require that the DDS perform a functional assessment of physically impaired children that relies on the pediatrician’s providing information according to the factors listed above. Reports should use the specific terms and reference the specific clinical tests included in the “Listings of Impairments.” In addition, when possible, formal test results regarding the child’s functioning and development should be provided in terms of percentiles, percentages, standard deviations, or the fraction or percentage of the child’s chronological age.

WHAT TO TELL FAMILIES ABOUT SSI APPLICATION, DISABILITY DETERMINATION, AND APPEALS PROCEDURES

Appendix C gives detailed information about how families can apply for SSI benefits for a disabled child.

CONCLUSION AND RECOMMENDATIONS

Pediatricians, individually and through state chapters of the American Academy of Pediatrics, can play a critical role in helping to ensure that all eligible children receive the SSI cash and associated benefits to which they are entitled. These efforts should include:
• providing information about the SSI program to families;
• increasing their knowledge about the SSI program and providing specific, detailed reports to the DDS in support of children's applications for SSI benefits; and
• advocating for better reimbursement and improved methods for providing reports to the DDS.

The SSA has a variety of brochures designed to inform families about the SSI program. Physicians and state chapters should contact their local SSA field office to develop ways for making this information available through physicians' offices.

The SSA and state DDS units have designated the staff responsible for educating the professional community about the SSI program. The chapters of the American Academy of Pediatrics should invite the staffs of the SSA and DDS to participate in local and state-wide educational meetings and workshops. This will help ensure that the pediatric community is informed about the SSI program and skilled in providing medical evidence to support their patients' applications for SSI benefits. Such efforts can also help to develop working relationships between these agencies and the pediatric community.

Reimbursement for reports provided by physicians to the DDS is generally considered inadequate. State chapters can advocate for change in the reimbursement schedule and can also work with the state DDS unit to develop more efficient methods for providing reports. Some state DDS units have implemented a system whereby local physicians can call the DDS office and dictate their report on a child applicant. The DDS takes responsibility for transcribing this information and entering it into the child's application. Some state DDS agencies also provide report outlines to help focus the information on the pediatrician's report. Other agencies also use a professional advisory board. State chapters can advocate for the use or expansion of such a board to ensure that there is a good working relationship between the agency and the pediatric community.

These activities will help ensure that the SSI program is implemented more fully and that low-income, disabled children and their families receive the support and benefits they need.

APPENDIX A: SSI SCREENING—PARENT TO CHILD DEEMING

TABLE. Monthly Deeming Breakeven Points for Federal SSI Payment, Effective January 1, 1994, Through December 31, 1994*

(All income must be below the following amounts)

<table>
<thead>
<tr>
<th>No. of Ineligible CHILDREN</th>
<th>All Income Is Work Income</th>
<th>All Income Is Nonwork Income†</th>
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<tr>
<td></td>
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<td>$3469</td>
</tr>
<tr>
<td>6</td>
<td>$3246</td>
<td>$3692</td>
</tr>
</tbody>
</table>

* Notes:
1. These income amounts refer to eligibility for the federal benefit only. Add the applicable state supplementation amount to these amounts.
2. All amounts assume that all children have no income and there is only one eligible child in the household. In any other case, refer to SSA.
3. For each additional ineligible child in the household (over six ineligible children), add $218 to the amount shown.
4. This chart does not work if the ineligible parent(s) has/have both work and nonwork income.

† Common types of income not counted in deeming:
1. Public income maintenance payments.
2. Income used to figure public income maintenance payments.
3. Foster care payments.
4. Food stamps, Department of Agriculture donated foods.
5. Income set aside under a plan for self-support.
6. Income used to pay court-ordered or Title IV-D support payments.
7. The value of in-kind support and maintenance.
‡ For a two-parent household, even if only one parent has income.

APPENDIX B: SSI CITIZENSHIP AND RESIDENCY ELIGIBILITY CRITERIA

To be eligible for SSI, a child must be a U.S. citizen or a naturalized citizen. The SSA defines a child as an individual who is younger than 18 years or younger than 22 years and a student, not married, and not the "head of a household." Children authorized to remain in the U.S. 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 U.S. Virgin Islands may be U.S. citizens but do not meet the SSI requirements for residency. The exception is children of military personnel who are assigned overseas duty.

APPENDIX C: WHAT TO TELL FAMILIES ABOUT SSI APPLICATION, DISABILITY DETERMINATION, AND APPEALS PROCEDURES

How to Apply
To apply for SSI benefits for a disabled child, a parent must complete, sign, and file a form that can be obtained by either

- visiting the local SSA field office or
- calling the SSA's toll-free number (1–800–772–1213) to make an appointment for a telephone interview.

Telephone Interview
If parents make an appointment for a telephone interview by calling the toll-free number, they should be contacted by staff of the SSA's telephone screening service. The interviewer will provide general information to parents about the medical, disability, and functional criteria that are used in determining eligibility for SSI. Information about disability criteria is provided to help parents decide whether they should proceed with the application process. The SSA prefers that parents use the telephone screening 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 (or does not appear) 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 will be sent by mail to their home;
- 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" and, if the child is found to be eligible for SSI, benefits will be paid back to this date;
- they should keep a record of all contacts with the SSA, including the date and the person with whom they spoke;
- the process of determining disability can take 2 to 3 months; and
- financial eligibility for young adults 18 years or older is based on what they own and/or earn; 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 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 time the parents have to wait when filing an application.

If parents have a problem gathering all of the required information, they should still go to the SSA field office to begin the application process to establish a protected filing date. When the SSA has the needed information about family income and financial resources, financial eligibility for SSI will be determined.

Suggested Readings
Sullivan v Zebley, 88–1377 (U.S. Supreme Court, 20 Feb 1990)
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*Pediatrics* 1995;95;603

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