

Chapter Four

Recommendations to Congress

1. Purpose of the Supplemental Security Income (SSI) Childhood Disability Program

Current Law

Title XVI of the Social Security Act provides no statement of the purpose of the Supplemental Security Income program. The 1972 House Committee on Ways and Means report which accompanied the legislation that established SSI stated that:

... disabled children who live in low-income households are certainly among the most disadvantaged of all Americans and ... they are deserving of special assistance in order to help them become self-supporting members of our society. Making it possible for disabled children to get benefits under this program, if it is to their advantage, rather than under the program for families with children, would be appropriate because their needs are often greater than those of non-disabled children. The bill, accordingly, would include disabled children under the new program.

The Senate Committee on Finance disagreed with the Committee on Ways and Means report. The Committee report stated:

The House justified its inclusion of disabled children under age 18 under aid to the disabled, if it is to their advantage, rather than under the program for families with children, on the grounds that their needs are often greater than those of non-disabled children. The needs of disabled children, however, are generally greater only in the area of health care expenses. In all but the two States that do not have Medicaid programs, children now eligible for cash assistance are covered under existing State medical assistance programs. Disabled children's needs for food, clothing, and shelter are usually no greater than the needs of non-disabled children.

The Senate ultimately receded in conference to the House position on this issue. The conference report does not include an explanation for this decision.

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Reason for Change

The ambiguity in the fundamental purpose of the SSI childhood disability program makes it difficult to assess the program's success. Legislative clarification of the purpose of the program is needed in order to ensure that the program is meeting its objective.

Recommendation

The Commission recommends that the SSI statute be amended to state that the purpose of the SSI childhood disability program is to assist low-income families (and other individuals and organizations) who care for eligible children with disabilities in:

- (a) providing basic necessities to maintain a child with a disability at home or in another appropriate setting;
- (b) covering the additional costs of caring for and raising a child with a disability;
- (c) enhancing the child's opportunity to develop; and
- (d) offsetting lost family income because a parent (or parents) remains out of the labor force or underemployed to care for the child.

2a. Treatment of Retroactive Lump-sum Benefits

Current Law

When SSA awards SSI benefits to an applicant and determines that he or she became disabled prior to the award date, the agency pays the individual a retroactive lump-sum benefit for the period that lapsed since the onset of the disability (but no earlier than the individual's application date). In some cases, the period between onset of the disability (or application date) and the award of benefits can be lengthy, perhaps because of delays in obtaining medical evidence or because the individual successfully appealed an initial denial. As a result, the retroactive benefit payment can be large. To enable SSI recipients to make optimal use of retroactive benefits, the Social Security Act (section 1613(a)(7)) allows a six-month exclusion of these benefits from countable resources. In the absence of this exclusion, the retroactive lump-sum payment could make the SSI recipient ineligible unless it were spent immediately.

Reason for Change

The six-month exclusion of retroactive lump-sum benefits from countable resources is particularly burdensome for children, who may require, or benefit from, these resources for education, training, or treatment of a disability. This provision serves as a disincentive for parents and other representative payees to spend such sums on the disability-related needs of the child and prevents the conservation of resources for the child's long-term benefit.

Recommendation

The Commission recommends excluding retroactive lump-sum benefits from a child's countable resources. The Commission also recommends requiring that these benefit payments be spent to cover the cost of needs related to the child's disability or to increase his or her independence over the long term.

2b. Continued Medicaid Eligibility for Children Who Lose SSI Eligibility

Current Law

Currently, 38 states and the District of Columbia use SSI criteria to determine Medicaid eligibility for children with disabilities. Thus, when a child is no longer eligible for SSI, he or she loses that link to Medicaid. If the child meets the eligibility criteria for another program linked to Medicaid, then he or she can continue to receive Medicaid services; otherwise the child loses Medicaid eligibility. Since the income thresholds for other programs with links to Medicaid are much lower than that for SSI, some children do not qualify for other programs and therefore lose Medicaid eligibility when they leave the SSI rolls.

In 1994, a child with a disability living with both parents could receive the maximum SSI benefit if the family's earned income was less than \$17,500. If the parents' income was less than \$28,200, the child was eligible for a reduced benefit. The federal poverty rate for a family of three in 1994 was \$11,817, so the SSI thresholds were approximately 150 percent and 240 percent of the poverty level, respectively. By contrast, the average Aid to Families with Dependent Children (AFDC) threshold in 1994 for a family of three was \$5,296, or 44 percent of poverty, and the average threshold for Medically Needy programs was \$6,347, or 53 percent of poverty.¹

Children who no longer meet the SSI eligibility criteria may still qualify for Medicaid in one of the following ways:

- 1) AFDC and AFDC-UP - Eligibility for AFDC is restricted to single-parent families or, for AFDC-UP, to two-parent families where the primary wage earner is unemployed. In the latter case, states are allowed to limit benefits to as few as six months in a 13 month period. Since the income standards for AFDC are substantially lower than those for SSI, many children who qualified for SSI will be ineligible for AFDC.
- 2) Medically Needy - Families whose incomes are too high for AFDC, but who have extraordinarily high medical expenditures, may qualify for a state's Medically Needy program. If, after subtracting medical expenses, a family's income is below the state's Medically Needy threshold, then the family may

¹ The SSI payment level is established by the federal government. AFDC payment standards are set by individual states. As a result, AFDC support available to families with children varies sharply across the nation. For example, in January 1994, a family of four residing in Suffolk County, New York, could qualify for financial support of up to \$703 per month. In Mobile, Alabama, the same family would have received a maximum of \$164 per month. Committee on Ways and Means, U.S. House of Representatives, *Overview of Entitlement Programs*, July 15, 1994, p. 1148.

qualify for Medicaid services. States are allowed to set their own thresholds up to 133 percent of the state's maximum AFDC payment for a family of similar size. Only 31 states and the District of Columbia offer a Medically Needy program. If a state offers this program, it must include all children under age 18 who "spend down" to the income threshold.

- 3) "Safety net" programs - States are required to provide Medicaid coverage to all children under age 19 who were born after September 30, 1983, and whose family incomes are below 100 percent of the federal poverty level. In addition, states are required to cover all children under age six whose family incomes are below 133 percent of the federal poverty level. Many states have expanded their eligibility criteria to include older children and/or children at higher income levels. Few states have expanded their programs to cover children up to age 19, however, and few states that do include older children include those above 100 percent of poverty.

As a result of the restrictions, a child who loses SSI eligibility may not be able to access services through Medicaid, especially if the child lives in a two-parent family.

Reasons for Change

The link between SSI and Medicaid penalizes families who provide their children with treatment and services necessary for improvement. This is because a child who loses Medicaid by becoming ineligible for SSI may not be able to access necessary services if his or her family does not qualify for the other programs and cannot afford private insurance.

Take, for example, an eleven-year-old child who receives Medicaid services via his or her eligibility for SSI. The child receives treatment through Medicaid and shows improvement. As a result, the child is found no longer to meet the SSI disability criteria. Both parents work, so the family cannot qualify for AFDC or AFDC-UP. The state does not have a Medically Needy program, and the child cannot qualify under the expansion of eligibility criteria because the family's income is too high. The state's "safety net" program includes children below 100 percent of poverty and the child's family is at 150 percent of poverty. Since the child does not meet the eligibility criteria for any of the programs with links to Medicaid, the child loses his or her Medicaid eligibility. The private insurance available to the family does not cover the child's impairment, so the child discontinues treatment. Without treatment, the child's condition deteriorates.

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Recommendation

The Commission recommends continuing Medicaid eligibility for children who leave the SSI rolls due to medical improvement but who need treatment to maintain their improved condition, so long as the child meets SSI income and asset tests and is under age 18.

2c. Increase Earned Income Exclusion for Students Who Are Minor Siblings of Children Who Receive SSI

Current Law

When determining a child's financial eligibility for SSI, SSA considers the income of the child's parents if they and the child live in the same household. After excluding certain amounts of the parents' income, SSA "deems" the remaining income as available to the child with a disability.

Among the exclusions that are allowed in the deeming formula is an allocation for each ineligible child in the household. This allocation is intended to recognize the costs that the parents incur in caring for the ineligible child. In 1995, this allocation is a maximum of \$229 per month. If the ineligible child is not working, \$229 is subtracted from the family's countable income each month. However, if the ineligible child has income, earned or unearned, that is countable under SSA regulations, the allocation is reduced or eliminated. (The allocation is also eliminated for any ineligible children receiving public assistance payments such as AFDC.)

Those minor siblings who are students may earn a limited amount of income without reducing their allocation as an ineligible child under the deeming formula. Intended as a work incentive, this amount is \$400 per month or \$1620 per year.

Reasons for Change

The rules which allow ineligible children to earn limited amounts of income while in school, without causing a reduction in their allocation under the deeming formula, are intended as a work incentive. However, the amounts of income which can be excluded under these rules -- \$400 per month and \$1620 per year -- were set in 1972 and have not been increased since. Inflation has eroded the value of these exclusions substantially over the last three decades.

The problem is illustrated by the following example. Assume that a two-parent family has one child with a disability and an ineligible teenager who works during the summer. The teenager earns a total of \$700 per month. The amount the family can allocate for the living expenses of the teenager is affected as follows:

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\$700 teen's earned income
- \$400 earned income exclusion
\$300 teen's countable income

\$229 maximum allocation under deeming
- \$300 teen's countable income
\$-71 amount exceeding maximum allocation

Because the teen's countable earnings (\$300) are greater than the maximum allocation allowed (\$229), the family cannot allocate any of the family's income for his or her living expenses. As a result, the amount of parental income available to the child with a disability increases, causing the child's benefit to be reduced.²

Recommendation

The Commission recommends that the earned income exclusion for students who are minor siblings of children receiving SSI be increased to \$1,200 per month and \$10,000 per year. It also recommends that these amounts be adjusted annually for inflation.

² The amount of this reduction is dependent upon whether the parents' income is earned or unearned. If the parents' income is earned, the SSI payment to the child with a disability is reduced by \$114.50, or one-half the maximum allocation for the ineligible child. If the parents' income is unearned (e.g., Social Security benefits), the SSI payment to the child is reduced by the full \$229.

**2d. SSI Eligibility for Children With Disabilities Whose Parents Are
Military Personnel**

Current Law

Children with disabilities whose parents are military personnel stationed overseas are eligible to receive SSI benefits if such benefits were applied for and awarded while the child was residing in the United States. Children born overseas or those who become disabled while living overseas are ineligible for participation in the SSI program.

Reason for Change

The Commission believes it is a matter of fairness to allow the children of overseas military personnel to become eligible to participate in the SSI program. The expansion of coverage could help a small number of children (estimated in January 1993 to be less than 50 by the Department of the Army's Office of the Surgeon General) who otherwise could not participate in the program because of residence abroad.

Recommendation

The Commission recommends expanding SSI eligibility for children with disabilities whose parents are military personnel to include those who apply while overseas.

2e. Public/Private Partnerships to Improve Service Delivery to Children Who Receive SSI

Current Law

Children with disabilities may be eligible for a variety of federal and state programs which provide cash benefits, access to medical care and social services, service coordination, and education. The following list, which is not exhaustive, indicates the scope and range of such programs:

- * Children's SSI disability program, authorized under title XVI of the Social Security Act, including Plan for Achieving Self Support (PASS);
- * Title II Social Security benefits for children of workers who are retired, disabled, or deceased (these Social Security dependents benefits are paid to both children with disabilities and children who are not disabled);
- * Maternal and Child Health block grant programs authorized under title V of the Social Security Act, including title V Children with Special Health Care Needs programs in the states;
- * Medicaid, authorized under title XIX of the Social Security Act, including the Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) program;
- * Aid to Families with Dependent Children, authorized under title IV-A of the Social Security Act (not available to a child who receives SSI benefits, but could be available to other family members);
- * Food stamps, administered by the Department of Agriculture;
- * Women, Infants, and Children (WIC) nutrition program, administered by the Department of Agriculture;
- * Education Programs: Individuals with Disabilities Education Act (IDEA), including Part B, authorizing a free and appropriate education to all school-age children with disabilities; and Part H, authorizing comprehensive early childhood services to infants and toddlers who meet state eligibility criteria; title I of the Elementary and Secondary Education Act, as amended by Improving America's Schools Act of 1994 (Public Law 103-382), which provides supplemental assistance to school districts and schools in high poverty areas to help low-achieving students; and Goals 2000: Educate America Act (Public Law 103-227), which provides funding for a wide range of educational reforms, including innovations in special education;

- * Work Training: Vocational Rehabilitation, School-to-Work Transition Programs, and the Job Training Partnership Act (JTPA);
- * Administration on Developmental Disabilities, including state Protection and Advocacy Systems; basic state grant programs, including the state Developmental Disabilities Planning Councils; University Affiliated Programs; and Projects of National Significance;
- * State and Local Developmental Disabilities/Mental Retardation and Children's Mental Health programs; and
- * State Family Support Programs.

Note: Not all the programs listed above are available in every community. However, those authorized in federal or state law as entitlements to individuals (e.g., SSI and Medicaid) must be available to all children and/or families who meet eligibility criteria.

Reasons for Change

Section 202(e)(2)(C) of Public Law 103-296 requires the National Commission on Childhood Disability to determine

... the extent to which the Social Security Administration can involve private organizations in an effort to increase the provision of social services, education, and vocational instruction with the aim of promoting independence and the ability to engage in substantial gainful activity ...

In response to this requirement, the Commission established a Task Force on Public-Private Partnerships. The task force identified two key areas in which private and other relevant organizations can assist families of children receiving SSI and seven areas in which such organizations can work with SSA to improve service delivery to children and families. The areas of direct assistance to families are:

- * making critical choices on the use of SSI cash benefits to meet the child's immediate and longer term needs, including options for education, assistive technology, specialized care, and treatment; and
- * developing a record keeping system which enables the family to respond to requests from SSA and other government and private agencies.

Seven additional areas in which private organizations can assist SSA in improving service delivery to families are:

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1. Information and Referral - Local and state private non-profit organizations can serve as information clearinghouses for families of children receiving SSI, helping them to identify and access other public and private programs for children with disabilities. These organizations can disseminate information on application procedures, eligibility requirements, program parameters, and funding sources. They can also link families with services such as parent-to-parent support, recreation opportunities, counseling, tutoring, specialized day care, technical assistance in meeting SSI requirements, transportation, home and equipment retrofits, financial management, and transition to adult programs.
2. Outreach - In recent years, SSA has conducted successful outreach programs aimed at identifying eligible children with disabilities. As part of this effort, it has contracted with many local, state, and national private non-profit organizations. Some of these organizations have provided families with assistance in applying for SSI benefits.
3. Service Coordination - As noted above, families of children receiving SSI also frequently participate in a number of other services and programs. Most such programs have service coordinators. In fact, many children have more than one service coordinator. Whether there are several service coordinators or none, access to a service coordinator from a local private non-profit organization can help ensure that a child is receiving whatever services are needed. Service coordination can be of particular importance when a child's condition or circumstances change and during transition into adult programs.
4. Rights and Benefits Counselors - Counselors may be useful in helping families of children with disabilities in understanding their rights, benefits, and entitlements; in obtaining benefits to which they are entitled; and in providing access to the justice system by offering advocacy, advice, and representation. The Wisconsin Legal Assistance/Benefit Specialist Program, which provides legal assistance under the Older Americans Act of 1965, provides a good prototype for the structuring of such programs for children with disabilities.
5. Advocacy - Families who choose to raise a child with a disability at home frequently encounter problems in accessing needed programs and services. For example, a family that speaks a language other than English, lacks a telephone, lives in a rural area without transportation, or has other children who also require care may have difficulty accessing SSI and other programs. During the application process, private organizations can assist such families with translation, transportation, and obtaining needed documents. They can also provide ongoing assistance in working with a government agency on a child's behalf.
6. Access to Transition Services and Supported Employment Opportunities - While the existing section 1619 program and Plan for Achieving Self-Support (PASS) provide financial incentives to secure employment, young adults in the SSI program may require additional services to achieve work success. These include school to work/community transition plans, an inventory of the student's skills, an inventory of community job opportunities, job training, access to job coaches, and supported employment opportunities. In many communities,

private non-profit organizations work with public sector agencies to facilitate the transition of a young adult with disabilities from secondary school to working and living in the community.

7. **Training** - Families frequently require training and technical assistance to establish their child's eligibility for SSI and to document their use of cash benefits. At the same time, professionals who work within the SSI program, especially disability examiners, require a detailed understanding of the impact of childhood disabilities. Private non-profit organizations can provide both kinds of training, using experienced parents to assist in training efforts.

Recommendation

To encourage public-private partnerships in the areas described above, the Commission recommends that:

- * SSA should establish a federal Advisory Committee on Public-Private Partnerships. The Advisory Committee would guide SSA in establishing additional partnerships with private organizations, including setting annual goals and formulating strategies to achieve them. The Committee should include representatives from SSA, the Maternal and Child Health Bureau, the Office of Special Education and Rehabilitative Services, the Health Care Financing Administration, the Administration on Developmental Disabilities, and the Substance Abuse and Mental Health Agency. Representation should also include national disability advocacy, family, and service provider organizations; colleges and universities; and medical associations.
- * The Advisory Committee should treat SSI Outreach as a model. In recent years, state and national outreach initiatives have targeted specific populations or programmatic goals, and the mechanics of SSI Outreach have involved soliciting requests for proposals (RFPs) for state and national contracts. Both these practices have proven successful and should be treated as a model for other public-private partnership activities.
- * Local Social Security offices should compile and disseminate information about other services, supports, and benefits for children receiving SSI and their families, including public and private projects funded by SSA. SSA should make this information available at the time families apply for benefits, as part of the continuing disability review process, and in the annual notification of the SSI cost-of-living adjustment.
- * SSA should involve families of children receiving SSI in the training of agency staff. Family members and others who care for children with disabilities can provide the agency with valuable insights into the meaning of disability, particularly its functional aspects. SSA should incorporate these insights in training disability examiners, claims representatives, and other staff.

2f. Treat Worker's Compensation and Unemployment Compensation as Earned Income for Purposes of SSI Parent-to-Child Deeming

Current Law

When determining a child's financial eligibility for SSI, SSA considers the income of the child's parents if they and the child live in the same household. After excluding certain amounts of the parents' income, SSA "deems" the remaining income as available to the child.

In the deeming calculation, earned income is treated more favorably than unearned income (as it is under SSI law generally). The initial exclusion applied to earned income is \$65, whereas the initial exclusion applied to unearned income is only \$20. Of the remaining countable earned income, 50 percent is excluded as a work incentive. This 50 percent exclusion is not available for unearned income. The Social Security Act defines unearned income to include:

private pensions	Social Security benefits
disability benefits	veterans' benefits
worker's compensation	railroad retirement annuities
unemployment benefits	alimony
dividends and interest	prizes and awards
rent received from property	

The more favorable treatment of earned income can result in children with the same amount of parental income receiving different SSI payments because of the source of the income. For example, if a family of four receives \$1,200 per month in earned income only, then a child with a disability in that family qualifies for the full \$458 monthly payment. However, if the \$1,200 consists entirely of unearned income, then the child qualifies for a monthly payment of \$214.

Reason for Change

In most cases, worker's compensation or unemployment benefits are short-term substitutes for earned income. Parents generally become eligible for such benefits as a result of circumstances beyond their control, such as injury or job loss. Thus, the Commission believes it is a matter of fairness that these wage replacement payments be treated in the same manner as earnings for purposes of SSI parent-to-child deeming.

Recommendation

The Commission recommends that worker's compensation and unemployment benefits be given the same treatment as earned income for purposes of SSI parent-to-child deeming.

3. Recommendations to Strengthen the SSI Definition of Childhood Disability

Present Law

The Social Security Act requires that SSI benefits be awarded to children with impairments that are comparable in severity to those that would prevent an adult from working. Under SSA's eligibility determination procedures, children may meet this standard in one of two separate ways.

First, a child's impairment may meet or equal one of SSA's listings of medical impairments. SSA treats these listings as *prima facie* evidence of disability and does not, in general, require a functional evaluation of children with listed impairments.

The major exception to this rule applies to children with mental impairments. Here, SSA has included functional criteria in most of its medical listings. To be awarded benefits, children must demonstrate *both* that they have a listed mental impairment and that it causes marked limitations in at least two of four functional domains. For children ages three and older, these domains are:

- * cognitive-communicative functioning;
- * social functioning;
- * personal/behavioral functioning, including
 - activities of daily living,
 - maladaptive behavior; and
- * concentration, persistence, and pace.

Under SSA's listings, children may also qualify for benefits by showing they have an impairment or combination of impairments that "functionally equal" a listed impairment. To do so, a child must show that his or her impairment (which need not be one included in the listings) or combination of impairments causes the same restrictions required under the functional criteria in a listing.

The second path to SSI eligibility applies to children who do not have impairments that meet or equal the listings. These children may qualify for SSI by demonstrating a substantial reduction in their ability to function independently, appropriately, and effectively in an age appropriate manner. SSA makes this determination using an Individualized Functional Assessment. Created in response to the 1990 *Sullivan v. Zebley* Supreme Court decision, the IFA has less stringent eligibility criteria than the functional test in SSA's mental impairments listings. SSA provides guidelines stating that generally, but not always, a child will be found disabled when his or her physical or mental impairment causes moderate functional limitations in at least three of six functional domains *or* one marked and at least one moderate limitation in two of these six domains. For children ages three and older, the IFA domains are:

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- * cognitive functioning;
- * communicative functioning;
- * motor functioning;
- * social functioning;
- * personal/behavioral functioning; and
- * concentration, persistence, and pace.

Options for Change

The Commission regards functional assessment as an essential part of disability evaluation for children. The most valid test of a disabling impairment is, and must be, a functional one. Given the variety of childhood impairments, a medical listings-only approach to disability determination would inevitably prevent some children with rare conditions from establishing SSI eligibility. Such an approach would also unfairly deny benefits to children with combinations of impairments, no one of which is disabling alone. For these reasons, the Commission strongly supports the retention of an individualized functional evaluation in SSA's eligibility determination process and favors assigning it greater importance in the medical listings of impairments.

The Commission also agrees that the criteria which SSA now uses to award benefits based on impeded functional capacity need to be strengthened. However, on a vote of seven to seven, the Commission was divided between two options for accomplishing this task. The following paragraphs summarize the areas of agreement, the rationale for differences, and the two alternative proposals.

Areas of Agreement: The Commission recommends --

- a. Eliminating the double counting of maladaptive behavior by deleting it from the personal/behavioral domain in the SSI childhood mental impairments listings. As a result of this change, maladaptive behavior would be considered for diagnosis and for its impact on remaining domains, but would no longer be of domain level alone. This deletion would leave activities of daily living (ADLs) under the personal domain, which would correspond to SSA's existing criteria for adults.
- b. Providing only Medicaid for children who meet current SSI eligibility criteria but who would not meet the stricter standard(s) proposed by the Commission. Under one option for tightening eligibility ("I" below), Medicaid would generally be provided to children with moderate limitations in at least three functional domains or one

marked and at least one moderate functional limitation.³ Under the second option (see "II"), Medicaid would generally be provided to children with three or more moderate functional limitations.

- c. Requiring that, after all available evidence has been obtained, if SSA judges that such evidence could support a severity determination of either "marked" or "moderate" in a particular functional domain, a presumption that the limitation is "marked" would be applied.

Strengthening SSI Eligibility Criteria: Two Options

OPTION I

Rationale:

To achieve basic fairness, SSA's process for eligibility determination must include a means by which children with rare impairments or combinations of impairments can demonstrate that they have a qualifying disability. This need is met under the agency's current procedures by both the "functional equals" step in the medical listings and the Individualized Functional Assessment. As presently designed and implemented, however, the IFA is problematic in three ways.

First, it provides for benefit allowances based in whole or in part on "moderate" limitations. The moderate criterion for functioning in any one domain seems reasonable on the surface, but it creates much opportunity for variation in assessment by adjudicators. Despite SSA's definition of moderate by standard deviations, the reality is that children rarely come with testing that allows determination of one or two standard deviations. Even where standard tests exist for several domains, reliable data on developmental variations only occasionally provide a basis on which to determine whether the child meets the definition of moderate. Mental health practitioners also note much greater agreement among observers and testers when mental impairments are severe (or marked) rather than moderate. Thus, keeping moderate as a criterion leaves the program continually susceptible to attack for providing inconsistent (and easy) criteria for enrollment.

A second problem with the IFA is the existence of overlap among its functional domains. This overlap can lead to double counting of certain impairments. In its study of the use of the IFA by state disability determination services (DDSs), the HHS Inspector General reported that double counting appears to exist among several domains: personal-

³ SSA guidelines state that a child will generally, *but not always*, be found disabled when his or her physical or mental impairment causes moderate functional limitations in at least three of six functional domains or one marked and at least one moderate limitation in two of these six domains.

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social, cognition-communication, and cognition-concentration.⁴ A similar potential exists with respect to maladaptive behavior, only here the problem is more far reaching, encompassing both the IFA and the mental impairments listings. A child with a behavioral disorder that is manifested by maladaptive behavior toward teachers and classmates may have this behavior counted in both the personal domain and the social domain, under both the IFA and the mental impairments listings.

Third, SSA's guidance to adjudicators for using the IFA provides no firm rule for when to allow benefits. Rather, as described previously, SSA provides examples of combinations of moderate limitations and marked and moderate limitations that are frequently disabling. At the same time, SSA advises adjudicators that, after completing an IFA, they should "step back," review all the evidence, and make a global decision about whether a child is disabled. This guidance is an additional source of subjectivity in the IFA process.

All three of these problems are rooted in the lack of a clear rationale for SSA's policy that at least three moderate limitations or a combination of a marked limitation and at least one moderate limitation in two of six functional domains could (but may not) demonstrate a child's disability. SSA's establishment of this process seems to have been a somewhat arbitrary effort to respond to the *Zebley* decision with a less severe standard than was provided under the listings, even with the innovation of functional equals (which SSA also introduced in response to *Zebley*). The IFA process can be viewed as a variation on the functional equals concept, but with no clear rationale for why this approach will reliably establish that a child has an impairment of comparable severity to a disability in an adult. Moreover, it should be noted that the process of assessing disability by way of examples of marked and moderate impairments was not a recommendation of the experts who assisted SSA when it wrote the regulations in response to *Zebley*, but was added in the final drafting after the last meeting of that group.

Proposal:

This option would retain an individualized functional evaluation as an integral part of the disability determination process for children but increase the stringency of the functional test. This result can be achieved by establishing a new standard for evaluating childhood impairments which is based on, and builds upon, the "functional equals" step in SSA's current sequential evaluation process.

⁴ Department of Health and Human Services Office of Inspector General, *Supplemental Security Income: Disability Determinations for Children with Mental Impairments*, January 1995.

This option would:

- * Establish a new statutory standard requiring that individuals under age 18 be determined disabled for purposes of SSI only if they have a medically determinable physical or mental impairment, or combination of impairments, which --
 - (a) can be expected to result in death or which has lasted or can be expected to last for a continuous period of at least twelve months, and
 - (b) is of such severity as to cause marked limitations affecting at least two major domains of functioning or development appropriate to the age of the individual or to cause an extreme limitation in one major domain of functioning or development.

Notwithstanding the foregoing provisions, no individual under age 18 shall be considered to be disabled if he or she is engaging in substantial gainful activity.

The pragmatic effect of this change would be to eliminate SSI benefit allowances based in part or in whole on moderate limitations.

The new definition would require the development of domains which measure a broader range of limitations than the domains currently in SSA's mental impairments listings.⁵ While the definition of specific domains would be left to regulation, this task should be undertaken with close reliance on the fields of mental health, child health, pediatrics, and child development, where the concept of "domains" is used widely in assessing disabilities in children. Further, SSA should define the domains that it establishes pursuant to this definition so as to minimize their overlap.

⁵ Because they focus on mental disabilities, the mental impairments listings do not include a motor domain, nor do they include a domain which measures stamina.

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The following seven Commission members supported this option:

Jim Slattery, Chair

Adrienne Asch, Ph.D.
Wellesley College

Dolores Berkovsky, M.S.N., L.M.S.W.
St. Teresa's Home, Catholic Charities

Wade F. Horn, Ph.D.
National Fatherhood Initiative

James M. Perrin, M.D.
Massachusetts General Hospital

Carol Rank, M.S., M.P.A.
Kansas Disability Determination
and Referral Service

Barbara Wolfe, Ph.D.
University of Wisconsin

OPTION II

Rationale:

Seven Commission members voted to tighten IFA allowances by permitting allowances based on one marked and one moderate limitation. The pragmatic effect of this change would be to preclude benefit allowances based on moderate limitations in three or more domains. This decision was primarily predicated on the view that too many currently eligible children and future eligibles would be hurt by the adoption of the stricter standard of two marked limitations.

These seven Commission members firmly believe that a number of the Commission's recommendations, taken singly and in combination, will remedy the real and perceived problems with the SSI children's program. Key among these recommendations are:

- * Precluding allowances based on three or more moderate limitations;
- * Eliminating double counting of maladaptive behavior;

- * Performing CDR's every two years for children whose condition is likely to improve;
- * Requiring health care treatment in appropriate cases; and
- * Establishing a sliding benefit scale for families with multiple children receiving benefits.

These seven Commission members believe that moving to the eligibility standard of two marked limitations would be "raising the bar" too high, thus making numerous low-income children ineligible for SSI benefits.

Proposal:

This option would preserve the SSA guideline which permits IFA allowances based on one marked and at least one moderate limitation and continue the use of the IFA for determining eligibility at this stricter level of severity. The pragmatic effect of this change would be to preclude benefit allowances based on moderate limitations in at least three functional domains.

These seven Commission members wish to stress the importance they place on the Commission's unanimous recommendation to establish a presumption that a functional limitation is "marked" in those cases where all medical evidence has been obtained and could support a severity determination of either "marked" or "moderate." They believe that this presumption is particularly important because they want to ensure that, when there is a doubt about children's eligibility, they are allowed rather than denied SSI benefits.

Commission members supporting the second option are:

Polly Arango
Family Voices

Jennifer Howse, Ph.D.
March of Dimes Birth Defects Foundation

Sharman Davis Jamison
Parent Advocacy Coalition Educational Rights Center

Dan Johnson
Madison, Wisconsin

Paul Marchand
The Arc

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M. Carmen S. Ramirez
Executive Board for the Association for People
With Severe Handicaps

H. Rutherford Turnbull, III, LI.B./J.D., LI.M.
Beach Center on Families and Disabilities
The University of Kansas

Options I and II – Fiscal and Program Impacts

According to the Social Security Administration's Office of the Actuary, the SSI childhood disability rolls would be reduced by 260,000 children (both current beneficiaries and new applicants) over five years under option I. This equals approximately 20 percent of caseload. Cumulative program savings would be \$5.8 billion over five years (fiscal years 1996 - 2000).

Under option II, the actuaries estimate that the SSI childhood disability rolls would be reduced by 110,000 children over five years. This equals approximately eight percent of program caseload. Cumulative program savings would be \$2.9 billion over five years (fiscal years 1996 - 2000). The effect of these options on program growth is illustrated in Appendix 7-A.

Assumptions Underlying the Estimates

Assumption #1 -- Program Growth:

SSA used the following caseload baseline in developing both estimates. The baseline represents the average caseload for the fiscal year.

(In thousands)

<u>1995</u>	<u>1996</u>	<u>1997</u>	<u>1998</u>	<u>1999</u>	<u>2000</u>
930	1,028	1,119	1,202	1,279	1,352

This baseline shows caseload growth of approximately 100,000 from 1995 to 1996, declining gradually to approximately 75,000 from 1999 to 2000. Compared to the two-year period preceding this estimate, these numbers represent a lessening of program growth. Caseload increases for 1993 and 1994 were approximately 145,000 and 120,000, respectively.

Assumption #2 -- Allowances Based on Individualized Functional Assessments:

SSA assumes that, absent legislative changes in the program, the IFA share of awards will rise from 32 percent to 35 percent over the next five years.

Assumption #3 -- Number of Children on the SSI Rolls by IFA Allowance Who Could Also Meet the Listings:

SSA assumes that 30 percent of those children terminated from the SSI rolls would requalify for benefits if their claims were more fully documented. SSA bases this estimate on a targeted sample of 600+ case files of children who were allowed benefits based on an IFA.⁶ SSA staff reviewed these files and, based on a combination of analysis and judgment, estimated the portion of each subgroup in the sample who could qualify for benefits by meeting the listings if the agency obtained additional medical evidence of their impairment. Estimates formed from this review were then projected to the universe of children on the SSI rolls, resulting in an average requalification rate of 30 percent.

Assumption #4 -- Allowances Based on Moderate Limitations:

To estimate the number of allowances based on at least three moderate limitations, SSA relied on a coding of such allowances by state disability determination services. This coding system, which has been in place for about 18 months, showed that allowances based on at least "three moderates" constituted just two percent of all allowances. Suspecting under-reporting of moderates by the DDSs, SSA doubled the reported number, raising it to four percent.

Assumption #5 -- Allowances Based on Maladaptive Behavior:

SSA assumes that five to ten percent of allowances would be denied under the Commission's proposal on maladaptive behavior. To develop this estimate, SSA examined a set of cases coded for mental retardation and other mental impairments. After making adjustments for overlap, SSA projected the data to the universe of children receiving SSI.

SSA reports that this five to ten percent range cannot be narrowed to a point estimate because the extent of interaction between the Commission's tighter eligibility standards (that is, two marked limitations or one marked and at least one moderate limitation) and its proposal on maladaptive behavior varies significantly in the SSA estimate according to type of disability.

⁶ Social Security Administration, *Findings from the Study of Title XVI Childhood Disability Claims*, May 1994.

Comparison with Congressional Budget Office (CBO) Estimates

CBO did not provide estimates for options I and II of the Commission recommendations. However, it did estimate legislation introduced by Senator Patrick Moynihan, S. 828, and Senator Kent Conrad, S. 798, which is similar (but not identical) to the Commission's option I and II, respectively.

CBO estimated that Senator Moynihan's bill would reduce SSI rolls by approximately 19 percent over five years. As a result, SSI caseload would be reduced by 239,000 children by the year 2000. Program costs would decline by \$5.3 billion over the years 1996 - 2000. Senator Conrad's bill would reduce SSI rolls by approximately eight percent, meaning 103,000 fewer children would be on the rolls by the year 2000. Program costs would decline by \$2.5 billion from 1996 - 2000.

CBO also estimated that Senator Packwood's welfare reform legislation, approved by the Senate Committee on Finance as H.R. 4, could reduce SSI rolls by ten percent to 28 percent. This range is calculated based on the uncertainty associated with SSA's regulatory interpretation of the revised statute. Of those children currently eligible, ten percent could be rendered ineligible under a loose interpretation of the provisions, whereas 28 percent of children currently eligible could become ineligible under a tight interpretation. In providing a point estimate, CBO judged that 21 percent of children eligible for benefits under current law would be rendered ineligible.

Assumption #1 -- Program Growth:

(In thousands)

	<u>1995</u>	<u>1996</u>	<u>1997</u>	<u>1998</u>	<u>1999</u>	<u>2000</u>
Congressional Budget Office	913	1,000	1,074	1,141	1,200	1,253

The CBO baseline of program growth represents the average caseload for the fiscal year. CBO projects somewhat less growth in the SSI childhood disability program than does SSA. For example, this baseline shows growth of approximately 90,000 from 1995 to 1996, declining to approximately 53,000 from 1999 to 2000.

Assumption #2 -- Allowances Based on IFAs:

CBO assumes that IFA awards will constitute 35 percent of future awards. This is nearly identical to the SSA assumption.

Assumption #3 -- Children on the SSI Rolls by IFA Allowance Who Could Also Meet the Listings:

CBO estimates that 20 percent of those children removed from the SSI rolls will be redetermined eligible. CBO describes this as a somewhat arbitrary but reasonable estimate and points out that the apparent difference between its estimate and SSA's is narrowed if one focuses on the proportion of children who could not meet the listings -- 80 percent versus 70 percent.

Assumption #4 -- Allowances Based on Moderate Limitations:

CBO used data from a January 1995 HHS Inspector General (IG) report to project the number of Individualized Functional Assessment allowances based on "one marked, one moderate," and "three moderates."⁷ The IG report reviewed awards based on mental impairments only (both under the listings and through an IFA), and constructed a targeted sample aimed at identifying cases where parental coaching was possible. Cases were coded for mental retardation, ADHD, and "other." Awards based on mental impairments constitute 85 percent or more of all IFA awards.

Extrapolating from this report data, CBO estimates that about 20 percent of IFA awards are based on "one marked, one moderate," and about 20 percent of such awards are based on at least "three moderates." (Since IFA awards constitute just under 1/3 of total awards, total awards based on at least "three moderates" would be about seven percent, compared to SSA's estimate of four percent.)

Assumption #5 -- Allowances Based on Maladaptive Behavior:

Based on 1994 award data from SSA, the National Academy of Social Insurance (NASI) tabulated that personality disorders (the only category of disorders for which maladaptive behavior is required) constitute three percent of listing awards and four percent of IFA awards. However, noting that maladaptive behavior could constitute an element in many other types of awards, CBO made the rough assumption that removing maladaptive behavior entirely from consideration would bar five percent of listing awards and seven percent of IFA awards.

As stated previously, SSA did not develop a specific estimate for maladaptive behavior but incorporated its impact into the overall estimate for options I and II.

⁷ Department of Health and Human Services Office of Inspector General, *Supplemental Security Income: Disability Determinations for Children with Mental Impairments*, January 1995.

4. Establish A Sliding Scale for Family Benefits

Current Law

Section 1611(b) of the Social Security Act specifies two SSI federal benefit rates, generally referred to as the individual rate and the couple rate. The monthly maximum federal individual rate in 1995 is \$458; the monthly couple rate is \$687. One of the two benefit rates applies to each eligible person in a household regardless of the number of SSI eligibles in the household.

Reasons for Change

Families living in the same household are subject to economies of scale that reduce their per capita living expenses. While federal poverty guidelines take account of these savings, SSI payment levels do not. As a result, SSI payments to families can rise significantly above federal poverty guidelines as the number of eligible members increases.

In 1995, for example, a family that included two SSI recipients is eligible for a maximum federal SSI payment of \$916 per month, or \$80 above the 1995 poverty guideline of \$836. A larger family consisting of four recipients is eligible for a maximum federal SSI payment of \$1,832 per month, or \$570 above the poverty guideline of \$1,262. With eight eligible family members, the maximum federal SSI payment rose to \$3,664, or \$1,548 above the poverty guideline of \$2,116 for that sized unit.

Recommendation

The Commission recommends the establishment of a scale which reduces SSI benefits for each additional child in a family with multiple child recipients. The new poverty scale, developed by the National Research Council, should be the basis for this sliding scale reduction in benefits. Using this scale, the reduction would be determined by taking the number of eligible children in a family to the exponent, .7. This number is then multiplied by the maximum benefit amount (\$458 for 1995). The result is the maximum total monthly benefit that a family could receive for its eligible children collectively. This average weighted number reflects economies of scale in the consumption of food, clothing, shelter, and other items by families of various sizes. It produces the following results:

NUMBER OF CHILDREN	AVERAGE BENEFIT PER CHILD**	MAXIMUM TOTAL MONTHLY BENEFIT****
1	\$ 458	\$ 458
2	372	744
3	329	988
4	302	1208
5	283	1413
6	268	1605
7	256	1788
8	245	1963
9	237	2132
10	230	2300
11	223	2454
12	217	2608

**Total payments to children divided by number of eligible children in the family.

***These benefit amounts are based on the 1995 maximum Federal Benefit Rate (FBR) of \$458 for an individual. Since the FBR is subject to annual cost-of-living adjustments, the benefit amounts under the Commission's proposed scale would also be adjusted annually to reflect cost-of-living adjustments.

5. Require Continuing Disability Reviews (CDRs)

Current Law

Title II of the Social Security Act requires periodic continuing disability reviews (CDRs) of Social Security beneficiaries with disabilities. For those beneficiaries whose impairments are not permanent, CDRs must generally be performed every three years. Beneficiaries with permanent disabilities are required to receive CDRs at such times as the Commissioner of Social Security determines appropriate. CDRs are funded through the administrative budget of the Social Security Administration, which is subject to annual appropriations and falls under the Domestic Discretionary Spending Cap.

Enacted in 1994, Public Law 103-296 (section 208) requires the Social Security Administration to conduct periodic continuing disability reviews of at least 100,000 SSI recipients with disabilities per year for a period of three years (fiscal years 1996-1998). In implementing this requirement, SSA plans to provide CDRs for approximately 20,000 children per year. Public Law 103-296 also requires SSA to reevaluate under adult disability criteria the eligibility of at least one-third of children receiving SSI who turn age 18 in each of the fiscal years 1996, 1997, and 1998. No later than October 1, 1998, SSA must report to Congress on its implementation of both of these requirements.

Reasons for Change

The natural process of growth and development results in changes which may cause some children to overcome their disabilities as they mature. Health care treatment and early intervention may also be effective in remediating some disabilities. For these reasons, it is appropriate to periodically redetermine children's eligibility for SSI benefits. Requiring continuing disability reviews for children who are expected to improve will remove those who are no longer disabled from the SSI rolls, thereby eliminating unnecessary and inappropriate SSI program expenditures.

Recommendation

The Commission recommends that CDRs be performed every two years for children with disabilities who have the likelihood of enough improvement to make them ineligible for cash benefits. SSA would be authorized to conduct CDRs more frequently for some children if determined appropriate. For example, it may be appropriate to provide more frequent CDRs for children with low birth weights or for those who have undergone surgery which is expected to improve the condition.

A revolving fund would be established to finance additional CDRs. Each year, the Commissioner of Social Security would be responsible for estimating the present value of benefit savings resulting from the performance of CDRs during the prior year, and a

percentage of these savings would be credited to the revolving fund. These funds would be available to perform additional CDRs the following year and in future years. For the first two years, the entire amount of the estimated savings would be credited to the revolving fund. In future years, 50 percent of the benefit savings would be transferred to the fund.

The Commission recognizes that the Office of Management and Budget (OMB) generally opposes the establishment of revolving funds which allow benefit savings to be used for additional administrative enforcement activities. The Commission understands that OMB opposition is partly due to the difficulty of estimating accurately the future benefit savings that derive from enforcement activities such as CDRs.

The Commission urges OMB to reconsider this position. While OMB frequently hears claims that additional spending of one kind or another will result in federal savings, its caution in failing to credit any such claim causes it to miss real opportunities to reduce unnecessary spending.

CDRs represent a small investment in program enforcement that can yield a large savings of benefit payments. The Commission is confident that upon examination of the evidence, OMB will conclude that a CDR revolving fund will yield real savings for taxpayers and help restore public confidence in the SSI childhood disability program.

6. Requirement for Treatment

Current Law

In general, SSA regulations require that Social Security and SSI recipients with disabilities undergo treatment when it is prescribed by their physicians. These regulations apply to children as well as adults. If an individual refuses to follow prescribed treatment without justifiable cause, SSA has authority to terminate his or her benefit payments.

SSA can make a determination of failure to follow prescribed treatment only if several conditions are met:

- * Treatment must be prescribed by the physician attending to the individual's medical needs (SSA consultative physicians do not have authority to prescribe treatment).
- * Treatment must clearly be expected to restore ability to engage in substantial gainful activity (SGA).
- * If the individual fails to follow prescribed treatment, he or she must be given the opportunity to cite specific reasons for that decision. Acceptable reasons for declining treatment include:
 - 1) acceptance of prescribed treatment would be contrary to the teachings and tenets of the individual's religion;
 - 2) the individual's fear of a procedure may be so intense as to make the person an unsuitable candidate for the procedure; and
 - 3) affordable services are unavailable in the individual's community.

Reasons for Change

The Commission believes that the SSI program should be structured to aid and encourage children with disabilities to reach their full potential. Consistent with this goal, the Commission believes that appropriate health care treatment should be required as a condition of continuing eligibility for SSI childhood disability benefits when treatment is available, affordable, likely to improve or prevent deterioration in the child's condition, and developed by qualified professionals in collaboration with the family.

Two features of SSA's current regulations concerning treatment make it difficult to achieve this objective. First, under its current rules, SSA must establish a clear link between participation in treatment and restoration of capacity to work (or, in the case of a child,

restoration of capacity to engage in age appropriate behavior). This is a high standard which precludes requiring treatment in those cases where it would be likely to improve or prevent deterioration in the individual's condition but where its effect in restoring capacity to work (or age appropriate behavior) cannot be predicted with certainty.

Second, SSA may require treatment only after a treating physician prescribes it. Further, if an individual receives conflicting opinions from two physicians, he or she may follow either opinion. These requirements provide substantial discretion to pursue treatment or decline to do so; hence, SSA's rule is effectively applicable only when an individual is willing to have treatment prescribed.

Recommendation

The Commission recommends that children with disabilities be required to undergo appropriate health care treatment as a condition of continuing SSI eligibility in those situations where treatment is:

- * readily available in the child's community;
- * affordable to parents;
- * likely to result in improvement or prevent deterioration in the child's condition; and
- * developed by qualified professionals in collaboration with the family.

SSA would be authorized to recognize other good cause exceptions to this requirement.

Children who are terminated for failure to participate in treatment would continue to be eligible for Medicaid.

7. Provide Categorical Eligibility for Medicaid for All Children Receiving SSI

Current Law

In general, states are required to extend Medicaid eligibility to individuals who receive SSI benefits. However, states may use more restrictive eligibility standards for Medicaid if they were using those standards immediately before the implementation of the SSI program. States that have chosen to apply at least one more restrictive standard are known as section 209(b) states, after the relevant section of the Social Security Act Amendments of 1972. These states vary in their definition of disability or in their standards related to income and resources. There are eleven 209(b) states:

Connecticut	Minnesota	Ohio
Hawaii	Missouri	Oklahoma
Illinois	New Hampshire	Virginia
Indiana	North Dakota	

By federal law, 209(b) states must allow applicants to deduct medical expenses from income in determining eligibility. This process is known as a "spend-down."

Children receiving SSI who do not meet the more restrictive Medicaid eligibility criteria that apply in 209(b) states might still qualify for Medicaid in one of two ways:

- * If the child's medical expenses are high in relation to the family's income, he or she may qualify under a state Medically Needy program. This is, however, an optional program that is available in only 31 states and the District of Columbia. Moreover, federal law mandates that a state's Medically Needy threshold cannot exceed 133 1/3 percent of the state's maximum AFDC payment for that sized family. Since Medically Needy thresholds are typically low, there are families who, even after deducting medical expenses, will not qualify because their remaining income is above the eligibility threshold.
- * The child may qualify for poverty-related Medicaid coverage. However, such coverage is mandatory for only two groups of children: children under age six with family incomes at or below 133 percent of the federal poverty level, and children born after September 30, 1983, with family incomes at or below 100 percent of the federal poverty level.

Reasons for Change

The restrictions on eligibility in 209(b) states can preclude children receiving SSI from obtaining health care treatment that is critical to prevent deterioration in their conditions or to ensure medical improvement. The Commission's recommendation for a treatment requirement for children receiving SSI makes the elimination of this barrier particularly important.

Recommendation

The Commission recommends repeal of the 209(b) Medicaid option as it applies to children who receive SSI (or would be considered SSI-eligible for Medicaid purposes). This ensures that children who qualify for SSI in all states will also be eligible for Medicaid.

8. Revise Reporting Requirements for Children's Representative Payees

Current Law

The Social Security Act requires the Commissioner to establish a system of payee accountability monitoring, whereby representative payees report no less often than annually. The Act also states that the Commissioner must establish and implement statistically valid procedures for reviewing accounting reports to identify instances in which payees are not properly using beneficiary payments. The Social Security Act is silent, however, regarding the procedures SSA is to use for representative payee accounting.

Reason for Change

SSA spends an estimated \$7.2 million on representative payee accounting for children receiving SSI. However, the usefulness of the information obtained is limited. SSA's current representative payee accounting form asks only broad questions about the use of the beneficiary's payments, and SSA does not routinely ask for collateral verification of expenditures (e.g., receipts) or verification of responses written on the form. Also, SSA's current systems do not permit electronic storage of payee responses and do not tabulate cumulative data obtained from the forms. As a result, SSA has no way to analyze or report trends regarding uses of recipient funds.

Recommendation

The Commission recommends elimination of the annual reporting requirement and existing reporting form for representative payees of children receiving SSI. Instead, periodic random surveys of these payees should be required. SSA should notify all individuals when initial eligibility is established (or when there is a change of payee) of the survey process, of the questions that would be asked, and of how long records should be retained. The surveys should be designed to elicit more extensive information about the child's disability, treatment, and use of SSI benefits.

The Commission notes that the cost of SSA's representative payee reporting system as a whole exceeds \$60 million annually. Having found this system to be of little value in monitoring the expenditures of children's representative payees, the Commission recommends that Congress undertake a review of the system as a whole to determine whether this level of expenditure is justified.

9a. Exempt Parents of Children Receiving SSI from Welfare Work Requirements and Time Limit on Benefits

Current Law

The Social Security Act places no limit on the time that an individual may receive AFDC benefits as long as he or she is eligible.

Individuals who receive AFDC are required to participate in a state's job opportunities and basic skills training program if available in the recipient's area. However, individuals are excluded from this requirement if they are "needed in the home because of the illness or incapacity of another member of the household" (section 402(a)(19)(C)(ii)).

Reasons for Change

Legislation to reform the welfare system is under consideration in Congress. In both the House of Representatives and the Senate, legislation has been approved which would eliminate the federal entitlement to AFDC benefits and establish a state block grant for temporary assistance to needy families. If Congress determines that eligibility for this block grant should be time-limited and/or include a work requirement, the Commission urges that the needs of children with disabilities be taken into account in structuring these provisions.

This is because there are times when parents of children with disabilities are prevented from working because of their child's special needs. These include providing regular medication, being on call in the event of an emergency at school, and remaining at home with the child during periods of illness. The disabilities of some children require that a parent provide constant, or near constant, care. The imposition of a work requirement or time limit on eligibility could impose severe hardship on children and families in such cases, placing some children at risk of institutionalization.

Recommendation

The Commission recommends that:

- * Parents of children who receive SSI should be exempted from the five-year limit on welfare benefits under the block grant established in H.R. 4. This exemption should cover the duration of the child's SSI eligibility and extend for two years thereafter.
- * One parent of a child with a disability who receives SSI should be exempted from any work requirement under the new block grant, if the presence of that parent is needed in the home to care for the child.

9b. Maintain Current AFDC Disregard for SSI Benefits

Current Law

Section 402(a)(24) of the Social Security Act states that, for the purposes of determining AFDC eligibility, an individual receiving SSI benefits will not be counted as a member of the household; and the income received from SSI will not be considered as income available to others living in the household.

Reasons for Change

If Congress replaces the AFDC program with a state block grant (see item 9a), states could be authorized to include SSI recipients as members of a household in making eligibility determinations. They could also count SSI payments in determining a family's eligibility.

As a result, a child's SSI payment could prevent a family from qualifying for assistance or reduce the benefit it receives, forcing the family to use the SSI payment to meet the basic needs of other members. Such a policy would contradict the purpose of the SSI program which is to assist in meeting the needs of the recipient.

Recommendation

The Commission recommends adding to any new block grant a requirement similar to the one in section 402(a)(24) of the Social Security Act, which excludes SSI benefits from consideration in the eligibility determination of other members of the household applying for welfare assistance.