

Supplemental Security Income for Children with Disabilities

Report to Congress

of the

National Commission on Childhood Disability

**October 1995
Washington, D.C.**

National Commission on Childhood Disability

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Table of Contents

Preface	iv
Executive Summary	1
Chapter One: Overview of the Supplemental Security Income Childhood Disability Program	5
Chapter Two: Profiles of Children Receiving SSI	25
Chapter Three: The Commission's Deliberations	33
Chapter Four: Recommendations to Congress	39
Chapter Five: Alternative Forms of Support	75
Chapter Six: Health Care Coverage for Children With Disabilities	91
Chapter Seven: Research for Future Policy Directions	109
Statements by Commission Members	
Appendices	

Preface

The National Commission on Childhood Disability was established by Congress in the Social Security Independence and Program Improvements Act of 1994 (Public Law 103-296). The Commission was charged with reviewing the definition of childhood disability in the Supplemental Security Income (SSI) program authorized by title XVI of the Social Security Act, and with addressing a number of associated questions. Public Law 103-296 requires the Commission to report its findings to the House Committee on Ways and Means and the Senate Committee on Finance by November 30, 1995. The Commission submits this report in satisfaction of that requirement.

P. L. 103-296 requires the Commission to determine the appropriateness of the present definition of disability and the advantages and disadvantages of alternatives. It calls on the Commission to examine the following issues as part of its analysis:

- whether the need by families for assistance in meeting high costs of medical care for children with serious physical or mental impairments (whether or not they are eligible for SSI) might appropriately be met through expansion of federal health assistance programs;
- the feasibility of providing benefits to children through noncash means, including the use of vouchers, debit cards, and electronic benefit transfer systems;
- the extent to which the Social Security Administration (SSA) can involve private organizations in increasing the provision of social services, education, and vocational instruction needed to promote independence and the ability to engage in substantial gainful activity;
- alternative ways of providing retroactive SSI benefits to children, including possible conservation of a portion of the benefits to promote the well-being of a child over the long term;
- the desirability and methods of increasing the extent to which benefits are used in the effort to assist children with disabilities in achieving independence and engaging in substantial gainful activity; and
- the effects of the SSI program on children and their families.

P. L. 103-296 requires that the Commission be composed of experts in the fields of medicine, law, education, psychology, rehabilitation, administration of disability programs, and social insurance. Although the Commission was established by Congress and reports to it

directly, Congress delegated to the Secretary of Health and Human Services the authority to appoint the Commission's members. The Secretary, Donna Shalala, appointed 14 members:

Jim Slattery, Chair
Polly Arango
Adrienne Asch, Ph.D.
Dolores Berkovsky,
M.S.N., L.M.S.W.
Wade F. Horn, Ph.D.
Jennifer Howse, Ph.D.
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Dan Johnson
Paul Marchand
James M. Perrin, M.D.
M. Carmen S. Ramirez
Carol Rank, M.S., M.P.A.
H. Rutherford Turnbull, III,
L.I.B./J.D., L.I.M.
Barbara Wolfe, Ph.D.

A professional profile of each member of the Commission appears in Appendix 2.

The report is organized as follows.

The Executive Summary provides a short description of the Commission's recommendations.

Chapter one provides general background on the SSI program: its statutory basis and history, SSA's process for establishing eligibility, the impairments of children who receive SSI, and the causes of recent growth in benefit awards to children.

Chapter two describes a number of children who currently receive SSI. The children profiled are not the result of any systematic sampling of the SSI beneficiary population. Rather, they are children whose parents came forward to tell the Commission of their experiences. The profiles offer a glimpse into the lives of these families and show the role that SSI plays in their efforts to raise their children at home.

Chapter three traces the work of the Commission: its hearings, analysis, and decision-making process.

Chapter four, the core of the report, presents the Commission's recommendations in detail. These proposals respond to Congress' directives concerning the SSI definition of childhood disability, alternative ways of paying retroactive lump-sum benefits, and means by which SSA can involve private organizations in improving service delivery to children and families. For each recommendation, the chapter describes present law and the Commission's reasons for proposing change.

Chapter five considers vouchers and electronic benefit transfer (EBT) systems as alternative means of support for children with disabilities and their families. This analysis

responds to Congress' expressed interest in the feasibility of in-kind support, as well as in the effects of the current SSI cash program on children and families.

Chapter six provides an overview of health care coverage for children with disabilities, including eligibility requirements for various programs and statistics on program participation, where available.

The final chapter lays out a plan for future research. Broad gaps exist in the current understanding of children with disabilities and their families -- the nature and scope of their impairments, their patterns of consumption, their use of services, and the evolution of their conditions over time. These gaps seriously hindered the Commission's review and analysis. Chapter seven suggests guidelines for research needed to inform future policy efforts.

Following chapter seven are several letters from individual Commission members expressing their views on the report as a whole or on particular issues.

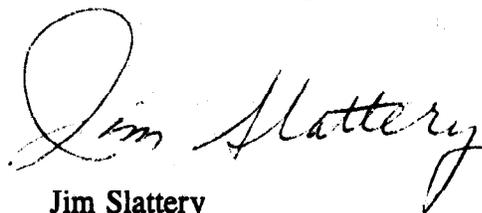
An appendix provides a set of statistical tables, lists the documents the Commission reviewed and the witnesses who helped inform our discussions, and provides further information the reader may find useful in gaining perspective on the questions addressed in the body of the report.

The Commission approved this report on October 10, 1995, by a vote of ten to four.¹

The Commission thanks the officers and staff of the Social Security Administration and the Department of Health and Human Services. The separation of the two agencies and the establishment of SSA as an independent agency occurred during the Commission's work. Despite the complexities associated with this transition, both agencies were forthcoming in providing the Commission resources, administrative support, ideas, and information. Both were also unfailing in observing the Commission's independence. The Commission extends its warm appreciation to Secretary Shalala and Commissioner Chater. Among the many staff of the two agencies who also deserve special thanks are Wendell Primus, Barbara Broman, Michelle Adler, Brian Coyne, Gil Fisher, Diane Garro, Barry Eigen, Chuck Haven, Michelle Hungerman, Alan Shafer, Mike Abassi, Eli Donkar, Karen Sherif, Jessie Allen, Mark Graydon, Don Johnson, Christy Provost, John Sabo, Armand Esposito, Towanda McIver, Kathy McCullough, Donna Merritt, and Brenda Jones. In addition, Margaret Malone, Thomas Joe, and Carmen Solomon were forthcoming with information about the legislative history of SSI; and Kathy Ruffing provided useful budget information. We thank, too, the many parents who shared their experiences with us, revealing the importance of SSI in their lives and the lives of their children.

¹ The Commission members who voted against the final report were Dan Johnson, Paul Marchand, M. Carmen S. Ramirez, and H. Rutherford Turnbull, III.

Finally, the work of this Commission would not have been possible without the dedicated efforts of a tireless team of professionals, headed by Elaine Fultz. Karen Hallows, Dianne Johnson, Carrie Kovar, Nivedita Misra, and Beverly Rollins worked hard to respond to the requests of Members of Congress, all members of the Commission, and other interested parties. Their commitment to this task is an inspiration to me, and it has been an honor and pleasure to have been associated with them. They deserve great credit for this report; however, the individual Commission members are entirely responsible for the recommendations made herein.

A handwritten signature in cursive script that reads "Jim Slattery". The signature is written in black ink and is positioned above the printed name and title.

Jim Slattery
Chair
October 10, 1995

Recommendations of the National Commission on Childhood Disability

Executive Summary

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

2. **Recommendations to Strengthen the Pro-Family Character of the SSI Program**
 - a. Eliminate the six-month limit on spending retroactive lump-sum benefits and require that such benefits be used to cover the cost of needs related to the child's disability and/or to increase his or her independence.

 - b. Continue Medicaid eligibility for children who leave the SSI rolls due to medical improvement but who need treatment to maintain their improved condition.

 - c. Increase the earned income exclusion for minor siblings of children receiving SSI (currently \$400 per month and \$1,620 per year) to \$1,200 per month and \$10,000 per year and adjust these amounts annually for inflation.

 - d. Expand SSI eligibility for children with disabilities whose parents are military personnel to include those who apply while overseas.

 - e. To improve service delivery to children who receive SSI and their families, require the Social Security Administration (SSA) to: (i) create a federal Advisory Committee to guide the agency in establishing partnerships with private organizations, using SSI outreach as a model; (ii) make available in local Social Security offices information about other services, supports, and benefits

Executive Summary 2

for children receiving SSI; and (iii) involve families of children receiving SSI in training SSA staff.

- f. Treat worker's compensation and unemployment compensation as earned income for purposes of SSI parent-to-child deeming rules, thus ensuring that children with disabilities do not lose SSI eligibility or benefits because their parents become injured or unemployed.

3. Recommendations to Strengthen the SSI Definition of Childhood Disability

- a. The Commission agreed on the need to strengthen the definition of childhood disability but differed on how to accomplish this task. The Commission was evenly divided (voting seven to seven) between two options:

- (i) Establish a new childhood definition of disability that builds on the "functional equals" step in SSA's current sequential evaluation process, thus retaining the concept of functional evaluation but requiring at least two marked limitations as a basis for functional allowances. This new definition would require expansion of domains in SSA's current listings to capture more impairments. The pragmatic effect of this change would be to eliminate benefit allowances based in part or in whole on moderate limitations.

OR

- (ii) Preserve the SSA guideline which permits Individualized Functional Assessment (IFA) allowances based on one marked and at least one moderate limitation. 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 three or more functional domains.

- b. Provide only Medicaid for children who meet current SSI eligibility criteria but who would not meet the stricter standard(s)

proposed by the Commission. Under (i) above, this recommendation generally applies to children with three or more moderate limitations or one marked and at least one moderate limitation. Under (ii) above, this recommendation generally applies to children with three or more moderate limitations.

- c. 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 domain, a presumption that the limitation is "marked" would be applied.
 - d. Eliminate double counting of maladaptive behavior by deleting it from the personal domain in the SSI childhood mental impairments listings.
4. **Establish a Sliding Scale for Family Benefits** - Establish a scale which reduces SSI benefits for multiple children in the same family to reflect economies of scale in the consumption of food, clothing, shelter, and other items.
 5. **Require Continuing Disability Reviews (CDRs)**
 - a. Require CDRs at least every two years for children who have the likelihood of enough improvement to make them ineligible for cash benefits; authorize SSA to conduct CDRs more frequently for some children, if appropriate.
 - b. Establish a revolving fund to cover the cost of CDRs.
 6. **Requirement for Treatment** - Participation in appropriate health care treatment would be required as a condition of continuing eligibility for SSI childhood disability benefits in those cases where it is:
 - * readily available in the child's community,
 - * affordable to parents,

Executive Summary 4

- * likely to result in improvement or prevent deterioration in the child's condition, and

- * developed by qualified professionals in collaboration with the family.

7. **Provide Categorical Eligibility for Medicaid for All SSI Children** - The Commission recommends elimination of the section 209(b) Medicaid option as it applies to children who receive SSI, thus making these children categorically eligible for Medicaid in all states.

8. **Revise Reporting Requirements for Children's Representative Payees** - Eliminate the annual reporting requirement and the existing reporting form for representative payees of children receiving SSI and instead require periodic random surveys of these payees. The surveys should be designed to elicit more extensive information about the child's disability, treatment, and use of SSI benefits.

9. **Recommendations Related to the State Block Grant That Could Replace Aid to Families with Dependent Children (AFDC) Under Welfare Reform** - The Commission recommends that:

- a. One parent of a child with a disability who receives SSI should be exempted from any work mandate if the presence of that parent is needed in the home to care for the child; and

Parents of children receiving SSI should be excluded from any limit that is placed on welfare eligibility; rather, such parents should continue to be eligible for benefits for two years after their child ceases to receive SSI childhood disability benefits.

- b. In determining eligibility, states should be prohibited from counting SSI childhood disability benefits as available support for other members of a family.