

ADVANCE  
COPY

**Report to Congress  
of the  
National Commission on Childhood Disability**

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**Supplemental Security Income  
for Children with Disabilities**

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*What will profile  
be post-IFA?*

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

**Supplemental Security Income for Children with Disabilities**

**Report to Congress  
of the  
National Commission on Childhood Disability**

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## **National Commission on Childhood Disability**

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## **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.  
Sharman Davis Jamison

Dan Johnson  
Paul Marchand  
James M. Perrin, M.D.  
M. Carmen S. Ramirez  
Carol Rank, M.S., M.P.A.  
H. Rutherford Turnbull, III,  
Ll.B./J.D., Ll.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.

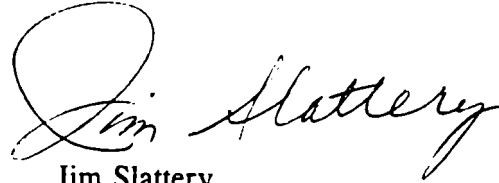
The Commission approved this report on October 10, 1995, by a vote of ten to four.<sup>1</sup>

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.

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<sup>1</sup> 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 fluid and elegant, with a large initial "J" and a long, sweeping underline.

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

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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,

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\* 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.

## Chapter One

### Overview of the Supplemental Security Income Childhood Disability Program

#### Introduction

The Supplemental Security Income (SSI) childhood disability program was enacted by Congress in 1972 and implemented in 1974. It is administered by the Social Security Administration and is funded entirely from general revenues. SSI provides monthly cash benefits to the parents or guardians of low-income children with disabilities. In 1995, the maximum federal SSI payment is \$458 per month. All but seven states supplement the federal payment.<sup>1</sup> Over the past two decades, SSI has played a critical role in helping many thousands of families raise children with disabilities at home.

As of June 1995, just over 940,000 children received SSI benefits. The average monthly benefit was \$420.<sup>2</sup> Nearly three-fourths of the children had no other countable income, and approximately one-half lived in one-parent households. More than half lived in the states of New York, California, Texas, Florida, Illinois, Ohio, Louisiana, Pennsylvania, and Michigan. Boys outnumbered girls by a ratio of three to two. Approximately 37 percent of the children were white, 34 percent were Black, and nine percent were Hispanic.<sup>3</sup> (See Tables 1-1 and 1-2.)

By statute, a child is considered disabled for purposes of SSI eligibility if he or she has a medically determinable physical or mental impairment that has lasted or is expected to last at least twelve months or result in death. The impairment must be comparable in severity to one that would prevent an adult from working.<sup>4</sup> Under regulations established by SSA in response to the 1990 *Sullivan v. Zebley* Supreme Court decision, comparability is interpreted to mean that the impairment(s) substantially reduces the child's ability to function independently, appropriately, and effectively in an age appropriate manner.<sup>5</sup>

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<sup>1</sup> These states are Arkansas, Georgia, Kansas, Mississippi, Tennessee, Texas, and West Virginia.

<sup>2</sup> This average is based on SSA data contained in the SSI ten-percent sample file for June 1995, which is drawn from 934,000 children (21 years old and under) who were due an SSI payment on July 1, 1995. Recipients ages 18-21 are included in the SSI childhood program if they are full-time students. This average includes federally-administered state supplemental payments.

<sup>3</sup> The remaining 17.5 percent of children were not identified by race.

<sup>4</sup> By regulation, SSA defines a medically determinable physical or mental impairment as one resulting from anatomical, physiological, or psychological abnormalities demonstrated by medically acceptable clinical and laboratory diagnostic techniques.

<sup>5</sup> *Sullivan v. Zebley*, 110 S. Ct. 885, February 20, 1990.

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The SSI childhood disability program is operated through SSA's 1300 local offices. SSA relies on state disability determination services (DDSs) to determine an applicant's medical eligibility for the program.<sup>6</sup>

**Table 1-1. Number of children receiving SSI, percentage distribution, and average amount of child's income, by type of income, June 1995<sup>7</sup>**

| Type of Child's Income            | Number  | Percent | Average monthly income or benefit amount |
|-----------------------------------|---------|---------|------------------------------------------|
| Total                             | 934,180 | 100.0   | —                                        |
| With income <sup>8</sup>          | 242,360 | 25.9    | \$152                                    |
| Earned income only                | 6,560   | 0.7     | 242                                      |
| Unearned income only              | 231,870 | 24.8    | 146                                      |
| Both earned and unearned income   | 3,930   | 0.4     | 374                                      |
| With unearned income <sup>9</sup> |         |         |                                          |
| Total                             | 235,800 | 25.2    | \$146                                    |
| Social Security                   | 75,190  | 8.0     | 163                                      |
| Veterans' benefits                | 2,350   | 0.3     | 62                                       |
| Income based on need              | 22,520  | 2.4     | 101                                      |
| Support from absent parents       | 75,540  | 8.1     | 152                                      |
| Interest, dividends, etc.         | 10,020  | 1.1     | 3                                        |
| Other                             | 4,220   | 0.5     | 145                                      |
| In-kind income                    | 66,770  | 7.1     | 115                                      |
| No earned or unearned income      | 691,820 | 74.1    | —                                        |

<sup>6</sup> The DDSs are funded entirely by SSA and are typically located in state departments of rehabilitation, education, or social services.

<sup>7</sup> Social Security Administration, *Children Receiving SSI*, June 1995, ten-percent sample file. File includes children under age 18 and individuals ages 18-21 who are full-time students.

<sup>8</sup> These amounts do not include income deemed to a child from parents in the household.

<sup>9</sup> Children with more than one type of income are included in each category.

**Table 1-2. Number of children receiving SSI, and percentage distribution by selected characteristics, June 1995<sup>10</sup>**

| Selected Characteristics | Number  | Percent |
|--------------------------|---------|---------|
| Total                    | 934,180 | 100.0   |
| Age                      |         |         |
| Under 1 year             | 13,920  | 1.5     |
| 1                        | 23,740  | 2.5     |
| 2                        | 27,500  | 2.9     |
| 3                        | 35,970  | 3.9     |
| 4                        | 42,640  | 4.6     |
| 5                        | 47,310  | 5.1     |
| 6                        | 51,020  | 5.5     |
| 7                        | 52,650  | 5.6     |
| 8                        | 55,560  | 5.9     |
| 9                        | 59,450  | 6.4     |
| 10                       | 61,480  | 6.6     |
| 11                       | 60,590  | 6.5     |
| 12                       | 61,700  | 6.6     |
| 13                       | 62,950  | 6.7     |
| 14                       | 59,920  | 6.4     |
| 15                       | 58,590  | 6.3     |
| 16                       | 55,470  | 5.9     |
| 17                       | 49,140  | 5.3     |
| 18                       | 22,070  | 2.4     |
| 19                       | 13,030  | 1.4     |
| 20                       | 11,200  | 1.2     |
| 21                       | 8,280   | 0.9     |
| Sex                      |         |         |
| Female                   | 341,530 | 36.6    |
| Male                     | 592,650 | 63.4    |
| Race                     |         |         |
| White                    | 340,730 | 36.5    |
| Black                    | 318,450 | 34.1    |
| Hispanic                 | 83,420  | 8.9     |
| Other                    | 27,910  | 3.0     |
| Unknown                  | 163,670 | 17.5    |

<sup>10</sup> Social Security Administration, *Children Receiving SSI*, June 1995, ten-percent sample file. The 18-21 year-olds included in the file are full-time students.

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Table 1-2 -- continued.

| Selected Characteristics           | Number  | Percent |
|------------------------------------|---------|---------|
| Total                              | 934,180 | 100.0   |
| Living Arrangements                |         |         |
| Own Household <sup>11</sup>        | 146,610 | 15.7    |
| Another's Household                | 30,030  | 3.2     |
| Parent's Household                 | 745,870 | 79.8    |
| Medicaid Institution <sup>12</sup> | 11,670  | 1.2     |
| Legal Status                       |         |         |
| U.S. citizen                       | 923,500 | 98.9    |
| Alien - total                      | 9,920   | 1.1     |
| Lawful admission                   | 6,730   | 0.7     |
| Color of law <sup>13</sup>         | 3,190   | 0.3     |
| Unknown                            | 760     | 0.1     |

### Eligibility Determination

The process of determining a child's eligibility for SSI begins when his or her parents (or other caregiver) contact the nearest Social Security office to obtain an application for benefits and other forms to document the child's health and financial status. Upon receipt of the completed forms, the local Social Security office sends the file to the state DDS, where an adjudicative team consisting of a physician or psychologist and a disability examiner determines whether the child is disabled. The team first attempts to obtain medical evidence from the child's own medical sources. If the medical evidence is insufficient or unavailable, the DDS arranges a consultative examination (CE) by a physician to obtain medical evidence.<sup>14</sup>

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<sup>11</sup> Children classified by SSA as "in their own household" may live with other relatives, in private hospitals, nursing homes, residential schools, foster care, or independently.

<sup>12</sup> A Medicaid institution is a medical facility where over half the cost of an individual's care is covered by Medicaid.

<sup>13</sup> Color of law refers to the immigration status of children living in the U.S. with the knowledge and permission of the Immigration and Naturalization Service (INS) and for whom the INS is not contemplating deportation.

<sup>14</sup> This team normally relies entirely on written documentation to make a determination and has no direct contact with the child.

By regulation, SSA has established two separate paths to SSI eligibility for children. One of these compares a child's condition to a list of impairments (and accompanying signs, symptoms, and laboratory findings) that the agency takes as prima facie evidence of disability.<sup>15</sup> The listings consist of over 100 of the most commonly-occurring impairments. Examples include cerebral palsy, quadriplegia, blindness, leukemia, and loss of speech resulting from evident brain injury. When a child's impairment meets or equals a listing,<sup>16</sup> the agency generally does not inquire about his or her functional capacity. The correlation between the listings and functional disability is assumed to be strong enough that eligibility is granted.

The major exception to this rule applies to childhood mental impairments, for which SSA has included functional criteria in the medical listings.<sup>17</sup> To be granted benefits, children ages three and older must demonstrate both that they have a listed impairment and that it causes marked limitations in at least two of four functional domains.<sup>18</sup> 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 that they have an impairment or combination of impairments that "functionally equals" a listed impairment. To do so, a child must demonstrate that his or her impairment (which need not be one

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<sup>15</sup> These signs, symptoms, and laboratory tests indicate the required level of severity.

<sup>16</sup> Medical equivalence applies to three categories of children: (1) those whose impairments are described in the listings but who do not exhibit one or more of the medical findings included in a specific listing; (2) those who exhibit all of the medical findings of a specified listing but not at the required level of severity; and (3) those who meet all of the functional criteria but only some of the diagnostic criteria.

<sup>17</sup> Some physical listings also include functional criteria, such as cerebral palsy and musculoskeletal disease.

<sup>18</sup> SSA regulations define "marked" as more than "moderate" but less than "extreme." When results from standardized tests are used as measures of functional limitation, a valid score that is two standard deviations below the norm for the test will be considered a marked limitation. However, SSA regulations state that, in assessing the validity of a test result, any discrepancies between formal test results and the child's customary behavior, functioning, and daily activities must be resolved.

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included in the listings) or combination of impairments causes the same restrictions required under the functional criteria in a listing.<sup>19</sup>

The second path to SSI eligibility applies to children who do not have impairments that meet or equal the listings. These children may demonstrate, through an Individualized Functional Assessment (IFA), a substantial reduction in their ability to function independently, appropriately, and effectively in an age appropriate manner. Created by SSA in response to the 1990 *Zebley* decision, the IFA is similar to the functional test in SSA's mental impairments listings but has a larger number of domains and less stringent eligibility criteria. SSA guidelines state that, in general, a child will be found disabled when his or her impairment causes moderate functional limitations in at least three of six functional domains<sup>20</sup> or causes one marked and one moderate limitation in at least two of six domains.<sup>21</sup> For children ages three and older, the IFA domains are:

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

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<sup>19</sup> For example, a child who is unable to stand and walk because of an unlisted impairment could be eligible for SSI benefits based on functional equivalence to a listed impairment.

<sup>20</sup> SSA regulations define "moderate" as the range between "minimal" and "marked."

<sup>21</sup> SSA guidelines do not provide adjudicators with a set formula for establishing eligibility based on the number of marked or moderate limitations a child demonstrates. Rather, they provide examples of combinations of moderate limitations and marked and moderate limitations that are frequently disabling.

A comparison between SSA's two functional assessments is provided in Table 1-3.

| Table 1-3. SSA's Functional Assessments of Childhood Impairments                                                                                                                                                                                                                                                                                                                                                                                                                                                                    |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                             |
|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Childhood Mental Impairments Listings                                                                                                                                                                                                                                                                                                                                                                                                                                                                                               | Individualized Functional Assessment                                                                                                                                                                                                                                                                                                                                                                                                                                                                                        |
| <p>The required level of severity is met when the child has marked limitations in two of the following:</p> <ol style="list-style-type: none"> <li>1. Cognitive/communicative functioning</li> <li>2. Social functioning</li> <li>3. Personal/behavioral functioning as evidenced by: <ol style="list-style-type: none"> <li>a. activities of daily living, or</li> <li>b. persistent maladaptive behavior destructive to self, others, animals or property</li> </ol> </li> <li>4. Concentration, persistence, and pace</li> </ol> | <p>Guidelines state that benefits <i>may</i> be provided when the child has at least one marked and one moderate limitation or at least three moderate limitations among:</p> <ol style="list-style-type: none"> <li>1. Cognitive functioning</li> <li>2. Communicative functioning</li> <li>3. Motor functioning</li> <li>4. Social functioning</li> <li>5. Personal/behavioral functioning</li> <li>6. Concentration, persistence, and pace</li> </ol> <p>42 - MR<br/>33 - Phys<br/>25 - other mental<br/>Who is IFA?</p> |

### Disabling Impairments

In 1995, nearly 67 percent of all children on the SSI rolls were eligible for benefits based on mental impairments. Approximately two-thirds of these (42 percent of the total) had mental retardation. Other common mental impairments included mood disorders, conduct disorders, oppositional defiant disorder, personality disorders, learning disorders, and Attention Deficit Hyperactivity Disorder (ADHD).

At the end of 1994, the total number of children receiving SSI based on a diagnosis of ADHD was 63,500. This included approximately 26,000 children who met the criteria in SSA's listing for ADHD, 2,500 children who equalled the ADHD listing, and 35,000 children who qualified on the basis of ADHD through an IFA.<sup>22</sup>

Children classified by SSA with physical disabilities as their primary diagnoses accounted for 33 percent of the SSI rolls in 1995. Among the most prevalent disabilities

<sup>22</sup> Because there was neither an IFA nor a medical listing for ADHD prior to 1991, SSA is unable to determine whether it made any allowances based on this impairment in the earlier period.

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were leukemia, asthma, Down syndrome, spina bifida, congenital heart anomalies, deafness, blindness, nervous system disorders, epilepsy (which is not adequately controlled with medication), cerebral palsy, and, for infants, low birth weight (under 1200 grams, or two pounds). An overview of disabling impairments is provided in Table 1-4, and a complete listing is provided in Appendix 7-F.

Because combinations of impairments occur frequently in children, primary diagnoses may not indicate the extent of a child's disability. Beyond these classifications, however, SSA data provides little insight into the nature and extent of these children's impairments. Because SSA stops gathering medical evidence when it has accumulated enough to allow a claim, the agency does not consistently determine or record secondary diagnoses. Moreover, little systematic information exists at present on these children's utilization of medical services or other supports such as assistive technology, child care, or special education.<sup>23</sup>

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<sup>23</sup> Research is now being conducted to address these questions. For example, the Department of Health and Human Services is comparing computer tapes of Medicaid utilization by children receiving SSI and diagnostic criteria contained in SSA administrative records. See chapter seven for further discussion.

**Table 1-4. Number of children receiving SSI, and percentage distribution by diagnostic group, June 1995<sup>24</sup>**

| Diagnostic group                                 | Total   |         |
|--------------------------------------------------|---------|---------|
|                                                  | Number  | Percent |
| Total                                            | 934,180 | —       |
| Total with diagnosis                             | 783,500 | 100.0   |
| Mental disorders:                                |         |         |
| Mental retardation                               | 331,820 | 42.4    |
| Psychotic and neurotic disorders                 | 189,310 | 24.2    |
| Physical disorders:                              |         |         |
| Infectious and parasitic diseases                | 2,860   | 0.4     |
| Neoplasms                                        | 12,570  | 1.6     |
| Endocrine, nutritional, and metabolic            | 8,030   | 1.0     |
| Diseases of the:                                 |         |         |
| Nervous system and sense organs                  | 94,700  | 12.1    |
| Circulatory system                               | 5,580   | 0.7     |
| Respiratory system                               | 21,570  | 2.8     |
| Digestive system                                 | 2,570   | 0.3     |
| Musculoskeletal system<br>and connective tissues | 9,090   | 1.2     |
| Congenital anomalies                             | 35,250  | 4.5     |
| Injury and poisoning                             | 4,910   | 0.6     |
| Other                                            | 65,240  | 8.3     |

37.2%

## Legislative History

In 1969, President Richard Nixon proposed legislation to reform the American welfare system, the Family Assistance Plan (FAP). This legislation would have replaced existing federal income maintenance programs with a guaranteed minimum income for all Americans. The original version of the bill maintained the existing federal-state program of assistance to individuals who are aged, blind, and disabled but established federal benefit standards and increased federal participation in the financing of benefits. After intense debate and numerous revisions, the House of Representatives passed two versions of FAP, first in 1970 and again in 1971.

<sup>24</sup> Social Security Administration, *Children Receiving SSI*, June 1995, ten-percent sample file.

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As approved by the House, the 1971 legislation (H.R. 1) federalized support for aged, blind, and disabled individuals and extended support to children. The principal author of this proposal was Thomas Joe, an analyst in the Office of the Secretary of Health, Education, and Welfare. He explained the inclusion of children in the program as part of a larger effort to create a uniform, national standard of support for individuals with disabilities. He stated:

The whole objective [of federalizing state programs of support for people with disabilities] was to establish uniformity, and we needed a common definition of who was eligible. Under the state programs, blind individuals were eligible at age 16, while other persons with disabilities weren't eligible until age 18. State rehabilitation programs had a third age standard -- their age criterion was 14. Younger children (in families whose resources and income did not exceed specified limits) would have been eligible under the family program. These age limits were completely arbitrary. Furthermore, I believed that, because of their special needs, children with disabilities deserved to be eligible in their own right, subject to income and resource limits.<sup>25</sup>

The Committee on Ways and Means report which accompanied H.R. 1 cited the special needs of children with disabilities in justifying their inclusion in the program. It 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 Senate did not approve H.R. 1. After a long debate, it approved legislation which omitted the House Family Assistance Plan provisions but included the establishment of the SSI program for aged, blind, and adults with disabilities. Explaining the decision to extend the SSI program to adults only, the Senate Committee on Finance report stated:

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<sup>25</sup> Telephone interview with Thomas Joe, August 6, 1995. Mr. Joe also stressed that the existence of disability-related needs beyond health care was evidenced at the time by "special needs allowances" offered in a number of states to children with disabilities.

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.

A House-Senate conference committee reached agreement in October 1972. In the agreement, the Senate accepted the House provision to extend SSI eligibility to children. The conference report does not include an explanation for this decision.

### Program Growth

SSA's early difficulties in implementing the adult SSI program have been well documented: short lead times, technological difficulties, and larger than expected groups of applicants.<sup>26</sup> These problems account in part for the agency's slow progress in implementing SSI for children. SSA did not formally issue its childhood disability listings until 1977. By 1979, 212,000 children had been granted eligibility. Growth in program rolls was modest between 1979 and 1989, increasing from 212,000 to 296,000 beneficiaries.

By contrast, the rolls nearly tripled between 1989 and 1994, increasing from 296,000 to 893,000 children. Program costs rose commensurately, from \$1.2 billion to approximately \$5 billion annually. While the SSI program as a whole also grew substantially during this period, childhood awards outpaced awards to adults. Children comprised six percent of the total SSI population in 1989, but 14 percent of the total SSI population in 1994. Table 1-5 traces SSI program growth over the past two decades.

The tripling of the SSI rolls results primarily from four factors: the *Zebley* decision, a 1990 revision of the listings of childhood mental impairments, enhanced SSI outreach activities, and an increase in the rate of childhood poverty.

The most widely noted source of growth is the 1990 *Zebley* decision, in which the Supreme Court found SSA's childhood disability regulations inconsistent with the Social Security Act. The Act entitles children to benefits whose disabilities are comparable to qualifying adult disabilities. SSA's procedures for evaluating childhood disability prior to 1990 did not, however, mirror its procedures for adult disability determination. For adults,

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<sup>26</sup> See, for example, Martha Derthick's *Agency Under Stress*, Washington, D.C.: The Brookings Institution, 1990.

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SSA had established two separate paths to SSI eligibility: a listing of qualifying medical impairments and, for those whose impairments are not described there, an individualized assessment of residual functional capacity (RFC). SSA uses the RFC assessment to determine whether there is work that an individual can do, given his or her age, education, and past work experience.

**Table 1-5. Number and percentage distribution of children who received a federal or state SSI payment, December 1974-June 1995**

|               | Blind and Disabled Children <sup>27</sup> |                                 |
|---------------|-------------------------------------------|---------------------------------|
|               | Number                                    | Percent of total SSI recipients |
| December 1974 | 70,900                                    | 1.8                             |
| 1975          | 128,175                                   | 3.0                             |
| 1976          | 153,128                                   | 3.6                             |
| 1977          | 175,214                                   | 4.1                             |
| 1978          | 197,499                                   | 4.7                             |
| 1979          | 212,088                                   | 5.1                             |
| 1980          | 228,564                                   | 5.5                             |
| 1981          | 230,094                                   | 5.7                             |
| 1982          | 229,151                                   | 5.9                             |
| 1983          | 236,380                                   | 6.1                             |
| 1984          | 248,633                                   | 6.2                             |
| 1985          | 265,325                                   | 6.4                             |
| 1986          | 280,137                                   | 6.6                             |
| 1987          | 288,725                                   | 6.6                             |
| 1988          | 290,256                                   | 6.5                             |
| 1989          | 296,298                                   | 6.5                             |
| 1990          | 340,230                                   | 7.1                             |
| 1991          | 438,853                                   | 8.6                             |
| 1992          | 623,845                                   | 11.2                            |
| 1993          | 770,501                                   | 12.9                            |
| 1994          | 892,543                                   | 14.2                            |
| June 1995     | 940,948                                   | 14.6                            |

For children, SSA had established only the first of these two paths: a listing of qualifying impairments. The Supreme Court ruled that the listings alone failed to provide

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<sup>27</sup> In June 1993, approximately 35,000 cases previously classified as children were reclassified as adults. Prior to that date, the counts may be slightly skewed because of the reclassification.

comparability with adult eligibility criteria. In response, SSA revised its childhood regulations to include the "functional equals" step and the Individualized Functional Assessment.

In addition to expanding eligibility criteria for children, the *Zebley* decision led to readjudication of a large number of previously denied claims. Following the decision, the district court required SSA to contact the families of 452,000 children who were denied benefits between January 1980 and February 1991. SSA offered to readjudicate their claims using the new functional criteria. Of this group, 339,000 children responded; and approximately 135,000 were ultimately found eligible and awarded benefits.<sup>28</sup> Many of these children were determined to have been eligible at the time of initial application. They therefore qualified not only for prospective benefits but for large retroactive lump-sum payments.

*same time as Zebley*

A second cause of program growth is SSA's 1990 revision of its listings of childhood mental impairments. SSA undertook this revision in response to the Social Security Disability Benefits Reform Act of 1984 (P.L. 98-460), which required the agency to update its mental listings. Prior to this revision, SSA had listed only four general categories of qualifying mental impairments for children -- mental retardation, chronic brain syndrome, psychosis, and functional non-psychotic disorders. To reflect medical advancements in disability evaluation and treatment, SSA expanded this number to eleven. These are:

- organic mental disorders
- schizophrenic, delusional (paranoid), schizoaffective, and other psychotic disorders
- mood disorders
- mental retardation
- anxiety disorders
- somatoform, eating, and tic disorders
- personality disorders
- psychoactive substance dependence disorders
- autistic disorder and other pervasive developmental disorders
- attention deficit hyperactivity disorder
- developmental and emotional disorders of newborn and younger infants (birth to age one)

This revision also placed increased importance on information from nonmedical sources, such as parents, teachers, and others knowledgeable about a child's day-to-day functioning.

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<sup>28</sup> Social Security Administration, Office of Disability.

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In September 1994, the General Accounting Office (GAO) issued a report comparing the impact that the new listings and the IFA had on program growth.<sup>29</sup> The GAO found that 59 percent of the growth in childhood benefit awards during 1991 and 1992 was attributable to the listings. The IFA, by contrast, accounted for only 41 percent of growth during this period. SSA's assessment of the relative importance of these changes assigns even greater weight to the mental impairment listings. The agency estimates that they account for 69 percent of SSI program growth since 1990, while the *Zebley* decision accounts for only 31 percent.<sup>30</sup>

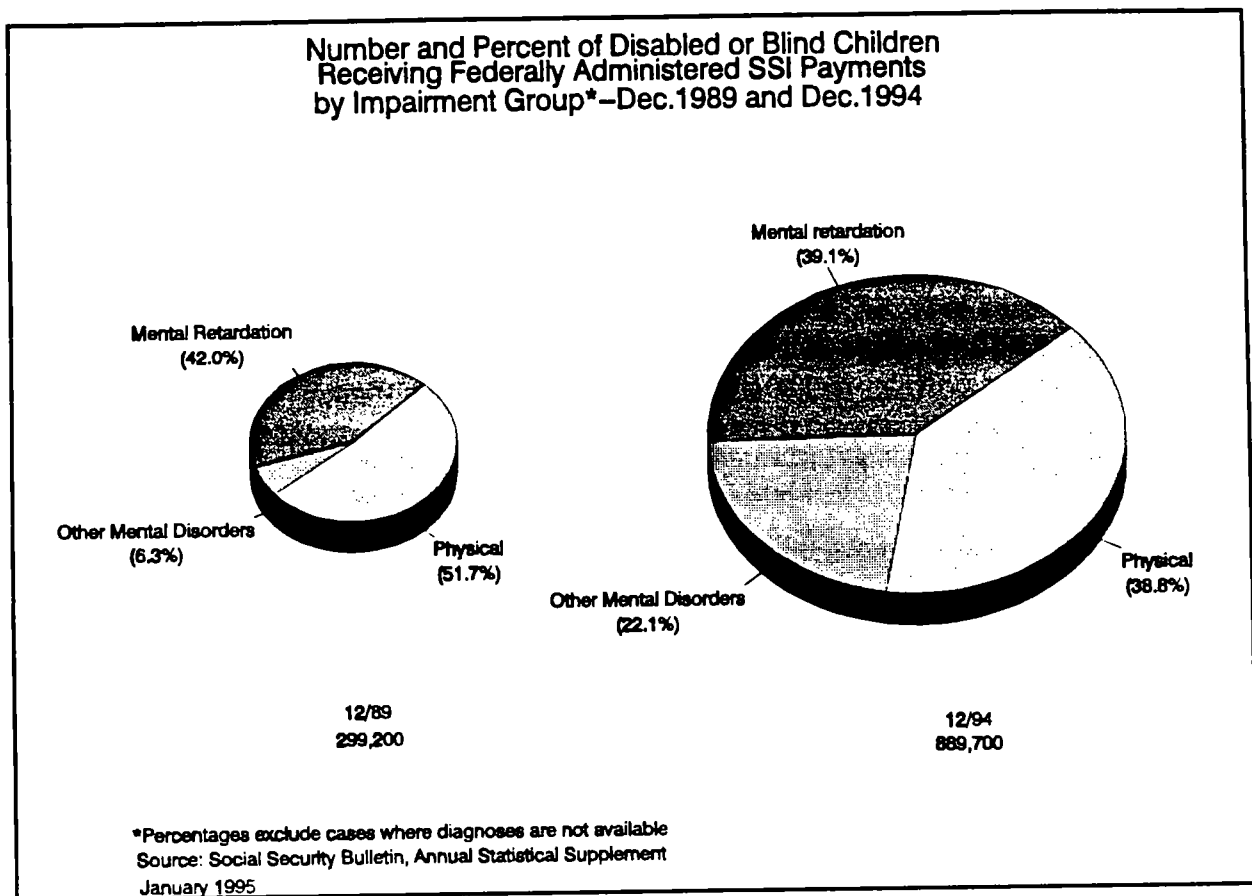
Together these changes not only led to a higher level of benefit allowances; they also altered the mix of impairments of children on the SSI rolls. In 1989, children with physical impairments comprised just over 51 percent of SSI recipients. Children with mental retardation and other mental impairments accounted for just over 48 percent. In 1994, children with physical impairments comprised nearly 39 percent of the rolls, and children with mental retardation and other mental impairments accounted for over 61 percent. Figure 1-6 illustrates these changes.

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<sup>29</sup> General Accounting Office, *Social Security: Rapid Rise in Children on SSI Disability Rolls Follows New Regulations*, September 1994.

<sup>30</sup> Social Security Administration, Office of Disability.

Figure 1-6.



A third factor contributing to the increase in SSI rolls is more difficult to quantify. This is SSI outreach activities. A 1989 statute required SSA to establish a permanent program of SSI outreach to low-income children.<sup>31</sup> The *Zebley* decision also called for additional outreach efforts. In 1990, Congress appropriated \$3 million for SSA to target hard-to-reach populations. Since then, it has appropriated \$6 million each fiscal year for SSI outreach activities.<sup>32</sup> As of August 1994, SSA had funded 136 outreach grants.

In targeting children, the agency sought organizations that could provide coordinated services, including Head Start affiliates, school districts, children's hospitals and clinics, Children with Special Health Care Needs Agencies, and state agencies administering programs

<sup>31</sup> The Omnibus Budget Reconciliation Act of 1989, Public Law 101-239.

<sup>32</sup> Congress appropriated no funding for outreach activities for fiscal year 1996, although SSA plans to fund outreach demonstration projects from unobligated funds of prior years.

under Part H of the Individuals with Disabilities Education Act. SSA targeted projects that it judged could continue after expiration of federal funding, as well as those that were readily transferrable to other communities on a regional or national basis.

Fourth, SSA's apparent outreach success may have been related to a larger economic trend -- an increase in the rate of childhood poverty. Between 1974 and 1993, the rate of poverty among American children increased by half, rising from 15 to 23 percent.<sup>33</sup> This increase brought the absolute number of children living in poverty to over 15 million. As more children joined the state AFDC rolls, many states aided in SSA outreach efforts by encouraging families to apply for SSI benefits. This effort intensified in the early 1990s, when the economic recession brought increased fiscal pressure on some states.<sup>34</sup> Because SSI is federally funded and provides higher benefits than the AFDC program,<sup>35</sup> these efforts simultaneously provided fiscal relief for state governments and increased the economic well-being of families whose children met the SSI definition of disability.

Table 1-7 illustrates the relationship between state poverty rates (ranked as high, medium, and low), SSI applications rates, and SSI benefit allowance rates for all fifty states in 1993. This table shows that, in general, high state poverty rates are associated with high SSI application rates and low allowance rates. Specifically, those states with 16 percent or more of the population in poverty have significantly higher application rates and lower benefit allowance rates than states with less than 11 percent of the population in poverty.

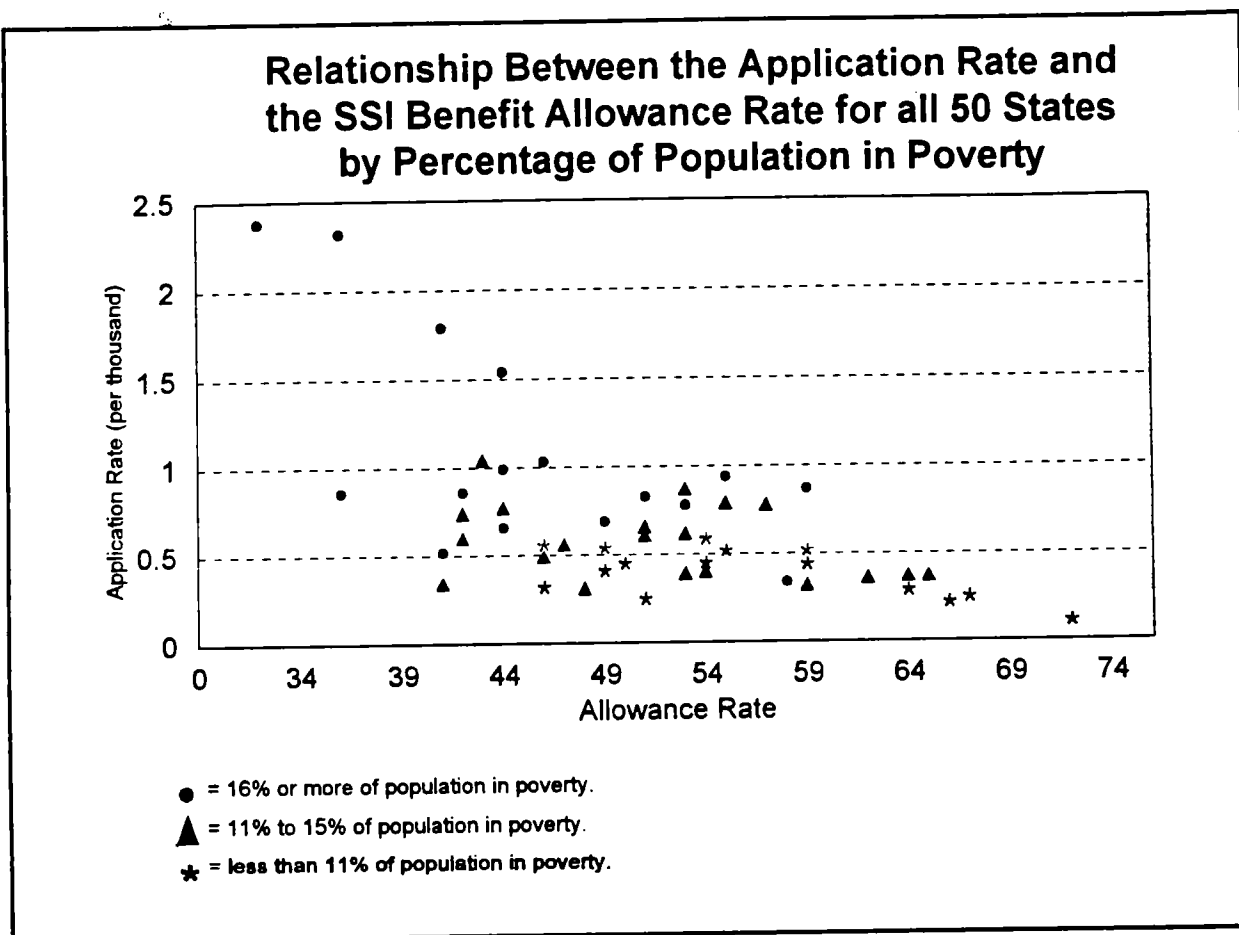
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<sup>33</sup> Committee on Ways and Means, U.S. House of Representatives, *Overview of Entitlement Programs*, July 15, 1994, p. 1148.

<sup>34</sup> While state poverty rates appear to drive growth in the SSI childhood program, there is no evidence that the unemployment rate has a similar impact. Under a contract with the Social Security Administration, Lewin-VHI, Inc., investigated the role of unemployment rates for the Social Security Disability Insurance (DI) and SSI programs. The researchers found that changes in the unemployment rate from 1988 to 1992 accounted for a substantial fraction of the growth in DI applications during that period. For the SSI adult program, they found that unemployment rates had a very small effect on applications. A separate analysis was conducted for the SSI childhood disability program. Although the result is not reported in the study, the researchers found no statistically significant relationship between unemployment and program growth. (Telephone interview with David Stapleton, August 30, 1995.)

<sup>35</sup> Individual states establish their own AFDC payment standards. As a result, AFDC benefits vary significantly across the nation. In 1993, they ranged from a low of \$164 per month in Alabama to a high of \$703 per month in Suffolk County, New York.

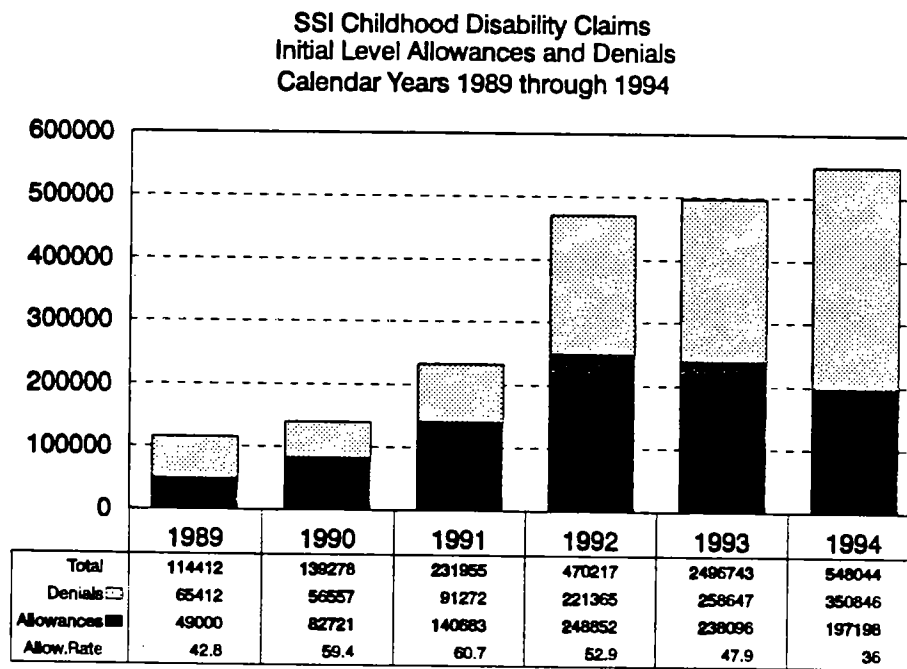
Table 1-7.



These four changes -- the *Zebley* Supreme Court decision, SSA's revision of its childhood mental impairments listings, SSI outreach efforts, and the increase in the rate of childhood poverty -- raised allowance rates for a time, but this trend has not continued. During 1992 and 1993, SSI childhood disability allowances rose from the pre-*Zebley* rate of 38 percent to a full 55 percent. The 1994 rate declined to 36 percent -- actually lower than in the pre-*Zebley* period.<sup>36</sup> The readjudication of *Zebley* class action claims has been completed and, as a result, SSA is no longer awarding very large retroactive lump-sum payments. High application rates have continued, however, and the lower allowance rate still represents a higher absolute number of allowances than in the pre-*Zebley* period. (See Tables 1-8 and 1-9.)

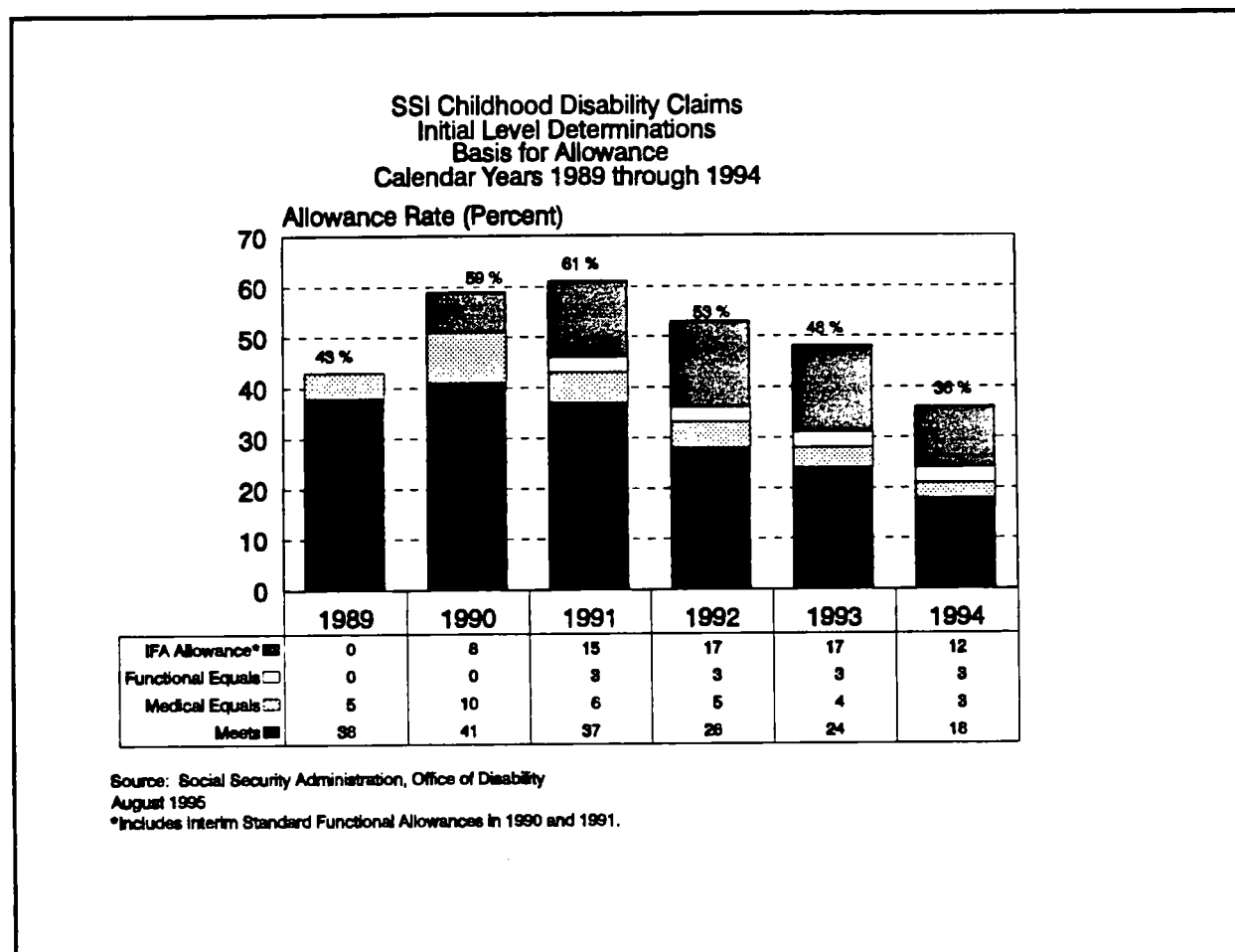
<sup>36</sup> Social Security Administration, Office of Disability.

Table 1-8.



Source: Social Security Administration, Office of Disability  
August 1995

Table 1-9.



An additional alleged source of program growth is fraudulent SSI claims. Some observers contend that increasing numbers of parents are successfully coaching their children to feign disabilities in order to receive SSI benefits. Despite the decline in allowance rates to below the pre-*Zebley* rate, the news media has continued to report allegations of coaching.<sup>37</sup> Such coverage has fueled Congressional interest and heightened public concern that fraud may constitute a major source of program growth.

The most comprehensive investigation of these allegations to date was undertaken by SSA itself. The agency's efforts are three-fold. First, in May 1994, SSA examined a sample

<sup>37</sup> For example, T. Hargrove, "Misuse of Aid to Learning-Disabled Children Alleged." *The Atlanta Constitution*, December 30, 1994. J. B. O'Donnell, "Children are Coached to Get Aid, Social Security Admits." *The Baltimore Sun*, April 8, 1995. H. MacDonald, "Teaching Johnny to Fail." *The Washington Post*, June 18, 1995.

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of 617 claims based on impairments involving behavioral abnormalities and learning deficits. Of these 617 claims, 13 case files contained evidence to suggest possible coaching or malingering. Of these 13, only three were allowances. SSA judged that all these allowances were proper.<sup>38</sup>

Second, in June 1994, SSA instructed the state DDSs to identify all childhood cases in which an adjudicator suspected coaching or sub-optimal performance. This suspicion could be based on as little evidence as a child's apparent failure to make his or her best effort on an IQ test. From June 1994 through August 1995, 690,644 childhood disability claims were processed by the DDSs. Of these, only 1,229 were identified for review, of which SSA determined that only 88 had been allowed benefits. Upon further review, the agency determined that all 88 allowances were proper.

Third, in September 1994, SSA established an 800-number to receive reports of fraud and abuse involving SSI childhood disability benefits. As of August 1995, 166 calls were received concerning 230 children. SSA determined that 108 of the 230 children had been allowed benefits. To date, it has reviewed 45 of these cases. Of these, 26 were upheld, four were terminated based on evidence in the case file, and the remaining 15 were terminated after additional evidence was gathered in a continuing disability review.

These findings are subject to two qualifications. First, SSA limited its analysis to its own written records. It did not interview parents, teachers, or other observers. Second, while the number of cases screened during this period was large, SSA did not screen the entire universe of children's claims. Given these limitations, SSA's finding cannot completely rule out that successful coaching and/or malingering is occurring in some instances or localities.<sup>39</sup> It does, however, suggest strongly that coaching is not a significant cause of growth in the SSI program.<sup>40</sup>

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<sup>38</sup> SSA, *Findings from the Study of Title XVI Childhood Disability Claims*, May 1994.

<sup>39</sup> The General Accounting Office has reviewed existing studies and found little evidence to suggest that coaching is prevalent. U.S. General Accounting Office, *Social Security: New Functional Assessment Process Results in Questionable Eligibility for Children*, February 1995.

<sup>40</sup> It should also be noted that, where coaching does occur, substantial civil and criminal penalties exist for SSI fraud.

## Chapter Two

### Profiles of Children Receiving SSI

Emily Rodgers, Kevin Sweet, Joshua Harper, Patricia Santos, Sarai Ortiz, Michael Murphy, Scott Wilson, and Eugene Wheeler have two things in common. They all receive SSI benefits, and their parents are among the 45 family members who came forward to talk with the Commission about their experiences with the SSI program.<sup>1</sup> The following profiles introduce these children. While broadly representative of the families who testified before the Commission, these profiles are not intended to represent the SSI population as a whole. Rather, they offer a glimpse of the lives of families who face special challenges, demands, and rewards each day in raising a child with a disability at home. They demonstrate the parents' determination and the role that SSI benefits play in their efforts.

\*\*\* Emily Rodgers is six years old. She appeared before the Commission in Baltimore with her mother, Carlita Rodgers, in her wheelchair. She has cerebral palsy, severe mental retardation, and is blind. She must be fed through a feeding tube. Five weeks after her birth, she was hospitalized for pneumonia and has had seizures every day since her release. Rather than improving as she matures, her health has steadily deteriorated over the past two years. Ms. Rodgers stated that Emily's father was unable to cope with the challenges of Emily's condition and care, so he left the family. Emily and her mother now live near her maternal grandparents.

At one point, Emily's grandmother cared for her while her mother worked outside the home. Ms. Rodgers' health insurance did not cover equipment and many medical services that Emily needed, such as a wheelchair, a suctioning machine, and a nebulizer. Ms. Rodgers was able to buy the wheelchair with the help of contributions from some of her high school classmates. Her costs were "\$922 a month ... for [Emily's care, including] formula, her feeding bags, her diapers and her underpads ..." She had additional expenses for medications, pediatric visits, appointments with specialists, and hospitalizations.

Ms. Rodgers first heard about the SSI program through a seminar at Emily's school. She was elated when she learned that Medicaid might provide the services and supplies Emily needed that were not covered by her own HMO.

When Ms. Rodgers first applied for benefits, she was denied because her salary was too high. She was advised that she had three choices: quit her job, have more children to decrease her income in relation to the size of her family, or surrender custody of Emily to grandparents or strangers. Ms. Rodgers would not give up custody of her daughter. "Emily's my daughter and I'm not giving up my parental or custodial rights ..." She

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<sup>1</sup> This report uses both real and fictitious names of children whose families testified before the Commission. The families have given permission for these profiles to appear in this report.

eventually quit her job so that Emily could qualify for SSI and thus receive Medicaid. But she would like to be employed.

I look in the employment section every week and there are so many positions that I qualify for and I want to work so bad but I have to look at, if I worked, she loses everything ... I'm Emily's mom, she is my responsibility. My job now is to take care of Emily and see that she gets what she needs.

Ms. Rodgers supports Emily and herself from the \$336 check she receives from SSI and a \$212 child support check. For her own future and that of other parents of children receiving SSI, she would like to see the program restructured to provide services for children without penalizing parents who can and want to work.

\*\*\* Kevin Sweet is six years old and has cerebral palsy. He and his mother appeared before the Commission in Washington, D.C. He is a lively child who occasionally twists and turns in his stroller. His mother calms him by tickling his cheek.

His mother, Dianne Nichols, is a young, single parent of two children. Kevin was awarded SSI benefits after testing showed his mental age to be nine months. He spends most of his time in his wheelchair or stroller.

Ms. Nichols is employed at a motel and earns five dollars per hour. She explained that she uses her son's SSI benefit of \$201 per month to purchase diapers, child care, special foods, vitamin supplements, and medication. In addition, she says SSI provides "speech and physical therapy and medical equipment to assist him at home to working towards becoming the most he can be and as productive as he can be in his lifetime, which is what we all want for our children."

Without her son's SSI benefit, Ms. Nichols fears that she would be unable to bear the cost of caring for him at home.

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Financially, if Kevin did not have his SSI, I could not keep him. That would be a very bad thing. It would be a loss of a family member. I'm sure you all have kids. It would be as if you had lost one of yours. No matter how [far from] normal, it's still a loss. You love them just the same, and you can't deny them the right like you wouldn't deny your other children the right to be the best that they could become, and that's through dedication, through monies from SSI to be able to give to these children.

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\*\*\* Joshua Harper is a 16 month old with Down syndrome. He also has two holes in his heart. At the Commission's Philadelphia hearing he sat attentively in his mother's lap, although at times he became restless. Sharon Harper is a single mother. The SSI benefit she receives for her son allows her to be employed part-time and thus to spend time at home caring for Joshua. She values the time she spends with him, because she believes that their personal interaction is critical to his development. She also uses his SSI benefit to buy toys that grab and sustain his attention. She said:

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By having the SSI, I am able to get equipment for him, I am able to keep a roof over our heads and food in our mouths basically ... I take him on bus rides. I take him to the Please Touch Museum. I -- you know, he likes Barney, so I have to buy video tapes of Barney because it makes him get up and crawl. It makes him want to do things.

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In response to questions, Ms. Harper expressed apprehension about a state block grant that would provide services in lieu of SSI cash benefits.

I hear about block grants and money going back to the states and things like that. But what I find out is when I request something from the state, it takes me six to eight or longer weeks before I get anything, and that's holding up his development. So I go buy it. It's easier. And then I don't get it from the state. I don't get reimbursed. I go buy it. That's what the SSI money is for. You know, he needed a special chair. It cost \$200. I bought it.

Ms. Harper concluded, "You know, we live in a nice neighborhood, and I am the working poor... I know if SSI is done, we're homeless. We're homeless."

\*\*\* Patricia Santos, a sixth grader, is enrolled in special education classes. She has a depressive disorder which began when her mother became ill with cancer and worsened with her mother's death. Patricia now lives with her grandmother, Sarah Pitt. Ms. Pitt quit her job to care for her daughter during her illness and to raise her granddaughter. She says that she is able to care for Patricia because of the SSI benefit she receives.

Ms. Pitt uses Patricia's SSI benefit to cover the costs of basic necessities, medicine, and psychological services. Patricia's grades have slipped since her mother's death, so Ms. Pitt bought Patricia a computer to help with her school work. SSI also helps to cover the cost of the medication that Patricia's doctor has prescribed for her depression, psychological counseling three times each week, and transportation to and from these appointments.

Patricia's grief over the loss of her mother continues to affect her performance at school. School officials have requested that Ms. Pitt or another relative be present at school so that Patricia does not disrupt the class. Ms. Pitt stated, "... they ask that I be there for her, and I want to be there for her because she's grieving over her mother right now."

\*\*\* Sarai Ortiz is a small, thin 16-year-old who was born with severe asthma and cerebral palsy. She lives in Philadelphia and has received SSI payments throughout her life. Doctors predicted that Sarai would never walk. However, after having undergone surgery eight times to correct problems with her legs, Sarai walks. Her gait is uneven, but she is fully mobile.

Sarai's mother, Evelyn Sostra, testified before the Commission about how SSI has helped her daughter.

Our family has fought to make sure that Sarai has the same opportunities that other children have... SSI has made this fight a success ... Throughout her life, she has needed special braces for her shoes and special braces for her legs and specially designed shoes. The shoes and braces are very expensive and she's needed new shoes constantly and braces throughout the years as she grows ... SSI helped us pay for Sarai's braces and shoes ... When she was recovering from her surgeries, we had to rent wheelchairs and special walkers for her. Those rentals were very expensive. SSI helped us pay for them. When Sarai was growing up, she had difficulty swallowing and had to have special foods so she wouldn't choke. SSI helped pay for the special food she needs.

Sarai is an honors student in the eleventh grade. She competes on the school debate team and volunteers at local day-care centers. She plans to attend college and to become an attorney.

According to Ms. Sostra, SSI has enabled her daughter to grow and mature. She said, "In a few years, Sarai will be independent. If she had not had help from SSI, that wouldn't be possible."

\*\*\* Robin Murphy is the parent of three children: Lucas (14), Page (11), and Michael (8). Mrs. Murphy receives SSI for Michael, who was diagnosed with severe cerebral palsy at age 13 months. Michael's SSI benefit helps to cover expenses related to orthopedic impairments, including numerous doctor visits.

The Murphy family lives in a rural area and incurs substantial expense associated with transportation so that Michael can get treatment. All of Michael's limbs are affected, and he must use a wheelchair for mobility. The family has spent \$300 to rework door frames so that Michael can use his wheelchair at home. Mrs. Murphy would like to modify the family van, but at a cost of about \$500 for a ramp or \$5,000 for an electric lift, this remains unaffordable. Michael requires constant care and depends on others for many types of assistance. Mrs. Murphy explained:

My son requires special equipment for eating, seating, bathing, mobility, just to give you a few ideas of what types of things he uses. Toileting for a child who has a physical disability especially is a lot harder and this can go on for years. It's not like with a normal toddler. You work on it for three or four months and he's potty trained. My son we've been working on for three years and he's still not, so he's still in diapers and he's eight years old.

Mrs. Murphy defended her son's SSI benefit of \$76 per month, arguing that at a minimum, a foster care provider would receive \$1,000 per month. Foster care providers also would have access to unlimited nursing services and respite care, while families who receive SSI are limited to 12 hours per month. According to Mrs. Murphy, minimum care at the nearest residential facility costs \$65,000 per year.

Mrs. Murphy worries that the family might lose Michael's SSI benefit temporarily if her husband has an extra pay period in a month. Mr. Murphy must also refuse salary increases and promotions for fear of losing Michael's SSI eligibility and Medicaid. When asked what would happen if the family lost Michael's SSI benefit, she stated, "Well, we've been there before. We lost our home. We almost went to bankruptcy ... Going through this again, I don't know if I could handle this emotionally. My son would end up going into an institution."

Mrs. Murphy is convinced of the worth of the personal care she gives Michael. Without it, she feels, "He would revert so severely, I don't think he would ever come out again if that would happen."

\*\*\* Scott Wilson is a 15 year old who is depressed and emotionally disturbed. He lives with his parents and two younger siblings. Scott began to engage in disruptive behavior in the second grade. School officials recommended psychological testing and increased social activities. His mother saw to it that he joined the Boy Scouts and a baseball team, but she explained that despite her efforts, "... he was very withdrawn from the other children and he just couldn't socialize very well ..." Scott's third grade teacher reported that he was a good student but required one-on-one instruction.

Scott was asked to leave the school he was attending in the fourth grade. He entered another school but his disruptive behavior continued and, in the seventh grade, he was diagnosed as emotionally disturbed and depressed. After this diagnosis, Scott's mother applied for SSI.

Scott is currently in the ninth grade. Mrs. Wilson attends parenting workshops to learn behavioral management techniques. She also meets regularly with a school social worker and a psychiatrist to discuss ways to keep Scott on task and encourage him to be independent. Mrs. Wilson quit her job in order to respond to frequent calls from school to help control Scott's behavior.

Despite weekly therapy sessions, Scott has been institutionalized twice. Upon his return home the second time, he threatened his parents. They were so fearful that they hid all knives in the home. Scott's mother explained:

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My son doesn't understand why he is the way he is ... he wants to be regular or normal, he just doesn't understand why, he doesn't know -- he wants to know why he was born to have to live this way.

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Mrs. Wilson uses Scott's SSI benefits to pay for his eyeglasses, clothing, school supplies, transportation, and social activities. His parents remain hopeful that therapy and medication will make it possible for him to cope with his illness and become increasingly independent.

\*\*\* Eugene Wheeler is five. He has chronic asthma, a speech impairment, and developmental delays. His mother, Charol Jamison, is a single parent who has found it difficult to hold a steady job because of her son's disabilities. Eugene's asthma attacks routinely require his day-care center teachers to call his mother, forcing her to leave work to care for her son. Ms. Jamison was fortunate in that her employer was understanding. As she explained:

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I was a good worker, so my managers were very patient, even though I had gone way beyond the company's policies for calling up and leaving work. They were trying to work with me, but I could tell they were getting frustrated and eventually they would have had to terminate me. Finally, I came to the conclusion that I could not be in two places at once, and it came to the point where I had to decide whether I was going to stay within this position or whether I was going to take some time out to try to stabilize my son's condition.

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Eventually, Ms. Jamison took a leave of absence. During this time, she came to understand what triggers Eugene's asthma attacks and how to prevent them from progressing. Through constant attention and close interaction with his doctor, Ms. Jamison was finally able to control his asthma. Eugene has required hospitalization just once in the past two years.

Ms. Jamison has returned to employment part-time. Eugene's SSI benefit allows her to spend time at home giving Eugene the special care and attention he needs while retaining her job. Ms. Jamison clearly sees the benefit to herself as well as to her son. She said, "I am a person -- I prefer working. I'm happiest when I'm working."

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These profiles illustrate the diverse needs of children who receive SSI. In some of them, SSI is necessary to provide food, clothing, and shelter. In others, it helps to cover the cost of needs resulting from a child's disability, such as medication and specialized transportation. The profiles also illustrate the potential overlap of a child's disability-related needs and his or her needs as a child from a low-income family. For example, all children need food and clothing, but some children with disabilities require extra quantities or special forms of such items. Finally, the profiles exemplify the potential seriousness of behavioral disorders and their impact on these children and their families.

Despite the diversity in the children's impairments and needs, the profiles are entirely consistent in one way: all demonstrate the deep commitment of families who are devoted to helping their children learn, develop, and become all that they can be.

## **Chapter Three**

### **The Commission's Deliberations**

#### **Introduction**

Congress usually creates commissions to help resolve difficult policy issues, making their work both challenging and controversial. Even by this standard, the circumstances that confronted the National Commission on Childhood Disability were unusual. In the four months between the August 1994 enactment of Public Law 103-296, which established the Commission, and Secretary Shalala's appointment of its members in January 1995, control of both houses of Congress shifted from the Democratic to the Republican party. The resulting change in political agenda was most marked in the House of Representatives, where the election campaigns of Republican challengers had centered on the Contract with America. This ten-point program called for reducing the federal deficit and narrowing the scope of federal government activities. One of its major targets was the welfare system, which the Contract promised to return to the control of the states. President Clinton had also sent Congress a welfare reform proposal, setting the stage for national debate. The new House leadership pledged that the body would vote on all ten legislative initiatives in the Contract within 100 days, by mid-April. By statute, the Commission's report was not due until November 1995.

#### **House Action**

In mid-January as the Commission began its work, the Subcommittee on Human Resources of the House Committee on Ways and Means began hearings on welfare reform, defined by the House leadership to include the SSI program. Within two weeks of the Commission's first meeting, the Subcommittee approved a welfare reform bill that reduced the number of children receiving SSI by approximately one-third and cut projected SSI program outlays to children by \$12.1 billion over five years. This legislation, unnumbered at the time of its approval by the Subcommittee, subsequently became H.R. 4, the Personal Responsibility Act of 1995. The Commission's first meeting was February 3. The Subcommittee approved welfare reform legislation on February 15. Revisions of the bill prior to full Committee consideration reduced the savings from \$12.1 billion to \$10.9 billion. The bill achieved these savings in two ways.

First, it eliminated the Individualized Functional Assessment that SSA established in response to the *Zebley* Supreme Court decision.<sup>1</sup> The pragmatic effect of this change would be to increase the stringency of SSA's eligibility criteria for allowances based on impaired functioning, since the agency's only other functional test, the "functional equals" step, has

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<sup>1</sup> The bill accomplished this by eliminating the "comparability standard" for children in the SSI statute. See chapter two for a complete discussion of the *Zebley* decision.

more stringent criteria.<sup>2</sup> Second, the bill prohibited the payment of cash benefits to nearly two-thirds of the remaining children -- those who are not institutionalized or at immediate risk of institutionalization.<sup>3</sup> No longer eligible for cash, these children could apply for services under new state block grants established by the bill. The proposed block grants would provide the states with funding equal to 75 percent of the SSI benefits that would have been paid to eligible children under current law. The bill imposed no requirements for the provision of specific services by states nor for the receipt of specific services by eligible children.

The legislation was placed on a fast track for consideration by the full Committee on Ways and Means, with the goal of securing approval of the full House within the leadership's 100-day deadline. By late March, it was approved as H.R. 4 by both the Committee and the House. This accelerated pace meant that the House was unable to consider the Commission's recommendations before acting on the SSI provisions of the bill.

### **The Commission**

While the House action gave Commission members reason to accelerate the pace of their work, doing so was problematic for several reasons. First, the charge at the core of the Commission's mandate -- to examine alternative definitions of childhood disability for the SSI program -- was a fundamentally technical one and not likely to yield to rapid analysis. A second obstacle was the generally sketchy understanding of the children who receive SSI today: the nature and extent of their disabilities, their current utilization of medical services, their need for and use of other disability-related goods and services, and their actual use of SSI funds. The Commission found little systematic data or analysis to shed light on these issues.

Third, as currently structured, the SSI program for children does not distinguish between their needs as low-income children and their needs as children with disabilities. As children from low-income families, their needs for food, shelter, and clothing are much like those of other such children. Yet as children with disabilities, their needs are highly diverse and often include modified forms of basic necessities, such as specialized food and clothing and home modifications. Given this diversity, a careful examination of children's need for SSI requires looking beyond the program itself to determine the adequacy of other services and benefits. HHS Secretary Shalala acknowledged this complexity and stressed the interaction of SSI with other federal and state programs. The Secretary urged the

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<sup>2</sup> For a comparison of eligibility determination under "functional equals" and the IFA, see chapter one.

<sup>3</sup> Here the criterion was whether the child would have to be institutionalized but for the personal care provided by a parent or caregiver.

Commission to conduct a broad, cross-cutting analysis of the children's needs rather than "limit its study to the causes and consequences of [the program's] growth."<sup>4</sup>

Despite the clear difficulties in expediting its work, the Commission decided that its first responsibility was to inform Congressional consideration that was already under way. Anticipating Senate action on welfare reform in early July, the Commission initiated a series of bi-weekly meetings. It declined to undertake new research projects to address its Congressional charge, opting instead for a comprehensive review of existing knowledge of the SSI program and the children it serves. To fill the numerous information gaps, the Commission consulted with medical and other professionals, families, educators, and other close observers of children with disabilities.

The Commission established three task forces to work on specific issues. One group analyzed options for revising the SSI definition of disability. A second considered the role that private organizations could play in improving SSA's service delivery. A third examined growth in the SSI program and the potential universe of eligible children.

In this way, the Commission collected and synthesized information from a wide range of sources. The most important of these were:

*Specialists in childhood disabilities.* The Commission sought expert testimony from specialists in childhood mental retardation, Attention Deficit Hyperactivity Disorder, behavioral and emotional impairments, and neurogenetics. It heard from specialists working in university research programs (including Duke, Johns Hopkins, and Vanderbilt Universities), and from representatives of professional organizations, including the American Academy of Pediatrics, the National Center for Learning Disabilities, and the National Association of School Psychologists.

*SSI administrators.* The Commission had extensive conversations with SSA staff responsible for the design of the medical listings for children and for the IFA; with agency staff involved in SSI outreach; with state DDS personnel, including psychologists, physicians, disability examiners, and staff liaisons with the public school system; and with representatives of the National Association of Disability Examiners.

*Families.* At public hearings in Washington, D.C., Baltimore, and Philadelphia, the Commission heard from 45 families -- primarily parents of children with disabilities -- who discussed their experiences. It also received testimony from representatives of family organizations, including Family Voices, the Federation of Families for Children's Mental

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<sup>4</sup> February 3, 1995, Commission transcript, pages 138-9.

Health, the National Parent Network on Disabilities, and Children and Adults with Attention Deficit Disorders.

*SSI regulations and program instructions.* The Commission reviewed SSI regulations implementing the 1990 *Zebley* decision and the 1990 revision of medical listings of childhood mental impairments; a series of instructions to the DDSs aimed at tightening adjudications; training materials for adjudicators; and agency instructions to physicians, nurses, social workers, and school personnel on providing medical evidence.

*Individualized Functional Assessments.* The Commission analyzed a sample of IFAs completed by state disability determination service (DDS) staff for 51 children who were approved for SSI disability benefits based on an IFA. The IFAs were altered to omit the children's identities.

*Advocacy groups.* The Commission met with representatives of major advocacy groups, reviewing with them their beliefs and experiences. These included national and local representatives of The Arc, United Cerebral Palsy, Community Legal Services of Chicago and Philadelphia, the Bazelon Center for Mental Health Law, and the Children's Defense Fund.

*Program critics.* The Commission met with many individuals who expressed concern about SSI childhood eligibility criteria, including DDS administrators, staff physicians, and a former staff psychologist; public school personnel; and Members of Congress.

*Studies by government agencies.* Commission members studied SSA's annual statistical profiles of children receiving SSI, as well as its audit of benefit allowances to children with emotional and behavioral impairments. They reviewed studies by the HHS Inspector General of SSI benefit allowances to children with mental impairments, Medicaid utilization by children with certain mental impairments, and the concerns of DDS program administrators about the IFA. The Commission also took notice of a General Accounting Office analysis of growth in the childhood disability program and its study of problems with the implementation of the IFA.<sup>5</sup>

*Non-government studies.* The Commission looked closely at the work of the National Academy of Social Insurance: its analyses of SSA's disability determination process, its profiles of families receiving SSI, and a study of services available to children with disabilities in Connecticut and Virginia. It also reviewed the 1995 Urban Institute study of federal programs for children with disabilities and an analysis by Mathematica Research, Inc., of a 1979 survey of parents of children receiving SSI. Further, the Commission reviewed a

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<sup>5</sup> See Appendix 4-D for a full listing of reviewed reports.

Human Services Research Institute survey which focused on the needs of children with disabilities and their families' use of SSI benefits.

*Experts on other benefit programs.* The Commission explored the concept of tiered benefits with a representative of the Department of Veterans' Affairs, which adjusts benefits to reflect the extent of impairment. It learned about disability benefits for children under European social insurance systems from an SSA specialist. It also received testimony from representatives of the Health Care Financing Administration (HCFA) who specialize in Medicaid coverage for children with disabilities, and with representatives of the Department of Education who specialize in the use of the Individualized Educational Plan (IEP) and Individualized Family Services Plan (IFSP) in Special Education programs.

A complete list of the Commission's sources appears in Appendix 3.

Several themes marked the Commission's discussions and analysis. All Commission members expressed the belief that the federal government can and should play a strong role in supporting children with disabilities and their families. Many members also expressed a concern that SSI be structured to motivate, not deter, parents in encouraging their children to accomplish all that they can. In addition, reflecting on their discussions with families, members expressed renewed recognition of the challenges and demands of raising a child with a severe disability and the importance of structuring government support to empower parents in this effort. The Commission's hearings showed great diversity in children's needs, suggesting the importance of a flexible form of government support. Finally, members expressed interest in formulating proposals to bring greater accountability to the SSI program.

Late in April, external events again influenced the Commission's deliberations. The Commission received a letter from Senator Bob Packwood, who was then Chairman of the Senate Committee on Finance, stating that consideration of welfare reform by that Committee was imminent.<sup>6</sup> Chairman Packwood urged the Commission to accelerate its deliberations and asked for preliminary recommendations.

At that time, the Commission had a list of policy options under consideration. At its April 21 Baltimore meeting, the Commission responded to Chairman Packwood's request by reviewing these options and reaching agreement on a set of preliminary recommendations. (See Appendix 5.) Chairman Slattery provided these to the Senate Committee on Finance and the House Committee on Ways and Means, stressing that they were subject to revision.

During May, the Commission refined and expanded its preliminary recommendations. The most significant expansion was the addition of an alternative definition of disability for children for use in determining eligibility for SSI. This second position emerged when the

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<sup>6</sup> Letter from Senator Bob Packwood to Jim Slattery, April 20, 1995.

Commission split on a tie vote (seven to seven) during reconsideration of its preliminary recommendations. Unable to resolve this disagreement, the Commission included both options in its recommendations, along with the names of the members who supported each (see chapter four). Bills that embodied both of these options were introduced by members of the Senate Committee on Finance.

On May 24, 1995, Chairman Slattery shared a draft of the Commission's final recommendations with all the members of the House Committee on Ways and Means and of the Senate Committee on Finance. Since the Committee on Finance had moved more slowly to consider welfare reform than its Chairman had anticipated, the Commission was able to present its final recommendations to the Committee several days before it considered welfare reform.

Paralleling the division within the Commission, the Senate Committee on Finance was equally divided on the extent to which SSI childhood eligibility criteria should be tightened. Ten Senators supported a tighter standard offered by Chairman Packwood which was similar to the Commission's option I, while the remaining ten Senators supported a less stringent tightening of eligibility proposed by Senator Kent Conrad, which was similar to the Commission's option II.<sup>7</sup> Chairman Packwood prevailed on the tie vote, and Senator Conrad's amendment was defeated. Senator Packwood's proposed eligibility criteria were subsequently included in a welfare reform bill sponsored by Senate Majority Leader Robert Dole and, in September 1995, was approved by the full Senate as part of that legislation.<sup>8</sup>

In July, the Commission formed a task force to propose a research agenda to address the informational gaps that had impeded its efforts. The agenda stresses the need to better understand the nature and extent of children's disabilities; the economic, social, and psychological impact of disability on families; the goods and services that children and families use; the extent to which education, technology, and treatment may improve children's long-term outcomes; and the evolution of childhood disabilities over time. The details of this agenda constitute the final chapter of the report.

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<sup>7</sup> These options are presented in the Executive Summary and in chapter four.

<sup>8</sup> Senator Packwood's provision underwent minor modifications prior to its inclusion in Senator Dole's bill, but these did not alter the pragmatic impact of the proposed eligibility criteria. The Social Security Administration and the Congressional Budget Office interpreted both these provisions as requiring children to demonstrate "marked" limitations in two functional domains, as under the Commission's option I.

## **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.

**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.<sup>1</sup>

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

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<sup>1</sup> 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.<sup>2</sup>

### **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.

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<sup>2</sup> 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:

## *Recommendations 50*

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:

- \* 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.<sup>3</sup> 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-

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<sup>3</sup> 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.

social, cognition-communication, and cognition-concentration.<sup>4</sup> 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.

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<sup>4</sup> 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.<sup>5</sup> 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.

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<sup>5</sup> 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, LL.B./J.D., LL.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.<sup>6</sup> 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.

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<sup>6</sup> 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<br>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."<sup>7</sup> 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.

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<sup>7</sup> 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<br>OF<br>CHILDREN | AVERAGE<br>BENEFIT<br>PER<br>CHILD** | MAXIMUM<br>TOTAL<br>MONTHLY<br>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.

## Chapter Five

### Alternative Forms of Support for Children with Disabilities

#### Introduction

A key issue in the current controversy over the SSI childhood disability program is the medium in which assistance should be provided. In the Commission's statutory mandate, Congress directed it to study

... the feasibility of providing benefits to children through noncash means, including but not limited to vouchers,<sup>1</sup> debit cards,<sup>2</sup> and electronic benefit transfer systems.

Early in 1995, the House of Representatives voted to replace cash benefits for some children with a service block grant to states.<sup>3</sup> Given this pending legislation, the Commission gave extensive consideration to providing benefits through noncash means. It carefully considered several forms of vouchers, recognizing that Medicaid can be considered as a voucher for medical services.

Based on this analysis, **the Commission agreed that cash benefits are the most efficient and effective way to assist children with severe disabilities who qualify for SSI (with the exception of those children who qualify only for Medicaid).** The Commission reviewed the many uses of vouchers by families and felt that, given the current state of knowledge, no voucher program could effectively meet the needs of children with disabilities and their families.

The Commission's proposals for noncash support all involve the extension of Medicaid. These proposals would: (1) continue Medicaid for children who do not meet the more stringent eligibility standards for SSI cash benefits that the Commission recommends, (2) provide Medicaid for all children who receive SSI, regardless of the state in which they live, and (3) continue Medicaid for children who lose SSI eligibility because of medical improvement but need continued care and treatment to maintain their improved condition.<sup>4</sup>

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<sup>1</sup> Vouchers encourage consumption of particular goods by a particular class of consumers. Eligible individuals are provided with a coupon that subsidizes their purchases in private markets. Examples of existing voucher programs include food stamps, section 8 housing vouchers, and vouchers for higher education. In addition, as noted above, Medicaid and Medicare may be considered as types of vouchers.

<sup>2</sup> Electronic benefit transfer (EBT) systems are an electronic means of delivering benefits, either cash or in-kind, to eligible individuals. Individuals access benefits by using debit cards and a personal identification number (PIN).

<sup>3</sup> H.R. 4, the Personal Responsibility Act of 1995.

<sup>4</sup> See chapter four.

No other proposals for vouchers, debit cards, or direct services were offered or voted on by members.

Some members favored continuing cash benefits because of the flexibility and choice that cash provides to families. Others placed primary importance on cash as a replacement for foregone wages of parents who remain at home to care for a child. Still others perceived the relatively simple, low-cost administration of a cash benefit as its primary advantage. The common thread in the members' disparate thinking was concern about the high cost of administering a voucher program. Because the needs of children with disabilities are diverse, all members expressed concern that operating a voucher program for this population could be complex and costly.

This chapter responds to the Commission's mandate by laying out the key issues involved in the choice to provide cash versus noncash support. The first section compares the advantages and disadvantages of cash benefits versus vouchers. The second analyzes existing federal voucher programs, identifying their similarities to and differences from a hypothetical SSI voucher program. The third section outlines the potential advantages and disadvantages of electronic benefit transfer systems as a means to deliver SSI benefits to children with disabilities.

## **I. Cash Versus Vouchers**

### **Cash Benefits - The Advantages**

The advantages of a cash payment as the means for supporting families of children with disabilities are five-fold.

**\* Cash benefits build on the natural strengths of families as caregivers.**

In general, children with disabilities fare better in families than in any alternative living arrangement that government can provide. Most families give children the sense of stability, predictability, caring, and control that feeds their growth. They also provide highly competent care. Providing cash to families acknowledges and enhances their role as the child's primary caregiver.

**\* Cash gives families flexibility and choice.**

Families of children with disabilities also face extraordinary challenges and stresses: the daily care of the child, the struggle to meet the child's special needs with restricted resources, and concern about the long-term implications of a child's impairment. For low-income families with such children, these challenges are even greater. Cash benefits enable

these families to devise their own ways of coping with the difficulties and challenges they face.

In particular, cash benefits can provide a baseline level of support for families, replacing income for parents who forego work to address their child's special need for care. When a child needs frequent, individualized attention, care by a parent is far less costly than other options -- e.g., specialized day care, institutionalization, or skilled home care -- making it a bargain for the government.<sup>5</sup>

**\* Cash allows families to meet their children's diverse needs.**

A cash benefit allows families to choose among available services according to their needs. This flexibility makes cash a highly efficient medium of support. The needs of children with disabilities may include obvious items such as medication and prosthetic aids. In addition, many less obvious ones, taken together, may add up to a substantial financial burden. These include:

- personal aids to facilitate living and learning, such as assistive technology for communication and mobility, special foods, modified instructional materials, and specialized transportation;
- heavier use of everyday goods and services, such as extended child care, electricity for around-the-clock electrical devices, more frequent laundering, transportation (for example, when therapy or treatment is not available in the community), repair and maintenance of special equipment, and repair and replacement of home furnishings and equipment;
- specialized day care and recreation, tutors and instruction (not included in a special education program), and personal assistance; and
- home adaptations, such as additional locks, manageable door knobs, enlarged doorways, and bathroom railings.

In addition, as children grow and develop, their needs change, sometimes dramatically. Cash benefits provide parents with the flexibility to respond swiftly to evolving needs.

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<sup>5</sup> A cash benefit may lead some parents to withdraw from the workforce, take a less demanding job, or work fewer hours. In economic terms, such decisions are a distortion and have a welfare cost. A cash benefit may, however, also cause some individuals to increase their work effort by enabling them to buy substitute child care. In these situations, the labor supply distortion would be positive.

**\* Cash benefits enable children to participate in community life.**

Like all children, children with disabilities benefit not only from a family life but from life in a larger social context. A child may learn new skills as part of a club or camp, increase his or her mobility and confidence by participating in sports, or develop contacts who become friends. Cash also makes it easier for families to access services in their communities.

The community benefits from the child's presence as well, since children with severe limitations in one area can make important contributions in others. Such contributions are not only important for the child. They also make communities richer, more diverse places for all who live there.

**\* Cash benefits can be administered simply, inexpensively, and efficiently.**

Issuing a monthly check is a relatively easy task for the government to perform. Unlike vouchers, it requires no bureaucracy to determine legitimate needs, to set standards for authorized goods and services, to authorize particular purchases, to identify and monitor vendors, or to approve requests for exceptions to rules. As a result, administrative costs are low.

**Cash Benefits - The Disadvantages**

Along with the preceding advantages, cash benefits also have some inherent disadvantages.

**\* Cash benefits make it difficult to monitor the use of funds.**

The flexibility that cash provides makes it inherently difficult to monitor family purchases. Moreover, the pooling of cash benefits with other family resources makes it more difficult to establish what has been spent on the child's behalf.

**\* Cash benefits may not address the public's preference for particular forms of support.**

Most studies show that low-income individuals spend a higher proportion of their income on basic necessities than middle-class individuals.<sup>6</sup> Yet taxpayers may derive

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<sup>6</sup> E. Browning and J. Browning, *Public Finance and the Price System*. New York: Macmillan Publishing Company, 1987, p. 280. In addition, in analyzing the Consumer Expenditure Survey (CEX), Michelle Adler (1995) found that families receiving SSI spent 69 percent of their incomes on four basic necessities -- food, shelter, transportation, and utilities -- compared to 61 percent for all families.

satisfaction from supporting higher consumption of food, vitamins, medical care, and education than beneficiary families may choose for themselves.<sup>7</sup> Because taxpayers finance government programs, their satisfaction in supporting these purchases -- termed by economists a positive externality -- is considered in economic measures of overall social welfare.<sup>8</sup>

When positive externalities exist, the optimum allocation of goods and services from society's point of view can be achieved only if low-income families increase their consumption of the items at issue beyond the level that they would otherwise select.<sup>9</sup> Cash payments cannot readily induce this shift in consumption. Vouchers, in theory, can more readily shift consumption in the direction of taxpayers' preferences.

- \* **Cash benefits may lead some families to emphasize or perpetuate a child's disability in order to establish or prolong his or her SSI eligibility.**

Because families are highly interdependent economic units, the needs of a child with a disability cannot easily be isolated from the needs of other family members. Given these interrelationships, SSI benefits do, and must necessarily, increase the economic well-being of the entire family. To the extent that cash benefits improve the family's living conditions, they create a rational incentive for families to establish or prolong a child's SSI eligibility.<sup>10</sup>

In a few cases, this incentive may lead families to coach their children to feign disabilities and even to withhold treatment needed to address disabling conditions.<sup>11</sup> In other cases, the rational incentive to maximize family income may manifest itself in more subtle ways. It could lead some parents to act less aggressively in pursuing treatment, tutoring, assistive technology, or other interventions to address the child's disability.

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<sup>7</sup> D. Hyman, *Public Finance: A Contemporary Application of Theory to Policy*. Dryden Press, 4th Ed., 1993, p. 237-8.

<sup>8</sup> The presence of an external benefit means that people other than the direct consumer benefit from the consumption of a particular commodity. For example, education is often alleged to involve external benefits such as a reduction in juvenile delinquency, an improvement in the functioning of the political process, or greater social stability in addition to benefits the recipients of the education receive.

<sup>9</sup> Where an external cost exists, there will be over-consumption of the good or service at issue; and the optimum allocation of the good will be less than what the recipients would choose for themselves.

<sup>10</sup> A general discussion of the incentive effects of transfer payments is provided in R. Moffitt. "Incentive Effects of the U.S. Welfare System: A Review." *Journal of Economic Literature*. March 1992.

<sup>11</sup> The most comprehensive investigation of coaching to date was conducted by the Social Security Administration. Its findings support the view that coaching is not a widespread phenomenon. See chapter one.

### **Tiered Cash Benefits - The Pros and Cons**

The preceding analysis assumes that cash benefits are paid as they are today, in the form of a flat grant. However, the diversity of disabling conditions among children and the disparities in the severity of these conditions result in substantial differences in the financial needs of families. Given these disparities, SSI program equity and efficiency could be increased by adjusting the size of the cash grant to match family needs. Equity would be increased because each child would receive a benefit that relates directly to his or her own need for care and support. In this same way, the tiering of benefits could increase SSI program efficiency, since children would be less likely to be overpaid or underpaid in relation to their needs. Models for tiered benefits exist in the European countries, many of which pay the parents of children with disabilities a caregiver allowance designed to cover the amount and type of special care that the child requires.<sup>12</sup>

These advantages of tiered benefits are major ones, but they are not easily achieved. Three obstacles stand in the way of their realization. First, no obvious rule or formula exists for classifying disabilities according to the extra costs they impose on families. There is little systematic data on the costs that families incur in raising a child with a disability. Moreover, even the most precise existing classifications of disability by type include children with widely varying disability-related needs. A child's needs can also vary widely depending on the family's circumstances -- e.g., whether a parent, older sibling, or member of the extended family is available to provide needed assistance.

Second, assigning children to benefit tiers would likely require more extensive and costly eligibility determinations. SSA would have to gather and assess additional information in order to establish the level of severity of the child's disability. The agency would also have to monitor a child's condition to identify and respond to changes in need, however defined.

Third, the experience of other industrialized countries suggests the design of tiered benefits affects program participation and cost. The Dutch system is a case in point. There, a fine gradation of benefit levels serves to motivate claimants to seek a more severe classification of their disability. It also leads adjudicators "to provide a little something for everyone," ratcheting down the general standard for benefit allowances and raising program costs significantly.<sup>13</sup> On the other hand, some countries have implemented much simpler

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<sup>12</sup> There are two important ways in which these European programs differ from SSI: (1) European caregiver allowances are structured, in general, as supplements to family allowances, which are not means-tested; and (2) all European systems provide some form of national health care.

<sup>13</sup> Addressing the Commission on March 10, 1995, and July 7, 1995, Ilene Zeitzer of the Social Security Administration described the multiple tiers in the Dutch system (which provides tiered benefits to adults only) as problematic from an administrative perspective. Testifying June 25, 1991, before the Social Security

tiered programs that appear to work effectively to provide benefits linked to levels of needed care.

### **Voucher System - The Advantages**

Vouchers bring into play a range of considerations, some of which mirror the pros and cons of cash payments and some of which are singularly related to vouchers as a medium of support. The major ones are:

- \* In principle, vouchers, like tiered benefits, could provide a level of support that matches a child's disability-related needs.**

In absolute dollar terms, in-kind support provided through vouchers might be considerably higher or lower than what a child would receive through a flat cash benefit. These adjustments could result in a more efficient and fairer allocation of public resources, ensuring that each child receives assistance that relates directly to his or her needs.

- \* Vouchers could bring into play a highly efficient self-selection process among families.**

Because the use of vouchers is restricted to specific items, they cannot easily be used for purchases unrelated to a child's disability. As a result, they would attract just those families who have high disability-related expenditures or unmet needs. The potential for misuse of support would be reduced relative to cash benefits, as would the need for government oversight.

Public interest in vouchers stems from concerns about the unrestricted use of cash and a wish to target support on children's disability-related needs. Vouchers could provide taxpayers with a level of assurance that public funds are going for publicly-supported purposes.

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Subcommittee of the Committee on Ways and Means, Gerben DeJong asserted that the Dutch "liberal eligibility criteria allowed one to acquire income protection against structural unemployment under the guise of a disability and thus legitimize one's exit from the labor force."

A similar incentive may exist within the U.S. Department of Veterans' Affairs disability program, which provides a ten-tiered veterans' compensation benefit. The lowest tier is ten percent disability, with tiers rising to 100 percent by ten percent increments. Additional benefits are provided for special care needs. A representative of the Department advised the Commission to consider simplicity above all in considering the structure of a tiered benefit system for children. Testimony of Dr. Carroll McBrine, Department of Veterans' Affairs, March 10, 1995.

- \* **Vouchers would reduce incentives to perpetuate a child's disability in order to establish or prolong his or her SSI eligibility.**

As noted previously, when cash benefits are used to improve a family's general welfare, the family faces a rational incentive to maintain that support. This incentive may lead some families to act less aggressively than they otherwise would in seeking remediation for a child's disability. Assuming the use of vouchers is restricted to disability-related items, the resulting incentives to perpetuate the general support for the family would be reduced.

### **Voucher System - The Disadvantages**

- \* **A voucher system would reduce family discretion.**

Vouchers would limit families' choices to a list of approved goods and services, and it would be likely to do so in ways that reflect designer, rather than consumer, expertise and preferences.<sup>14</sup> In addition, the standards which must be established for pre-approved items may encourage families to choose more expensive goods, when lower cost substitutes would be equally satisfactory to them. If this occurred, a voucher program would lead to higher expenditures with no attendant increase in the well-being of families.

- \* **A voucher system would be complex and costly to administer.**

The administrative requirements associated with a voucher program are numerous. They include:

- determining what type and level of support should be provided for children with various disabilities;
- deciding what goods and services would be provided (and devising this list so as not to duplicate goods and services provided through other programs);
- setting standards for purchasable goods and services;
- establishing and updating a vendor list;
- processing families' applications and adjudicating their appeals;

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<sup>14</sup> In economic terms, a social welfare cost arises because the voucher distorts family consumption decisions. Similar to cash, vouchers may also affect family members' labor supply decisions because the voucher is a subsidy to the household.

- providing oversight of suppliers and users of vouchers to ensure program integrity; and
- keeping records of families' uses of vouchers in relation to a program cap.

Relative to cash, these requirements would result in a high loss of administrative efficiency. Administrative costs for food stamps and section 8 housing vouchers are 13 and ten percent, respectively, compared to seven percent for the SSI program.<sup>15</sup> Given the diversity of needs among children with disabilities, a voucher program for this population could be considerably more costly than either of these existing programs. SSA estimates that it could raise existing administrative costs by more than \$180 million in the first year and \$100 million annually in subsequent years.<sup>16</sup> Such a program would be preferable to cash payments only if the social welfare gains associated with targeting benefits outweigh these very high losses in administrative efficiency.

- \* **Given the necessary complexities, a voucher system may fail to provide the required range of goods and services.**

With limited government resources, the complexity and cost of a voucher system may mean that its scope must be restricted. As a result, it may be possible to cover only some of the diverse range of goods and services required by children with disabilities. In addition, some families may find their choices so restricted that they choose not to participate, thus narrowing the group of eligible children who are reached by the program.

- \* **A voucher system could lead suppliers to provide inferior goods and services or to engage in fraud.**

Two features of a voucher program might lead to these outcomes. First, the face value of the voucher might be set significantly below the market value of required goods and services, leading suppliers to provide inferior substitutes. Second, in the absence of effective oversight, some participating suppliers might attempt to defraud the government by seeking reimbursement for goods and services they do not actually provide, as has occurred in the Medicaid program.

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<sup>15</sup> The administrative costs of the food stamp program were estimated by the Congressional Budget Office in *The Costs of Administering Selected Poverty-Related Programs*, October 26, 1993. The costs of section 8 housing vouchers were estimated by the Department of Housing and Urban Development in *Section VIII Administrative Fees: A Report to Congress*, January 1994. The administrative costs of the SSI childhood disability program were estimated in the fiscal year 1996 HHS budget.

<sup>16</sup> This would raise administrative costs to over ten percent in the first year and nine percent in subsequent years. Social Security Administration, "Proposal to Replace Cash Payment With a Voucher System to SSI Children," August 1995.

Tables 5-1 and 5-2 summarize the preceding discussion.

**Table 5-1.**

| <b>Advantages of Cash Benefits</b>                         | <b>Disadvantages of Cash Benefits</b>                                                                                 |
|------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------|
| Build on the natural strengths of families as caregivers   | Make it difficult to monitor the use of funds                                                                         |
| Give families flexibility and choice                       | May not address the public's preference for particular forms of support                                               |
| Allow families to meet their children's diverse needs      | May lead some families to emphasize or perpetuate a child's disability in order to prolong his or her SSI eligibility |
| Enable children to participate in community life           |                                                                                                                       |
| Can be administered simply, inexpensively, and efficiently |                                                                                                                       |

**Table 5-2.**

| <b>Advantages of Vouchers</b>                                                                             | <b>Disadvantages of Vouchers</b>                                                  |
|-----------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------|
| Could provide a level of support that matches a child's needs                                             | Would reduce family discretion                                                    |
| Could bring into play a highly efficient self-selection process                                           | Would be complex and costly to administer                                         |
| Would reduce incentives to perpetuate a child's disability in order to prolong his or her SSI eligibility | May fail to provide the required range of goods and services                      |
|                                                                                                           | Could lead suppliers to provide inferior goods and services or to engage in fraud |

## **II. Other Federal Voucher Programs**

A second approach to assessing the feasibility of a voucher program for children with disabilities is to compare a hypothetical SSI voucher program with existing federal voucher programs. These include section 8 housing subsidies, tuition for higher education, food stamps, and Medicaid.<sup>17</sup> In addition, Congress is considering a new use of vouchers in Medicare Managed Care proposals. This comparison will be most revealing if it targets those factors which are likely to determine a voucher program's success. These are:

- \* **Voucher Liquidity** - How easily can the voucher be converted to cash and used for purposes other than those targeted by the program? The more illiquid the voucher, the better.
- \* **Nature of Good or Service** - Is the good or service being provided a single, easily defined product, a packaged good, or a diverse range of unrelated items? The optimal product is one that is simple and distinct or is packaged so that the consumer acquires an integrated combination of goods or services in a single purchase.
- \* **Incentives for Consumers** - Is the voucher program structured to encourage consumers to shop selectively for the best buy? Such incentives are useful in both maximizing the purchasing power of vouchers and inducing competition in markets where they are used.
- \* **Market Competition** - Are there many competing suppliers in the market? Is the voucher program structured to encourage competition among suppliers? The presence of both conditions is optimal.
- \* **Discernable Quality** - How easily can consumers assess the quality of the goods and services they purchase with vouchers? The more discernable these distinctions, the better.

The Table 5-3 uses these criteria to compare federal voucher programs.

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<sup>17</sup> In addition, a federal voucher program not considered here is the special Supplemental Food Program for Women, Infants, and Children.

Table 5-3. Comparison of Federal Voucher Program Characteristics

|                                  | Liquidity of voucher (how easily converted to cash) | Nature of good (single, packaged, diverse range) | Incentives for the consumer to shop wisely                                                    | Extent of market competition (and effect of voucher on competition)          | Discernability of quality             |
|----------------------------------|-----------------------------------------------------|--------------------------------------------------|-----------------------------------------------------------------------------------------------|------------------------------------------------------------------------------|---------------------------------------|
| Housing voucher                  | illiquid                                            | single                                           | yes—voucher rate is set below market rate and consumer must pay difference                    | market competition varied; voucher impact minimal                            | high                                  |
| Voucher for higher education     | illiquid                                            | packaged                                         | yes—voucher does not cover full cost of education                                             | markets are highly competitive                                               | high                                  |
| Food stamp program               | highly liquid                                       | single                                           | yes—amount of food stamps a family receives varies with income and there is a monthly maximum | market is competitive                                                        | high                                  |
| Medicaid program                 | illiquid                                            | packaged                                         | no—consumer has no incentive to seek out lower-cost provider                                  | market competition is limited; voucher impact minimal                        | low                                   |
| Medicare Managed Care voucher    | fairly illiquid                                     | packaged                                         | yes—if value of voucher is set to cover cost of efficient health plan                         | market competition limited; voucher structured to induce greater competition | likely moderate                       |
| SSI-childhood disability program | fairly illiquid (depends on good)                   | diverse range of goods and services              | varied—depends on the good or service                                                         | varied—depends on the good or service                                        | varied—depends on the good or service |

Vouchers for higher education readily satisfy these conditions. Education vouchers are illiquid, meaning that students cannot easily exchange them for cash. Education is a packaged product, allowing students to gain access to many related goods and services -- buildings, teachers, books, computers, and athletic facilities -- by making a single purchase. Education vouchers do not cover the full cost of tuition, giving students an incentive to shop for the best value at the lowest price. Competition among colleges is vigorous, and their reliance on tuition as a primary source of income gives them an incentive to provide demanded services. Finally, colleges have very different reputations and specialties, making the quality of their services relatively easy to measure.

The food stamp program satisfies most, but not all, of the optimal conditions. Here vouchers provide a single, easily-identifiable category of goods. The amount of food stamps a family receives varies with income but is generally less than its food costs, providing an incentive to shop wisely. In most localities, there are a number of competing grocery stores and supermarkets. However, a major disadvantage of food stamps is that they are highly liquid, i.e., can be traded for cash without great difficulty.

Medicaid fails to satisfy most of the optimal conditions. Because consumers do not incur savings if they search out low-cost providers, they do not have an incentive to conserve health care resources. Also, the limits that government places on reimbursement reduce incentives for providers to offer services of high quality. Competition is restricted because low Medicaid reimbursement rates discourage some health care providers from accepting Medicaid patients. Moreover, the quality of health care is inherently difficult to gauge.<sup>18</sup>

The profile of the hypothetical SSI program contrasts markedly with the other voucher profiles. Unlike any existing federal program, SSI would have to provide a wide range of unrelated goods and services -- many types of assistive technology, home adaptations, special foods and clothing, diapers, over-the-counter medicines, additional home heating and cooling, specialized child care, and adapted transportation, in addition to meeting basic needs such as food, clothing and shelter. This diversity not only increases administrative difficulties; it also spills over to influence the other optimal criteria, making it virtually impossible to make any blanket statements about them. Thus, the most salient conclusion to be drawn from this comparison is that the range and scope of required services in an SSI voucher program would be unprecedented.

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<sup>18</sup> It is possible that a voucher program that replaces Medicaid with an array of private insurance options might address some of these shortcomings.

### **III. Electronic Benefit Transfers**

As Americans have turned increasingly to electronic banking to make deposits, pay bills, and make purchases, many government programs are using electronic means for delivering cash and in-kind support. Through electronic benefit transfer systems, the government can replace paper checks for delivering cash to program beneficiaries. Further, for in-kind support programs (e.g., food stamps), EBT can serve as an electronic voucher, limiting purchases to an authorized list of goods and services.<sup>19</sup>

Twelve states have initiated or completed EBT pilot projects. These projects aim principally at delivering food stamps, AFDC, and state general assistance. Other potential candidates for EBT include Social Security, veterans' benefits, railroad retirement, Medicaid, Medicare, student loans, and unemployment compensation. Maryland currently has the only statewide program that delivers both AFDC and food stamps through EBT.<sup>20</sup> Texas is the only state where the federal government currently operates an EBT system for delivering SSI benefits.<sup>21</sup>

As part of its reinventing government initiative, the Clinton Administration is working to develop a national EBT network linking the federal government and the 50 states by the year 2000. When in place, this system will enable program recipients to access multiple benefits using a single debit card. The Social Security Administration supports this initiative. Clearly, the technology is available. The issues of implementation will involve cost, the advantages and disadvantages of this technology in particular cases, and more general issues such as privacy versus public accountability. In general, EBT may have the potential to 1) lower costs of delivering benefits to children, 2) reduce the use of cash for unintended purposes, and 3) improve the services provided to children with disabilities.

#### **EBT for Cash Benefits**

With electronic payment of a cash benefit, the issues of interest are the cost and security of delivery and convenience. The cost to SSA to make a cash benefit payment electronically via EBT is two cents per transaction, which is the same cost to the agency of

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<sup>19</sup> EBT can enhance the ability of retailers to limit purchases to an authorized list of goods and services only if the necessary technology is available in their retail outlets. This technology is not required by the regulations of the food stamp program and is usually only available in large supermarket chains.

<sup>20</sup> About 468,000 recipients use the system, creating transactions of \$57 million each month during 1994. New Mexico will utilize EBT statewide by October 1995.

<sup>21</sup> SSA and the Department of Treasury have implemented a joint EBT in Texas for delivering Social Security, SSI, and other federal benefits to recipients who do not have bank accounts and therefore cannot use direct deposit. At present, the program is optional for SSI beneficiaries.

making a transaction via direct deposit to a recipient's checking account. This is considerably less expensive than the 40 cents it costs the agency to issue and mail a benefit check. Thus, there is considerable potential for government costs to decline through the elimination of paper check processing. In addition, the government may accrue savings through improved cash management flows and through economies of scale resulting from the consolidation of multiple benefit payments via EBT.

The total cost of EBT at the present time, however, is much higher than the two cents expended by SSA. In the Texas program, SSI recipients accessing their benefits via EBT are charged a \$3 monthly fee by the financial institution. In effect, the imposition of the fees lowers recipients' benefits. If the government were to pay the fee, its costs of delivering benefits would increase commensurately, to \$3.02. Thus, a major unresolved issue is who pays the fees for needs-based benefits delivered by EBT. This issue will become even more critical if one or more federal agencies propose to make EBT mandatory.

There are, however, other advantages associated with EBT. People move, and paper checks get lost, stolen, or misdirected in the mail.<sup>22</sup> EBT offers high potential to avoid these problems. Users of EBT in the Maryland pilot project gave it high marks for enhancing their security and sense of independence.

These advantages for consumers are not without some offsetting costs. EBT may be difficult to access in rural areas, and it may be a burdensome form of payment for individuals with certain physical and mental impairments.<sup>23</sup> In addition, some observers have raised privacy concerns related to the record that EBT creates of each beneficiary's transactions.

### **EBT for In-kind Support**

Quite different from cash transfers to children with disabilities is the possible use of EBT to pay for goods and services. The issues raised by this use are considerably more complex. In principle, an electronic voucher program could produce advantages similar to those achieved with EBT for food stamps -- increased use of targeted goods and services, lower administrative costs (relative to voucher coupons), and improved accountability. In Maryland, for example, government officials believe the debit card for food stamps saves the state \$3 million a year. In addition, the new system has eliminated theft of paper stamps. For merchants, the debit card eliminates time-consuming counting, bundling, storing, and redemption of the coupons.

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<sup>22</sup> To illustrate, of 17 million checks mailed by SSA in July 1995, slightly more than 35,000 intended recipients, or one in 500, claimed nonreceipt.

<sup>23</sup> This potential burden would apply only to those individuals with physical or mental impairments who do not have representative payees to manage their finances.

## *Alternative Forms of Support 90*

The use of the debit card in place of coupons has decreased so-called trafficking -- that is, the illegal sale of food stamps for cash. Moreover, the electronic paper trail created by EBT allows investigators to more easily detect fraudulent transactions when they do occur. EBT has also increased the use of food stamps for their intended purpose, buying food. Grocers in Texas reported that the EBT card for food stamps resulted in beneficiaries buying more food than ever before.<sup>24</sup> They also reported that since EBT debits are for the exact purchase amount, the sales of cigarettes, candy, and lottery tickets -- formerly purchased with change returned from food stamps -- dropped significantly.

How applicable is the food stamp experience to the SSI program? In one sense, the goals are the same: to ensure utilization of resources to improve the lives of the beneficiaries. There are two key differences, however.

First, with the food stamp program, the targeted goods are similar and readily identified. In the SSI program for children, needed goods and services vary widely among children with different conditions.

Second, most of what food stamps buy can be bought in any supermarket. By contrast, the list of locations where one must shop to obtain needed goods and services for children with disabilities are nearly as varied as the needed items. To use EBT for in-kind support, vendors in dozens of different types of retail establishments would have to code or label authorized goods and services. Third-party electronic processors in all parts of the country would have to program their machines to recognize these codes. The required infrastructure and technological sophistication far exceed that currently available through EBT.

In sum, EBT holds promise as a means of delivering cash to the families of children with disabilities in a more efficient and convenient manner. Its use for providing in-kind support is, like that of vouchers, rendered much more difficult by the diversity of children's disability-related needs.

## **Conclusion**

Based on its analysis, the Commission agreed that cash benefits are the most efficient and effective way to assist children with severe disabilities who qualify for SSI (with the exception of those children who qualify only for Medicaid). The Commission felt strongly that, given the current state of knowledge, no program of in-kind support could meet the needs of children with disabilities and their families.

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<sup>24</sup> From February to March 1994, food stamp sales rose \$4.4 million in two Texas counties studied.

## Chapter Six

### Health Care Coverage for Children with Disabilities

Children with disabilities access health care services through a decentralized network of federal, state, and local programs. States receive partial funding from the federal government for many of these services but retain a high level of discretion over program implementation. This creates substantial variation among the states in the provision of services. Federal/state programs serving children with disabilities include Medicaid, Children with Special Health Care Needs, Center for Mental Health Services grants, and health-related services under the Individuals with Disabilities Education Act. The following sections describe each of these programs, highlighting eligibility criteria, types of services offered, and statistics on program participation, where available.

#### **I. Medicaid**

During fiscal year 1993, approximately 796,000 children with disabilities were enrolled in Medicaid nationwide, of which about 665,000 received SSI benefits.<sup>1</sup> Of these, approximately 529,000 children actually received Medicaid services sometime during the year. The federal cost of serving these children was approximately \$3.4 billion (see Table 6-1). Throughout the states, federal funding ranged from 50 to 83 percent of program costs, with the federal/state matching rate inversely proportional to the state's per capita income.

Federal law mandates that states extend eligibility to certain groups and provide certain services. Beyond these requirements, states have wide latitude to define their plans by offering optional services and expanding eligibility to additional groups. As a consequence, Medicaid expenditures for children receiving SSI vary widely among the states. Table 6-1 shows state-by-state Medicaid expenditures for children with disabilities in 1993.

Medicaid changes currently under consideration in Congress may affect the access of children with disabilities to health insurance coverage. Such proposals would cut the growth in Medicaid at a time when increasing numbers of children are losing health coverage through the erosion of employment-related dependent benefits. Furthermore, a large proportion of current Medicaid expenditures support long-term care for the elderly, mainly in nursing home settings, where the ability to cut expenditures is minimal. Thus, depending on decisions made at the state level, measures to curtail the growth of Medicaid expenditures may have a disproportionate effect on children and adolescents. Moreover, unless the statutory link to Medicaid for SSI recipients is preserved, states may no longer provide Medicaid coverage for low-income children with disabilities.

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<sup>1</sup> Health Care Financing Administration, Office of the Actuary. Most of the remaining children qualified for Medicaid through a state medically needy program or a state 209(b) option, both of which are described later in this chapter.

Under current law, federally-mandated Medicaid services include:<sup>2</sup>

*inpatient hospital services*  
*rural health clinic services*  
*other laboratory and x-ray services*  
*nurse practitioner services*  
*family planning services and supplies*  
*physician services (including medical and surgical dental services)*

*nursing facilities for individuals age 21 and older*  
*outpatient hospital services*  
*nurse-midwife services*  
*early and periodic, screening, diagnostic, and treatment (EPSDT) services*

Optional services include:<sup>3</sup>

*podiatrist services*  
*optometrist services*  
*chiropractor services*  
*psychologist services*  
*medical social worker services*  
*nurse anesthetist services*  
*private duty nursing*  
*clinic services*  
*dental services*  
*physical therapy*  
*occupational therapy*  
*speech, hearing, and language therapy*  
*prescribed drugs*  
*dentures*  
*prosthetic devices*  
*eyeglasses*  
*diagnostic services*

*screening services*  
*preventive services*  
*rehabilitative services*  
*Intermediate Care Facility/Mental Retardation (ICF/MR)*  
*inpatient psychiatric services for children under age 21*  
*Christian Science nurses*  
*Christian Science sanatoriums*  
*nursing facilities (NF) for children under age 21*  
*emergency hospital services*  
*personal assistance services*  
*transportation services*  
*case management services*  
*hospice care*  
*respiratory care*  
*tuberculosis-related services*

Table 6-2 illustrates state diversity in providing optional Medicaid services. For example, 27 state plans cover psychological services. All states and the District of Columbia include prescription drug coverage; 47 states pay for eye glasses; and 18 states cover personal assistance services.<sup>4</sup>

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<sup>2</sup> Health Care Financing Administration, State-by-State Chart of Medicaid Services, October 1, 1994.

<sup>3</sup> List does not include inpatient hospital services and nursing facilities services for individuals age 65 and older who reside in institutions for the mentally ill.

<sup>4</sup> Optional services not provided under a state plan are required to be available to children under EPSDT.

Many of these services are critically important for children with disabilities. The current SSI debate has focused on issues of treatment and prevention that are particularly relevant to two of them.

Early and Periodic, Screening, Diagnostic, and Treatment Services - EPSDT is a program of preventive and acute care for children. Its purpose is to detect and treat medical conditions before they cause major damage and become more costly to treat. EPSDT services are defined in statute to include five components: screening, vision, dental, hearing, and other services to "correct or ameliorate defects and physical and mental illnesses and conditions discovered by the screening services, whether or not such services are covered under the state [Medicaid] plan."<sup>5</sup>

Under EPSDT, a state must reimburse providers for any Medicaid service that is determined medically necessary, even if it is not an optional service in the state's Medicaid plan. Thus, a child eligible for Medicaid in any state should, in principle, be able to access any service that is reimbursable under federal Medicaid law, despite the differences in state plans.

In practice, children's access to expanded Medicaid services through EPSDT is impeded by three factors. First, methods of determining medical necessity vary among states. Some states contract with physicians to make this determination, while others rely on review boards. Second, most states require prior authorization for diagnostic and treatment services not covered under a state's Medicaid plan. While this can be accomplished by telephone in a few states, most states with prior authorization policies require the submission of a written request. The processing time for expanded service requests varies among the states, from less than one week to four weeks. Third, some states establish limited periods of authorization for EPSDT services. These limits may apply to all services or may be specific to the type of service requested.<sup>6</sup>

Prescription Drug Coverage - While prescription drug coverage is an optional Medicaid service, all states and the District of Columbia include some coverage in their Medicaid plans. The plans differ widely in scope of coverage (see Table 6-3). Under federal law, only payments for drugs manufactured by companies that have signed rebate agreements with the Health Care Financing Administration are eligible for federal matching funds. Children in need of medication not produced by a pharmaceutical company with a rebate agreement may acquire the medication through EPSDT.

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<sup>5</sup> Section 1905(r) of the Social Security Act. Vision services include eyeglasses and hearing services include hearing aids.

<sup>6</sup> Memorandum, Fox Health Policy Consultants, April 8, 1991.

## **Medicaid Eligibility**

Children with disabilities have several paths to Medicaid eligibility: categorical eligibility, Medically Needy programs, the "Katie Beckett" option, Home and Community-based Waivers, and 1115 waivers.

### *a. Categorical Eligibility*

The term categorical eligibility refers to coverage that is mandated by federal law. Two groups of children are categorically eligible for Medicaid: those who receive cash assistance, such as AFDC or SSI, and those whose family income is low enough to qualify them for poverty-related coverage.

Since its inception, Medicaid eligibility has been linked to eligibility for cash assistance programs such as AFDC and SSI. Currently, 32 states automatically enroll children receiving SSI in Medicaid.<sup>7</sup> Another seven automatically extend eligibility to children receiving SSI but require them to complete an application to actually enroll in the program. These states are known as SSI-criteria states. Eleven states, known as 209(b) states, use Medicaid eligibility standards that are different, and generally stricter, than those used for SSI eligibility.<sup>8</sup> Table 6-4 indicates which states are in each of these three categories.

Federal law also requires states to extend categorical Medicaid eligibility to all children under age six with family incomes at or below 133 percent of the federal poverty level.<sup>9</sup> In addition, 1990 expansions require states to extend Medicaid eligibility to all children living at or below the federal poverty level who were born after

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<sup>7</sup> These are known as 1634 states, after the section of the Social Security Act which gives states the authority to allow the Commissioner of Social Security to make Medicaid eligibility determinations for individuals who are aged, blind, and disabled.

<sup>8</sup> When SSI was enacted in 1972, some states expected the number of elderly and disabled recipients of cash assistance to grow significantly. To determine Medicaid eligibility for aged, blind, and disabled recipients, Congress provided (in Section 209(b) of the Social Security Amendments of 1972) the option for states to continue using the financial standards and definitions of disability in effect in January 1972, rather than making all SSI recipients automatically eligible for Medicaid. All 209(b) states use Medicaid eligibility standards that are stricter in some way than SSI eligibility standards. However, Medicaid eligibility involves criteria related to disability, income, and resources, and 209(b) states need not be stricter in all of these. For example, two 209(b) states, Oklahoma and Virginia, use more generous Medicaid income standards; and Connecticut uses more generous Medicaid standards for both income and resources.

<sup>9</sup> Section 1902(l) of the Social Security Act, as amended by Public Law 101-239, the Omnibus Budget Reconciliation Act of 1989.

September 30, 1983.<sup>10</sup> Some states have further expanded their programs to include children with incomes above the federal poverty level and children born before September 30, 1983. See Table 6-5.

b. *State Medically Needy Programs*

Children who qualify as "Medically Needy" meet a state's non-financial criteria for Medicaid but do not meet income or resource requirements. Under this option, children can qualify for Medicaid coverage through a "spend down." Medicaid will pay the individual's qualifying medical expenses after he or she incurs monthly medical expenses that bring his or her income down to the income eligibility or "threshold."

Within broad federal guidelines, states establish eligibility thresholds for Medically Needy individuals. These thresholds can be as high as 133 1/3 percent of the state's maximum AFDC payment levels for families of similar size.<sup>11</sup> In practice, eligibility thresholds for Medically Needy individuals vary considerably from state to state, as illustrated in Table 6-5.

c. *Katie Beckett Option*

If a child lives at home, a state determines his or her financial eligibility for Medicaid by reviewing the parents' income. However, if the child enters an institutional setting and remains there for more than 30 days, parental income is no longer considered. As a result, there are children who do not qualify for Medicaid while living at home but do qualify once they are placed in institutional care.

In response to criticism that these rules create a bias toward institutional care, Congress changed federal Medicaid law in 1982 to provide states with the option to treat as SSI recipients those children under age 18 who receive medical care at home, provided three conditions are met: (1) the medical care must be at a level provided by a hospital or institution; (2) the child would be eligible for Medicaid if he or she were living in an institution; and (3) the cost of home care does not exceed the cost of hospital or institutional care.<sup>12</sup> This option is commonly known as the "Katie Beckett" option. The following states (and the District of Columbia) include the Katie Beckett option in their Medicaid plans.<sup>13</sup>

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<sup>10</sup> Section 1902(l) of the Social Security Act, as amended by Public Law 101-508, the Omnibus Budget Reconciliation Act of 1990.

<sup>11</sup> Section 1903(f) of the Social Security Act.

<sup>12</sup> Section 1902(e)(3)(A) of the Social Security Act.

<sup>13</sup> Health Care Financing Administration, *Medicaid spData System: Characteristics of Medicaid State Programs*, December 1993.

|                             |                      |                      |
|-----------------------------|----------------------|----------------------|
| <i>Alaska</i>               | <i>Maine</i>         | <i>Pennsylvania</i>  |
| <i>Arkansas</i>             | <i>Michigan</i>      | <i>Rhode Island</i>  |
| <i>Delaware</i>             | <i>Minnesota</i>     | <i>South Dakota</i>  |
| <i>District of Columbia</i> | <i>Mississippi</i>   | <i>Vermont</i>       |
| <i>Georgia</i>              | <i>Nebraska</i>      | <i>West Virginia</i> |
| <i>Idaho</i>                | <i>Nevada</i>        | <i>Wisconsin</i>     |
|                             | <i>New Hampshire</i> |                      |

18 + DC

If a state chooses to exercise the Katie Beckett option, it must extend eligibility to all children in the state who would qualify. Thus, states may incur substantial cost in exercising this option.

d. *Home and Community-based Services Waivers*

Another means of providing Medicaid coverage to children with disabilities is the Home and Community-based Services (HCBS) waiver. These waivers allow states to provide long-term care to individuals at home or in the community instead of in institutions. Under an HCBS waiver, states may provide an array of home and community-based services (excluding room and board) not otherwise covered under the Medicaid program. These include, but are not limited to, home health services, personal assistance services, and adult day care.<sup>14</sup>

In 1995, 49 states operate a total of 204 Home and Community-based Services waivers. There is, however, no national compilation of the number of children with disabilities who are being served.

e. *1115 Waivers*

Through section 1115 of the Social Security Act, the Secretary of Health and Human Services may allow states to waive federal Medicaid eligibility and service requirements in order to conduct demonstration projects to develop alternative health care delivery plans and expand Medicaid eligibility. As a result, children with disabilities who do not have access to health care may be eligible for medical services through demonstration projects. Twelve states have been granted 1115 waivers:<sup>15</sup>

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<sup>14</sup> Congressional Research Service, *Medicaid Source Book*, 1993, p. 384.

<sup>15</sup> An additional waiver request for South Carolina was approved by HCFA conditionally. Subsequently, on its own initiative, South Carolina suspended its waiver. Other states that have applied for 1115 waivers include: Alabama, Georgia, Illinois, Kansas, Louisiana, Missouri, New Hampshire, New York, Oklahoma, Texas, and Utah.

|                 |                      |                     |
|-----------------|----------------------|---------------------|
| <i>Arizona</i>  | <i>Kentucky</i>      | <i>Oregon</i>       |
| <i>Delaware</i> | <i>Massachusetts</i> | <i>Rhode Island</i> |
| <i>Florida</i>  | <i>Minnesota</i>     | <i>Tennessee</i>    |
| <i>Hawaii</i>   | <i>Ohio</i>          | <i>Vermont</i>      |

## II. Children with Special Health Care Needs

Established in 1935, the Children with Special Health Care Needs (CSHCN) program is the oldest federal assistance program for children with disabilities.<sup>16</sup> Since its inception, the program has been federally funded through block grants, giving states broad authority to determine its structure. Today CSHCN exists under the Maternal and Child Health Block Grant in title V of the Social Security Act. States must spend a minimum of 30 percent of their MCH Block Grant funds on Children with Special Health Care Needs.<sup>17</sup> In 1992, 678,640 children received medical services from CSHCN programs.<sup>18</sup>

Under the CSHCN program, states must provide: (1) rehabilitation services (unavailable through Medicaid) to children under age 16 who receive SSI, and (2) community-based services for children with special health care needs and their families.<sup>19</sup> States, however, have authority to define the population of children with special health care needs and to determine what services will be provided for eligible children. State programs differ in their requirements for eligibility, family financial participation, scope of services, and service delivery (i.e., hospital, home, school, or clinic). Generally, state CSHCN programs do not address the needs of children with mental impairments.

Since 1976, federal law has required coordination between CSHCN programs and the Social Security Administration to ensure that children who receive SSI also receive relevant CSHCN services and care coordination.

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<sup>16</sup> The original name of the program was the Crippled Children's Service. It was renamed in 1985.

<sup>17</sup> Section 505(a)(1)(3)(B) of the Social Security Act.

<sup>18</sup> U.S. Public Health Service, Maternal and Child Health Bureau. This number reflects under-reporting.

<sup>19</sup> Federal law also requires states to (1) ensure mothers and children access to quality maternal and child health services, and (2) reduce infant mortality and the incidence of preventable diseases and handicapping conditions.

### **III. Center for Mental Health Services**

Children with emotional and behavioral disorders who live in the community need a wide range of supports and services. These services include counseling, crisis intervention services, respite care, and therapeutic foster care.<sup>20</sup> However, many of these services are unavailable in community settings.<sup>21</sup>

In 1992, Congress responded to continued criticism that federal programs did not address the needs of individuals with mental impairments living outside institutions. It established the Center for Mental Health Services under the Substance Abuse Mental Health Services Administration of the Public Health Service.<sup>22</sup> One of the Center's objectives is to provide grants to communities to assist in developing comprehensive community mental health services for children with serious emotional disturbances. Presently, the Center is sponsoring a 22-site demonstration program to establish comprehensive community-based services for these children.

### **IV. Individuals with Disabilities Education Act**

The primary purpose of the Individuals with Disabilities Education Act (IDEA) is to ensure free appropriate public education to children with disabilities.<sup>23</sup> In addition, states must provide related services necessary for children with disabilities to benefit from education. Under IDEA, children with disabilities, from birth to age 21, receive services through three basic programs: Part H early intervention services, the Preschool Grant Program, Part B grants, and a number of discretionary programs.

Part H of IDEA was enacted in 1986 to provide early intervention services to infants and toddlers. These services aim to enhance their development and minimize their need for special education. Part H services include speech pathology, audiology, occupational therapy, physical therapy, psychological services, diagnostic medical services, vision services, and other health services necessary to enable the child to benefit from other Part H services.<sup>24</sup>

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<sup>20</sup> Beth Stroul, *Series on Community-Based Services for Children and Adolescents who are Severely Emotionally Disturbed*. Georgetown Child Development Center. 1988, Volume 1.

<sup>21</sup> Testimony of Gary DeCarolis before the Commission on April 21, 1995.

<sup>22</sup> The Center for Mental Health Services was established by section 115 of Public Law 102-321.

<sup>23</sup> Department of Education. *To Assure the Free Appropriate Public Education of all Children with Disabilities: 16th Annual Report to Congress of the Implementation of the Individuals with Disabilities Education Act*. Preface, 1994.

<sup>24</sup> Section 672(2)(E) of the Individuals with Disabilities Education Act.

Each child (between birth and age 3) served by Part H has an Individualized Family Service Plan (IFSP) that prescribes specific services needed by the child and his or her family.

The provision of health services under IDEA continues until a child leaves the education system, although the scope of services may not be as broad as those under Part H. Under the Preschool Grant Program, states receive federal funds to provide special education and related services to children ages three to five with disabilities. To provide such services to children ages six to 21, states receive federal funds under the IDEA Part B formula grant program. Health services provided by these two programs include, but are not limited to, psychological services, physical therapy, occupational therapy, rehabilitation, and speech/language services.<sup>25</sup> The individual needs of a child, outlined in an Individualized Education Plan (IEP), determine the scope of services provided under Part B and the Preschool Grant Program.

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<sup>25</sup> L. Aron, P. Loprest, and C. Eugene Steuerle, *Government Programs for Children with Disabilities, Part One: Size, Participation, Benefits and Expenditures* (Draft Final Report), February 1995, p. 56.

**Table 6-1: Medicaid Expenditures and Recipient Counts for Children Under Age 21 Receiving SSI and/or SSP in 1993\***

| State                | Medicaid Expenditures (millions) | Medicaid Recipients (thousands) | Medicaid Expenditures per child (thousands) |
|----------------------|----------------------------------|---------------------------------|---------------------------------------------|
| Alabama              | 66.9                             | 19.3                            | 3.5                                         |
| Alaska               | 8.6                              | 0.6                             | 14.6                                        |
| Arizona              | 11.8                             | 5.9                             | 2.0                                         |
| Arkansas             | 79.4                             | 12.7                            | 6.3                                         |
| California           | 379.9                            | 56.3                            | 6.7                                         |
| Colorado             | 42.0                             | 5.5                             | 7.6                                         |
| Connecticut          | 0.1                              | 0.0                             | 5.8                                         |
| Delaware             | 16.1                             | 1.4                             | 11.3                                        |
| District of Columbia | 13.8                             | 1.4                             | 9.6                                         |
| Florida              | 185.2                            | 34.0                            | 5.4                                         |
| Georgia              | 108.9                            | 21.3                            | 5.1                                         |
| Hawaii               | 0.4                              | 0.1                             | 6.4                                         |
| Idaho                | 3.0                              | 0.3                             | 10.7                                        |
| Illinois             | 134.6                            | 20.1                            | 6.7                                         |
| Indiana              | 39.4                             | 2.2                             | 18.2                                        |
| Iowa                 | 49.5                             | 6.1                             | 8.1                                         |
| Kansas               | 35.4                             | 4.7                             | 7.6                                         |
| Kentucky             | 82.7                             | 15.4                            | 5.4                                         |
| Louisiana            | 118.6                            | 25.7                            | 4.6                                         |
| Maine                | 26.4                             | 2.4                             | 11.1                                        |
| Maryland             | 62.8                             | 6.3                             | 10.0                                        |
| Massachusetts        | 110.5                            | 9.3                             | 11.8                                        |
| Michigan             | 110.6                            | 22.4                            | 4.9                                         |
| Minnesota            | 34.7                             | 2.2                             | 15.6                                        |
| Mississippi          | 66.5                             | 21.3                            | 3.1                                         |
| Missouri             | 1.1                              | 0.2                             | 5.2                                         |
| Montana              | 14.1                             | 1.8                             | 7.7                                         |
| Nebraska             | 14.7                             | 2.2                             | 6.6                                         |
| Nevada               | 0.9                              | 0.2                             | 5.7                                         |

**Table 6-1: Medicaid Expenditures and Recipient Counts for Children Under Age 21 Receiving SSI and/or SSP in 1993\***

| State             | Medicaid Expenditures (millions) | Medicaid Recipients (thousands) | Medicaid Expenditures per child (thousands) |
|-------------------|----------------------------------|---------------------------------|---------------------------------------------|
| New Hampshire     | 4.2                              | 0.9                             | 4.5                                         |
| New Jersey        | 112.9                            | 15.7                            | 7.2                                         |
| New Mexico        | 30.3                             | 3.9                             | 7.7                                         |
| New York          | 468.8                            | 42.0                            | 11.2                                        |
| North Carolina ** | 31.7                             | 3.4                             | 9.3                                         |
| North Dakota      | 8.8                              | 0.7                             | 11.8                                        |
| Ohio              | 2.1                              | 0.6                             | 3.6                                         |
| Oklahoma          | 28.3                             | 6.0                             | 4.7                                         |
| Oregon            | 5.4                              | 1.0                             | 5.2                                         |
| Pennsylvania      | 189.6                            | 31.6                            | 6.0                                         |
| Rhode Island      | 23.1                             | 4.4                             | 5.3                                         |
| South Carolina    | 48.2                             | 9.1                             | 5.3                                         |
| South Dakota      | 18.9                             | 2.2                             | 8.5                                         |
| Tennessee         | 70.4                             | 19.0                            | 3.7                                         |
| Texas             | 275.0                            | 40.4                            | 6.8                                         |
| Utah              | 14.9                             | 1.9                             | 8.0                                         |
| Vermont           | 8.5                              | 1.1                             | 7.5                                         |
| Virginia          | 53.2                             | 10.5                            | 5.1                                         |
| Washington        | 45.1                             | 8.2                             | 5.5                                         |
| West Virginia     | 34.8                             | 6.9                             | 5.1                                         |
| Wisconsin         | 90.9                             | 17.2                            | 5.3                                         |
| Wyoming           | 3.5                              | 0.5                             | 6.3                                         |
| United States     | 3387.4                           | 528.6                           | 6.4                                         |

Source: Office of the Actuary, Health Care Financing Administration.

\* States where Medicaid eligibility is not automatically provided to SSI recipients (i.e., 209(b) states and SSI-criteria states) are shaded to indicate uncertainty about data accuracy. These states sometimes under-count children with disabilities who receive Medicaid. The problem has two sources. Some states (e.g., Connecticut) do not code children receiving SSI as disabled in their Medicaid records. In other states, children with disabilities may be granted Medicaid because of low-income status rather than because of their disability (and, as a consequence, the state Medicaid bureau may be unaware that the child is disabled). Thus, the number of children with disabilities receiving Medicaid in 209(b) states and SSI-criteria states may be higher than this table indicates. Chapter seven includes a recommendation for improving the quality of HCFA data on children with disabilities.

\*\* North Carolina was a 209(b) state in 1993 but has since become a 1634 state.

| Table 6-2: States Providing Optional Medicaid Services      |                        |                                               |                            |       |
|-------------------------------------------------------------|------------------------|-----------------------------------------------|----------------------------|-------|
|                                                             | categorically<br>needy | categorically<br>needy and<br>medically needy | 1115 state-<br>wide waiver | TOTAL |
| Podiatrist services                                         | 11                     | 31                                            | 5                          | 47    |
| Optometrist services                                        | 13                     | 32                                            | 5                          | 50    |
| Chiropractor services                                       | 6                      | 22                                            | 1                          | 29    |
| Psychologist services                                       | 6                      | 19                                            | 3                          | 28    |
| Medical social worker services                              | 1                      | 3                                             | 2                          | 6     |
| Nurse anesthetist                                           | 6                      | 12                                            | 1                          | 19    |
| Private duty nursing                                        | 6                      | 18                                            | 2                          | 26    |
| Clinic services                                             | 14                     | 32                                            | 4                          | 50    |
| Dental services                                             | 13                     | 29                                            | 5                          | 47    |
| Physical therapy                                            | 11                     | 28                                            | 3                          | 42    |
| Occupational therapy                                        | 8                      | 24                                            | 3                          | 35    |
| Speech, hearing, and language disorders                     | 11                     | 27                                            | 3                          | 41    |
| Prescribed drugs                                            | 15                     | 31                                            | 5                          | 51    |
| Dentures                                                    | 8                      | 25                                            | 4                          | 37    |
| Prosthetic devices                                          | 15                     | 30                                            | 5                          | 50    |
| Eyeglasses                                                  | 14                     | 29                                            | 4                          | 47    |
| Diagnostic services                                         | 9                      | 19                                            | 3                          | 31    |
| Screening services                                          | 7                      | 19                                            | 2                          | 28    |
| Preventive services                                         | 5                      | 19                                            | 4                          | 28    |
| Rehabilitative services                                     | 15                     | 26                                            | 4                          | 45    |
| ICF/MR services                                             | 21                     | 24                                            | 4                          | 49    |
| Inpatient psychiatric services for<br>children under age 21 | 12                     | 25                                            | 5                          | 42    |
| Christian Science nurses                                    | 2                      | 3                                             | 1                          | 6     |
| Christian Science sanatoriums                               | 5                      | 9                                             | 2                          | 16    |
| NF services for children under age 21                       | 18                     | 28                                            | 4                          | 50    |
| Emergency hospital services                                 | 13                     | 24                                            | 4                          | 41    |
| Personal assistance services                                | 11                     | 20                                            | 2                          | 33    |
| Transportation services                                     | 14                     | 31                                            | 5                          | 50    |
| Care Coordination                                           | 12                     | 30                                            | 3                          | 45    |
| Hospice Care                                                | 11                     | 24                                            | 3                          | 38    |
| Respiratory Care                                            | 3                      | 8                                             | 3                          | 14    |
| TB-related services                                         | 2                      | 6                                             | 0                          | 8     |

Source: Medicaid Services State-By-State Chart  
Health Care Financing Administration, October 1994.

Table 6-3 Medicaid Limits on Prescription Drugs, by Jurisdiction, August 1994 (see key on back)

| State                 | Copayment Amount | Rx Limit Per Month | Refill Limit | Quantity Limit <sup>26</sup> | Limits on OTC's Reimbursed |
|-----------------------|------------------|--------------------|--------------|------------------------------|----------------------------|
| Alabama               | .50-3.00         | No                 | Yes-5        | Yes                          | Few                        |
| Alaska                | 0                | No                 | No           | Yes                          | Few                        |
| Arizona <sup>27</sup> | 0                |                    |              |                              |                            |
| Arkansas              | .50-3.00         | Yes-3              | Yes-5        | Yes                          | Few                        |
| California            | 1.00             | No                 | No           | Yes-100 days                 | Most                       |
| Colorado              | 2.00/.50         | No                 | No           | Yes-100 days                 | Few                        |
| Connecticut           | 0                | No                 | No           | Yes-240 caps/Rx              | Few                        |
| Delaware              | 0                | No                 | No           | No                           | Most                       |
| DC                    | .50              | No                 | Yes-3        | Yes                          | Few                        |
| Florida               | 1.00             | Yes-6              | Yes-C        | Yes                          | Few                        |
| Georgia               | .50              | Yes-A              | No           | Yes                          | Few                        |
| Hawaii                | 0                | No                 | No           | No                           | Most                       |
| Idaho                 | 0                | No                 | No           | Yes                          | Few                        |
| Illinois              | 0                | No                 | No           | Yes-varies                   | Few                        |
| Indiana               | 0                | No                 | No           | No                           | Most                       |
| Iowa                  | 1.00             | No                 | No           | No                           | Few                        |
| Kansas                | 2.00             | No                 | No           | Yes-100 days                 | Few                        |
| Kentucky              | 0                | No                 | Yes-5        | Yes-G                        | Few                        |
| Louisiana             | 0                | No                 | Yes-5        | No                           | Few                        |
| Maine                 | .50-2.00         | No                 | Yes-5        | No                           | All                        |
| Maryland              | 1.00             | No                 | Yes-2        | No                           | Few                        |
| Massachusetts         | .50              | No                 | Yes-5        | Yes                          | Few                        |
| Michigan              | 1.00             | No                 | No           | No                           | Few                        |
| Minnesota             | 0                | No                 | No           | Yes-varies                   | Few                        |
| Mississippi           | 1.00             | Yes-5              | Yes-5        | Yes                          | Few                        |
| Missouri              | .50-2.00         | No                 | No           | Yes-H                        | Most                       |
| Montana               | 1.00/2.00        | No                 | No           | Yes                          | Few                        |
| Nebraska              | 2.00             | No                 | Yes-D        | Yes-I                        | Most                       |
| Nevada                | 0                | Yes-3              | No           | Yes                          | Prior Approval             |
| New Hampshire         | .50/1.00         | No                 | Yes-E        | No                           | Most                       |
| New Jersey            | 0                | No                 | Yes-3        | Yes-J                        | Few                        |
| New Mexico            | 0                | No                 | No           | Yes-180 days                 | Few                        |
| New York              | 0                | Yes-B              | Yes-5        | No                           | Few                        |
| North Carolina        | 1.00             | Yes-6              | No           | No                           | Insulin Only               |
| North Dakota          | 0                | No                 | Yes-5        | No                           | Few                        |
| Ohio                  | 0                | No                 | Yes-F        | Yes-varies                   | Few                        |
| Oklahoma              | 1.00/2.00        | Yes-3              | No           | No                           | Few                        |
| Oregon                | 0                | No                 | No           | Yes-100 days                 | Prior Approval             |
| Pennsylvania          | 1.00             | No                 | Yes-5        | Yes                          | Most                       |
| Rhode Island          | 0                | No                 | Yes-5        | Yes                          | Few                        |
| South Carolina        | 1.50             | Yes-3              | Yes-varies   | Yes-100 days                 | Few                        |
| South Dakota          | 1.00             | No                 | No           | No                           | Few                        |
| Tennessee             | *                | No                 | No           | No                           | Few                        |
| Texas                 | 0                | Yes-3              | Yes-5        | Yes-180 days                 | Most                       |
| Utah                  | 0                | No                 | Yes-5        | Yes                          | Few                        |
| Vermont               | 1.00/2.00        | No                 | Yes-5        | Yes-K                        | Few                        |
| Virginia              | 1.00             | No                 | No           | No                           | Few                        |
| Washington            | 0                | No                 | Yes-2/mo     | Yes                          | Few                        |
| West Virginia         | .50-1.00         | No                 | Yes-5        | Yes                          | Few                        |
| Wisconsin             | 1.00             | No                 | Yes-11       | Yes                          | Few                        |
| Wyoming               | 1.00             | Yes-3              | Yes-E        | Yes                          | Few                        |

<sup>26</sup> Unless otherwise noted, a "Yes" response designates "30-34 days supply or 100 units limit."<sup>27</sup> Arizona has implemented a state-wide Medicaid waiver, the Arizona Health Care Cost Containment Waiver (AHCCCW), under which prescription drugs are subject to a general capitation limit.

**Key**

Unless otherwise noted, a "Yes" response for Quantity Limit has a 30-34 days supply or 100 units limit.

- A 5 Rxs per month/adult; 6 Rxs per month/child
- B Some, but not all Rxs
- C 1 refill per sleep aids, antianxiety products, H<sub>2</sub> antagonists
- D 3 month supply maximum
- E Up to one year
- G After initial filling, one dispensing fee per 30-day period for designated
- H Applies to aspirin/acetaminophen/prenatal vitamins
- I 30-day supply minimum
- J No more than the greater of 60 days or 100 units
- K No more than 60 days or less than 30-day supply

**Co-Payments**

- \* Sliding co-payment for those not covered by TennCare

Table 6-4: Link Between SSI and Medicaid Eligibility

| State                | Automatic enrollment in Medicaid | Automatic eligibility but separate application | 209(b) state | Medically Needy program |
|----------------------|----------------------------------|------------------------------------------------|--------------|-------------------------|
| Alabama              | X                                |                                                |              |                         |
| Alaska               |                                  | X                                              |              |                         |
| Arizona              | X                                |                                                |              |                         |
| Arkansas             | X                                |                                                |              | X                       |
| California           | X                                |                                                |              | X                       |
| Colorado             | X                                |                                                |              |                         |
| Connecticut          |                                  |                                                | X            | X                       |
| Delaware             | X                                |                                                |              |                         |
| District of Columbia | X                                |                                                |              | X                       |
| Florida              | X                                |                                                |              | X                       |
| Georgia              | X                                |                                                |              | X                       |
| Hawaii               |                                  |                                                | X            |                         |
| Idaho                |                                  | X                                              |              |                         |
| Illinois             |                                  |                                                | X            | X                       |
| Indiana              |                                  |                                                | X            |                         |
| Iowa                 | X                                |                                                |              | X                       |
| Kansas               |                                  | X                                              |              | X                       |
| Kentucky             | X                                |                                                |              | X                       |
| Louisiana            | X                                |                                                |              | X                       |
| Maine                | X                                |                                                |              | X                       |
| Maryland             | X                                |                                                |              | X                       |
| Massachusetts        | X                                |                                                |              | X                       |
| Michigan             | X                                |                                                |              | X                       |
| Minnesota            |                                  |                                                | X            | X                       |
| Mississippi          | X                                |                                                |              |                         |
| Missouri             |                                  |                                                | X            |                         |
| Montana              | X                                |                                                |              | X                       |
| Nebraska             |                                  | X                                              |              | X                       |
| Nevada               |                                  | X                                              |              |                         |
| New Hampshire        |                                  |                                                | X            | X                       |

| Table 6-4: Link Between SSI and Medicaid Eligibility |                                  |                                                |              |                         |
|------------------------------------------------------|----------------------------------|------------------------------------------------|--------------|-------------------------|
| State                                                | Automatic enrollment in Medicaid | Automatic eligibility but separate application | 209(b) state | Medically Needy program |
| New Jersey                                           | X                                |                                                |              | X                       |
| New Mexico                                           | X                                |                                                |              |                         |
| New York                                             | X                                |                                                |              | X                       |
| North Carolina                                       | X                                |                                                |              | X                       |
| North Dakota                                         |                                  |                                                | X            | X                       |
| Ohio                                                 |                                  |                                                | X            |                         |
| Oklahoma                                             |                                  |                                                | X            | X                       |
| Oregon                                               |                                  | X                                              |              |                         |
| Pennsylvania                                         | X                                |                                                |              | X                       |
| Rhode Island                                         | X                                |                                                |              |                         |
| South Carolina                                       | X                                |                                                |              |                         |
| South Dakota                                         | X                                |                                                |              |                         |
| Tennessee                                            | X                                |                                                |              |                         |
| Texas                                                | X                                |                                                |              | X                       |
| Utah                                                 |                                  | X                                              |              | X                       |
| Vermont                                              | X                                |                                                |              | X                       |
| Virginia                                             |                                  |                                                | X            | X                       |
| Washington                                           | X                                |                                                |              | X                       |
| West Virginia                                        | X                                |                                                |              | X                       |
| Wisconsin                                            | X                                |                                                |              | X                       |
| Wyoming                                              | X                                |                                                |              |                         |

Source: Health Care Financing Administration, July 1995.

| TABLE 6-5: Medicaid Income Eligibility Thresholds for Poor and Medically Needy Children |                      |                     |                                                    |                                                                                                    |                    |
|-----------------------------------------------------------------------------------------|----------------------|---------------------|----------------------------------------------------|----------------------------------------------------------------------------------------------------|--------------------|
| State                                                                                   | AFDC<br>Need<br>Std* | Medically<br>Needy* | Expanded<br>Medicaid<br>Eligibility<br>for Infants | Additional Poverty-related<br>Medicaid Expansions for<br>Children Beyond Mandatory<br>Requirements |                    |
| Alabama                                                                                 | \$8,076              |                     |                                                    |                                                                                                    |                    |
| Alaska                                                                                  | \$12,024             |                     |                                                    |                                                                                                    |                    |
| Arizona                                                                                 | \$11,568             |                     | 140%                                               | 100%                                                                                               | under age 14       |
| Arkansas                                                                                | \$8,460              | \$3,300             |                                                    |                                                                                                    |                    |
| California                                                                              | \$8,580              | \$11,208            | 200%                                               | 200%                                                                                               | under age 2        |
| Colorado                                                                                | \$5,052              |                     |                                                    |                                                                                                    |                    |
| Connecticut                                                                             | \$8,940              | \$9,276             | 185%                                               |                                                                                                    |                    |
| Delaware                                                                                | \$4,056              |                     | 185%                                               |                                                                                                    |                    |
| District of Columbia                                                                    | \$8,544              | \$6,720             | 185%                                               |                                                                                                    |                    |
| Florida                                                                                 | \$12,324             | \$3,636             | 185%                                               |                                                                                                    |                    |
| Georgia                                                                                 | \$5,088              | \$4,500             | 185%                                               | 100%                                                                                               | under age 19       |
| Hawaii                                                                                  | \$13,680             | \$8,544             | 300%                                               | 300%                                                                                               | general pop.       |
| Idaho                                                                                   | \$11,892             |                     |                                                    |                                                                                                    |                    |
| Illinois                                                                                | \$11,232             | \$5,904             |                                                    |                                                                                                    |                    |
| Indiana                                                                                 | \$3,840              |                     | 150%                                               |                                                                                                    |                    |
| Iowa                                                                                    | \$10,188             | \$6,792             | 185%                                               |                                                                                                    |                    |
| Kansas                                                                                  | \$5,148              | \$5,760             | 150%                                               | 100%                                                                                               | under age 16       |
| Kentucky                                                                                | \$6,312              | \$3,696             | 185%                                               |                                                                                                    |                    |
| Louisiana                                                                               | \$7,896              | \$3,096             |                                                    |                                                                                                    |                    |
| Maine                                                                                   | \$6,636              | \$5,496             | 185%                                               | 125%                                                                                               | ages 6 - 18        |
| Maryland                                                                                | \$6,204              | \$5,108             | 185%                                               | 185%                                                                                               | born after 9/30/83 |
| Massachusetts                                                                           | \$6,904              | \$9,300             | 185%                                               | 200%                                                                                               | under age 13       |
| Michigan                                                                                | \$6,612              | \$6,804             | 185%                                               |                                                                                                    |                    |
| Minnesota                                                                               | \$6,384              | \$8,508             | 275%                                               | 275%                                                                                               |                    |
| Mississippi                                                                             | \$4,416              |                     | 185%                                               |                                                                                                    |                    |
| Missouri                                                                                | \$10,152             |                     | 185%                                               | 100%                                                                                               | under age 19       |
| Montana                                                                                 | \$6,360              | \$5,700             |                                                    |                                                                                                    |                    |
| Nebraska                                                                                | \$4,368              | \$5,904             |                                                    |                                                                                                    |                    |

| TABLE 6-5: Medicaid Income Eligibility Thresholds for Poor and Medically Needy Children |                      |                     |                                                    |                                                                                                    |              |
|-----------------------------------------------------------------------------------------|----------------------|---------------------|----------------------------------------------------|----------------------------------------------------------------------------------------------------|--------------|
| State                                                                                   | AFDC<br>Need<br>Std* | Medically<br>Needy* | Expanded<br>Medicaid<br>Eligibility<br>for Infants | Additional Poverty-related<br>Medicaid Expansions for<br>Children Beyond Mandatory<br>Requirements |              |
| Nevada                                                                                  | \$8,388              |                     |                                                    |                                                                                                    |              |
| New Hampshire                                                                           | \$20,088             | \$7,824             | 170 %                                              | 170 %                                                                                              | under age 11 |
| New Jersey                                                                              | \$11,820             | \$7,092             | 185 %                                              | 300 %                                                                                              | under age 1  |
| New Mexico                                                                              | \$4,572              |                     | 185 %                                              |                                                                                                    |              |
| New York                                                                                | \$6,924              | \$9,600             | 185 %                                              | 160 %                                                                                              | under age 15 |
| North Carolina                                                                          | \$6,528              | \$4,404             | 185 %                                              | 100 %                                                                                              | under age 19 |
| North Dakota                                                                            | \$5,172              | \$5,580             |                                                    |                                                                                                    |              |
| Ohio                                                                                    | \$10,812             |                     |                                                    |                                                                                                    |              |
| Oklahoma                                                                                | \$7,740              | \$5,196             | 150 %                                              |                                                                                                    |              |
| Oregon                                                                                  | \$5,520              | \$7,356             |                                                    |                                                                                                    |              |
| Pennsylvania                                                                            | \$7,368              | \$5,604             | 185 %                                              | 185 %                                                                                              | under age 15 |
| Rhode Island                                                                            | \$6,648              | \$8,892             | 250 %                                              |                                                                                                    |              |
| South Carolina                                                                          | \$5,280              |                     | 185 %                                              |                                                                                                    |              |
| South Dakota                                                                            | \$6,084              |                     |                                                    |                                                                                                    |              |
| Tennessee                                                                               | \$6,000              | \$3,000             | 185 %                                              |                                                                                                    | uninsured    |
| Texas                                                                                   | \$9,012              | \$3,300             | 185 %                                              |                                                                                                    |              |
| Utah                                                                                    | \$6,816              | \$6,816             |                                                    | 100 %                                                                                              | under age 18 |
| Vermont                                                                                 | \$13,776             | \$10,392            | 225 %                                              | 225 %                                                                                              | under age 18 |
| Virginia                                                                                | \$3,864              | \$4,300             |                                                    | 100 %                                                                                              | under age 19 |
| Washington                                                                              | \$13,896             | \$8,004             | 185 %                                              | 100 %                                                                                              | under age 19 |
| West Virginia                                                                           | \$5,964              | \$3,480             | 150 %                                              | 150 %                                                                                              | under age 19 |
| Wisconsin                                                                               | \$7,764              | \$8,268             | 155 %                                              | 155 %                                                                                              | ages 2 - 5   |
| Wyoming                                                                                 | \$8,088              |                     |                                                    |                                                                                                    |              |

Source: National Governors' Association, "MCH Update," March 1995.

\* Figures are for a single parent of three. For larger families, the threshold could be higher.

## Chapter Seven

### Research for Future Policy Directions

#### Introduction

The following pages provide a blueprint for future consideration of support for children with disabilities and their families. This blueprint is needed because large gaps exist in the current understanding of childhood disability. These gaps severely impeded the Commission's deliberations and, until addressed, will continue to serve as a barrier to policy making. The needed investigation should focus on the following questions:

1. Who are children with disabilities in terms of their clinical, functional, and family status; their status over time; their relationship to the broader population of children without disabilities; and their relationship to the narrower population of children with disabilities who receive SSI?
2. What interventions are helpful (and harmful) in improving outcomes for children with disabilities and their families? What outcomes are achievable for children with disabilities?
3. Does the form in which support is provided (cash, direct services, or vouchers) influence outcomes for children with disabilities and their families and, if so, how?
4. What outcomes should public support for children with disabilities aim to achieve?<sup>1</sup>

In recommending research on these topics, the Commission wishes to stress several points. First, childhood disability is a complex phenomenon, not only medically but also in social, psychological, economic, and educational terms. Given this complexity, the questions posed above will not lend themselves to quick or easy analysis. In particular, the issue of what interventions work to improve outcomes for children with disabilities is difficult and elusive. Interventions can achieve different outcomes depending on the child, the impairment, and the family's circumstances.

Second, research to address all the questions should have a strong family-centered focus. Families are among the most valuable sources of information about children with disabilities. They should be approached less as research subjects and more as informants with important understanding and insights to share.

Third, while the proposed questions target a larger group of children than those receiving SSI, the optimal structure of the SSI program depends heavily upon their answers. For this reason, the Social Security Administration should assume central responsibility for this research. Some questions can be addressed through manipulation of existing agency data,

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<sup>1</sup> This final question relates more to values than to specific research. It is included because of its fundamental importance as the basis for public policy related to children with disabilities and their families.

while others will require involvement by other federal agencies and private research organizations. The Commission particularly encourages SSA to coordinate its efforts with federal agencies that interface with families, such as the Department of Health and Human Services and the Department of Education. However, SSA itself should assume responsibility for ensuring that the full range of questions is addressed.

Fourth, the Commission notes that children and adolescents, especially those with disabilities, have been consistently undervalued with respect to investment in research. The lapse extends not only to their use of medical and other services but to investment in the development of technology that could improve their functioning and participation in activities of daily life. The Commission believes that it is essential to increase attention to children and families in these areas of research.

## Question 1: Who Are Children with Disabilities?

The first and largest problem in developing a profile of children with disabilities is a conceptual one: there is no consensus on what disability is or how to measure it.<sup>2</sup> Without such consensus, national surveys and data bases rely on different criteria for measuring disability,<sup>3</sup> and federal benefit programs employ widely differing eligibility requirements.<sup>4</sup>

Second, in the absence of regular and systematic collection of national data on children with disabilities, inquiry at the state and local level has proceeded in a piecemeal fashion. Study samples of children with disabilities are typically small and non-random. They provide little information on important subgroups of children with disabilities, such as infants and toddlers and those with mental health problems. There is also little information on the use of assistive technologies by children.

Third, findings from some studies may be skewed by adult respondent biases. For example, some research indicates that families are more likely to report conditions that affect their child's daily activities and less likely to report those that they consider embarrassing or stigmatizing.<sup>5</sup> Other studies report substantial differences in the perspectives of three groups -- parents, teachers, and therapists -- in assessing children's intellectual functioning, social skills, and capacity for receptive and expressive communication.<sup>6</sup>

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<sup>2</sup> Three major conceptual models of disability are: (1) the International Classification of Impairments, Disabilities and Handicaps (ICIDH), (2) a functional limitation framework developed by Saad Nagi, and (3) a relatively new functional assessment scale developed by Stein and Westbrook for the National Child Health Assessment Planning Project (NCHAPP).

<sup>3</sup> For example, the National Health Interview Survey (NHIS) uses daily activity limitation, while the Survey of Income and Program Participation (SIPP) focuses on activities of daily living, instrumental activities of daily living, and functional limitation in a set of sensory and physical activities.

<sup>4</sup> Federal laws and programs include more than 50 definitions of disability. These programs fall into eleven categories: education, employment, health, housing, income maintenance, rights, social services, vocational rehabilitation, taxation, veterans' benefits, and miscellaneous programs. C. Domzal, *Federal Statutory Definitions of Disability*. Falls Church, Virginia: Conwal Incorporated, February 1995.

<sup>5</sup> For example, during a field testing of the NCHAPP, parents did not report that their children looked different from other children, even though staff reported the child had a visible disfigurement. R. Stein, & L. Westbrook, *Final Report of the National Child Health Assessment Planning Project: A planning proposal for a national survey of children with special health needs*. Bronx, NY: Division of General Pediatrics and the Preventive Intervention Research Center for Child Health, Albert Einstein College of Medicine/Montefiore Medical Center, 1993. Also see P.W. Newacheck and W.R. Taylor, "Childhood Chronic Illness: Prevalence, Severity and Impact," *American Journal of Diseases of Children*. 1992, Volume 145, p. 1367-1373.

<sup>6</sup> Donald Bailey, Rune Simeonsson, Virginia Buysse, and Tina Smith, "Reliability of an Index of Child Characteristics," *Developmental Medicine and Child Neurology*. 1993, Volume 35, p. 813.

These shortcomings of existing studies make it difficult to answer basic questions about children with disabilities. They do not provide systematic information on the costs of raising a child with a disability, the ways in which families cover these costs, the medical or nonmedical services that children use, how families spend SSI funds, or the evolution of children's impairments over time. By piecing existing studies together, however, one can observe a few recurrent patterns:

- \* **Low-income families tend to spend most of a cash benefit on basic necessities.** Michelle Adler (1995; n = 7,200 families with children under 18 per year in 1991-1993 from the Consumer Expenditure Survey) found that expenditure patterns of families receiving SSI are similar to those of families receiving welfare (AFDC or general assistance), in that more than half of all expenditures are for food, clothing and shelter.<sup>7</sup> Studies analyzing family support programs in three states (Louisiana: n = 483, Iowa: n = 120, and Michigan: n = 315) support the contention that low-income families tend to spend a cash benefit on essentials.<sup>8</sup> A 1995 survey by The Arc of 954 families from 37 states showed that they typically spend their child's SSI benefit on a cluster of expenses related to meeting basic needs for food, clothing, and shelter.
- \* **Beyond these basic expenditures, there is no typical spending profile.** Sandra Herman (1994; n = 315) found substantial inter-family variability in spending patterns among Michigan families. Disability-related purchases included special foods, day care services, adaptive equipment, educational aids, toys and recreational activities, transportation to medical appointments, medical bills not covered by other insurance, and clothing and other personal items for the child.
- \* **The extent of children's disability-related needs is highly variable.** Maxfield and Kendall (1981; n = 1852) reported that only five percent of families had expenditures that exceeded their SSI benefit payment. Based on a review of national and community studies, Perrin, Shayne, and Bloom (1993) reported that chronically ill children make greater use of medical services than other children (2.7 times as many doctor visits and 14.5 times as many hospital days).<sup>9</sup> Birenbaum and Cohen (1993; n = 326 children) found that the average health care expenditures for children with

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<sup>7</sup> Michelle Adler, "Expenditure Patterns for Families Receiving SSI: 1988-1993." Unpublished draft, May 1995.

<sup>8</sup> K. Melda and J. Agosta, "Family Support Services in Louisiana." Human Services Research Institute, 1994. S. Herman, "Cash Subsidy Program: Family Satisfaction and Need," *Mental Retardation*, December 1994. J. Agosta, "Evaluating Family Support Services: Two Quantitative Case Studies," *Emerging Issues in Family Support*. Washington, D.C.: AAMR Monographs, 1992.

<sup>9</sup> J. Perrin, M. Shayne, and S. Bloom, *Home and Community Care for Chronically Ill Children*. Oxford: Oxford University Press, 1993.

severe mental retardation are ten times higher than health care expenditures for all children.

- \* **While a wide variety of services exist for children with disabilities, many families do not secure the help they need.** Knoll (1992; n = 92) found that less than half of surveyed families reported that their children received the disability and health-related services that they regarded as necessary.
- \* **Disability has a major impact on families' lives.** Agosta, Deatherage, Bradley, and Keating (1991; n = 140 families) found that a child's disability affects a wide range of family decisions, including where to live, whether to continue education, and whether to accept job transfers or promotions.

Systematic national research is needed both to confirm these patterns from small, often selected populations and to answer the many basic questions they do not address. This research should focus on the following:

- \* **What is the clinical status of children with disabilities?** Policy makers need a more robust and detailed classification of children's impairments. Of particular importance are:
  - What are the secondary impairments of children with multiple disabilities?
  - How extensively do children use basic medical services, such as primary and specialty medical/surgical care?
  - How extensively do children use other health care services, such as home care and nursing, therapies (occupational, physical therapy, speech, respiratory, and nutrition), genetic services, and EPSDT?
  - What medical supplies and medicines are purchased by families of children with disabilities?
- \* **What is the functional status of children with disabilities?** In what ways, and to what extent, do children's impairments affect their ability to function in age appropriate ways?
  - What is their functional status in educational settings, including special education, early childhood/preschool programs, regular

education, tutoring, vocational training, transition to higher education, and community colleges, colleges, and universities?

- How extensively do these children use personal assistance services, including personal attendants, home maker services, and peer companions?
- What enabling services, such as transportation, home modifications, and assistive technology, are used by children with disabilities?
- How do these children utilize community services (either specialized or general), including recreational programs, summer camps, and sports?

**\* What is the family status of children with disabilities (defined to include impact on siblings)?**

- What is the cost of raising a child with a disability? How do families cover these costs? What proportion of low-income families would be so if they did not have child with a disability?
- What proportion of parents withdraw from the workforce, take a less demanding job, or work fewer hours in order to care for a child with a disability? What proportion of parents of children receiving SSI are unable to work because of their child's special need for care?
- What disability-related expenditures do families incur? In particular, how do families spend the children's SSI benefits? What expenses do families incur beyond the amount of this benefit?
- What are the stresses of raising a child with a disability, and what is the psychological impact on the child and the family?

**\* What is the status of children with disabilities as they grow and mature?**

- How remediable are children's impairments?
- What are the key transitions in the lives of children with disabilities, such as hospital to home, home to school, adolescence, graduation from high school, and school to community?

- What are their long-term pathways, including educational status and dependence on public programs?
- \* **How do children with disabilities compare to the broader population of American children without disabilities and to the narrower population of children with disabilities who receive SSI?**
  - In particular, what is the potential universe of children in the general population who might become eligible for SSI using a variety of definitions?<sup>10</sup>

To obtain results that reflect the diversity of children of families, the research should determine how both vary according to several key classifications. For children, these classifications should include gender, age, clinical groupings (defined broadly by mental versus physical disability and narrowly by impairment type), as well as by whether the child's impairment has been diagnosed. For families, these classifications should include sociodemographic variables (economic status, household structure, employment status, cultural ethnic group), and health insurance status.

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<sup>10</sup> The Commission Task Force on Investments in Children examined existing studies which address this question and found a substantial range -- from 1.075 million to 1.775 million.

**Question 2: What interventions are helpful (and harmful) in improving outcomes for children with disabilities?<sup>11</sup>**

Existing research focuses heavily on the efficacy of medical interventions. This focus should be broadened to include the following five categories:

- **medical care and related services**
  - primary and specialty medical/surgical care
  - other health care services (specialized therapies, e.g., occupational therapy, respiratory therapy, nutrition), home care, genetic services, and psychological services/counseling
- **personal assistance services**
- **technical supports and accommodations, including**
  - equipment
  - environmental accommodations
- **psychosocial interventions**
  - child
  - family and family support (including respite services)
  - coordination of care
- **educational services**
  - integration into schools
  - educational planning
  - regular and special education
  - in-school health services and access to education - In particular, what mechanisms are available to maximize families' access to the school-based health services they need, such as National School-Based Services funded by Medicaid?

An important, related question is whether efforts to coordinate these interventions (e.g., title V and special education programs) affect the quality of service provided to children and families, the level of families' satisfaction, or the outcomes that children achieve. If so, what approaches to service coordination are most effective?

Further, public funds are increasingly used to support private programs to serve children with disabilities, such as Medicaid contracts with private health organizations. Do efforts to coordinate these public and private resources aid children with disabilities and their families and, if so, how?

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<sup>11</sup> Outcomes should be measured in terms of the status measures defined in question #1.

Finally, the Americans with Disabilities Act offers additional opportunities for individuals with disabilities. Its influence on children and adolescents and their transition to adulthood merits attention.

**Question 3: Does the form in which support is provided (cash, direct services, or vouchers) affect outcomes for children with disabilities and their families and, if so, how?**

At one level, in-kind services and cash benefits serve the same purpose -- providing general support for children with disabilities and their families. However, it is possible that the medium by which support is provided may influence outcomes for children with disabilities. The nature and extent of this difference are important issues for investigation.

Such investigations should examine three alternative (though not necessarily exclusive) means of providing assistance -- cash, direct services, and vouchers. Research should examine differences resulting from different means of providing assistance on the health and functioning of children and families. The main questions include:

- \* Do these various forms of assistance provide different incentives for children and families with respect to long-term dependence or independence on public support?
- \* Do different forms of assistance offer more or less flexibility with respect to meeting the complex and varied needs of children and their families?

In addition, research should compare these forms of assistance with respect to:

- the mix of goods and services offered and actually used by participants,
- satisfaction levels of program participants,
- the overall cost of service delivery, including the cost of administration,
- the extent of program overlap and interaction with other programs for children with disabilities, and
- the extent and mix of the population that is actually served.

This research should also address questions specific to each medium of support, such as:

- \* **Vouchers** - How can a voucher program promote competition among providers? How can vouchers support sufficient flexibility to meet the varied needs of families whose children have very different disabilities?

\* **Direct services** - How can support for direct services ensure adequately broad and accessible service options, coverage, coordination, and standards of care? Does the variety of providers and auspices of care affect the status of children with disabilities and their families?

\* **Cash benefits** - How do families use their cash benefits? How does the need to maintain cash benefits affect families in positive and negative ways?

Finally, the research should determine how variations in SSA program administration affect the passage of children in and out of the SSI program (e.g., different ways and times of determining income eligibility, problems of under and over payment, and opportunities to diminish administrative costs). Currently many families go through complex maneuvers to meet monthly eligibility tests that would otherwise cause them to go on and off the program. Research is needed to identify alternatives that are more family-centered and that limit administrative costs.

**Question 4: What outcomes should public support for children with disabilities and their families aim to achieve?**

The answer to this question is critical to the formulation of effective public policy for children with disabilities and their families. However, it is difficult to answer this question because it involves equity, a concept whose definition varies widely from individual to individual.<sup>12</sup> The range of possible answers includes:

- Should support be aimed at making a family equally well off following the disability of a child as prior to this occurrence? If so, how should support levels be set? One approach would be to conduct an individualized, family-by-family calculation. Another would be to ask what a well-informed family with adequate income would purchase for their child with a disability. This raises the issues of what it means to be "well-informed" and what income should be treated as "adequate."
- Should public support be aimed at "leveling the playing field" between children with disabilities and those without disabilities, so that disability ceases to be a factor (so far as is technically feasible) in a child's achievement?<sup>13</sup>
- Should support be aimed at compensating for children's functional limitations in cases where it is cost-effective to do so from the taxpayers' perspective? If so, what factors should enter into the calculation of cost effectiveness? How should levels of compensation be set?
- Should support aim simply to provide basic medical care and a floor of income, without targeting particular outcomes beyond a subsistence level? Alternatively, should support be aimed at enabling a child with a disability to function in his or her family, school, and community, but not necessarily at the same level as a child without a disability (ex: *Westchester County v. Rowley* Supreme Court Decision)?

The Commission recognizes that these questions are fundamentally about values. However, their importance as a basis for public policy cannot be overstated.

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<sup>12</sup> Research, such as production function studies, could help determine which outcomes are most achievable.

<sup>13</sup> What is meant by "leveling the playing field" may vary from observer to observer. Generally, the Commission has taken a family perspective, defining equality in terms of family preferences.

### **Process Recommendations**

In addition to developing a blueprint for future research, the Commission developed proposals for improving the quality of information collected through existing surveys and data bases. Implementation of these proposals will not fulfill the Commission's full research agenda. It will, however, fill some important information gaps. The recommendations are:

1. **Repeat on a regular basis the Disability Supplement of the National Health Interview Survey.** Implementation of the Disability Supplement of the NHIS began in January 1994 and will continue through 1995. The most comprehensive national survey of disability ever undertaken, it will provide extensive information about the severity of children's impairments, their use of medical services, family expenditures, receipt of SSI, unmet needs, and much more. The major missing element in the Disability Survey is information about changes in the population of children with disabilities over time. This survey should be repeated periodically to obtain this longitudinal data.
2. **Strengthen the Social Security Administration's research capacity.** As part of SSA's downsizing in the mid-1980s, the agency reduced its institutional capacity for research and policy analysis. As a result, it has limited information on children receiving SSI. Enhanced analytical capacity is particularly important now that SSA has been given independent status. Moreover, the great growth in the child and adolescent SSI program and the public interest in this program create a need for SSA to develop specific research capacities regarding children and adolescents, with trained staff dedicated to this purpose. SSA should also involve private researchers in this effort by funding and coordinating public-private research partnerships.
3. **Add questions about childhood disability to major national surveys.**
  - a. Revise the Consumer Expenditure Survey (CEX) to distinguish children who receive SSI childhood disability benefits from adult SSI beneficiaries. Sponsored by the Bureau of Labor Statistics, the CEX collects detailed annual consumer expenditure data from a variety of households. The CEX includes a question which identifies families with an SSI recipient, but it does not ask whether this individual is an adult or a child. The addition of this question to the CEX would provide this distinction, thus making available detailed information on the spending patterns of families of children receiving SSI.

- b. The Survey of Income and Program Participation (SIPP) includes information obtained from parents on children between the ages of three and 14. The SIPP has included data on children's disabilities since its inception, but none on children's SSI participation. This question should be added to the SIPP.
  - c. The National Medical Expenditure Survey (NMES) includes questions on the utilization and expenditures of families with disabilities. The sample sizes of children with disabilities are small, however. Increasing the size of these samples would increase the reliability of findings.
  - d. Questions on children with disabilities should be added to the decennial census by the Bureau of the Census.
  - e. The Current Population Survey (CPS) includes questions on disability resulting in inability to work for individuals over age 18. Questions should be added about children with disabilities, including family circumstances and receipt of SSI.
4. **Study the impact of restricting SSI eligibility for children.** If Congress enacts eligibility restrictions for the SSI program, it will be important to assess their effects. SSA should track the effects of these changes over time on children who lose SSI benefits, those who continue to receive SSI, and new SSI beneficiaries. In drawing this comparison, SSA should target such variables as health status, utilization of other federal and state benefit programs, family income, living conditions, and educational achievement.
5. **Capture additional data in Medicaid statistics.** Most states maintain substantial data regarding utilization of services by Medicaid recipients. Although some states identify the reason for Medicaid eligibility (e.g., receipt of SSI or AFDC), others do not. The Commission recommends the consistent use of an identifier indicating SSI status by all states. This would allow analyses of health care services utilization by children and adolescents receiving SSI, compared to other low-income children. Even though children and adolescents account for about 40 percent of all Medicaid recipients, relatively little research has addressed Medicaid utilization and utilization of other health care services by this population. The Commission recommends focused and ongoing attention to Medicaid research regarding children and adolescents, especially those with disabilities.

6. **Collect outcomes data on children in special education.** Over the past four years, the Outcomes Center at the University of Minnesota has been attempting to develop outcomes measures for children in special education. It has also been attempting to develop a national consensus on what such measures should be. In addition, SRI International has recently completed a major outcomes study for children in special education. Beyond these efforts, data on outcomes are sparse. Both the Department of Education and state education departments should accelerate their efforts to collect comprehensive outcomes data on children with disabilities.

*Letters by Commission Members*

*Wade F. Horn, Ph.D.  
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09/25/95

The Honorable Jim Slattery, Chairman  
National Commission on Childhood Disability  
801 Pennsylvania Avenue, N.W.  
Room 625  
Washington, D.C. 20004

Dear Chairman Slattery:

It is with great pleasure that I endorse the final report of the National Commission on Childhood Disability. My vote in support of the final report reflects my agreement with many, but certainly not all, of the recommendations contained in the report. It is impressive that a group of advocates, researchers and practitioners with diverse beliefs and viewpoints were able to forge a series of recommendations which, if implemented, would serve to strengthen an important program of support for children with disabilities residing in low-income families.

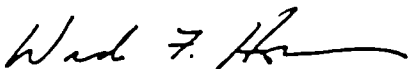
I do, nonetheless, wish to clarify several items. First, while it is true that no Commissioner either proposed or voted to replace the Children's SSI program with a voucher system, it would be inaccurate to conclude that there was no support within the Commission for examining the eventual replacement of the cash-based system with one utilizing vouchers. I, for one, did not proffer any proposals for a system of vouchers because I do not believe we have, as yet, adequate knowledge about how such a voucher system should be structured. As acknowledged in Chapter Five ("Alternative Forms of Support for Children with Disabilities"), there are some compelling reasons favoring the replacement of cash with vouchers. Nevertheless, we currently lack an adequate knowledge base upon which one could rely to structure such a system. As recommended in Chapter Seven ("Research for Future Policy Directions"), there is a need for further research to determine whether, and under what conditions, a voucher system might be a viable alternative to the Children's SSI program. Indeed, the Commission explicitly recognizes the possibility that for at least some children a voucher program is acceptable in its consensus recommendation that only Medicaid be provided to children who meet current SSI eligibility criteria but who would not meet the stricter standards proposed by the Commission.

Second, it is true the Commission did not find evidence that significant numbers of children were coached successfully to feign a disability in order to obtain SSI benefits. However, we were presented with no information as to the prevalence of children being coached unsuccessfully. This is an important issue because even unsuccessful coaching has costs associated with it. There are, for example, the financial costs to the administrators of the program who must expend funds to examine the applicant's claim. There are also psychological costs to the child when he or she is taught that it is permissible to try to deceive the government in order to obtain benefits. Unfortunately, there are simply no data available that address the issue of how much of a problem coaching is in this broader perspective.

Third, I voted against, and maintain strong objections to, the recommendation that parents of children with disabilities should be excluded from any time limit that is placed on welfare eligibility. This recommendation fails to recognize that not all children with disabilities require that their parent forgo paid work in order to care for the child. Allowing this blanket exemption would provide a further incentive for low-income parents to try to establish eligibility under the SSI program. In addition, such an exemption sends the message that if a family member has a disability, one should not be expected to follow the same rules as everyone else. While I strongly endorse the principle that a just and fair society supports and includes persons with disabilities, I do not believe that it is fair and just to issue wholesale exemptions based only upon the fact of a disability. I would be able to support such a recommendation if it had added the proviso that it pertained only to those parents whose presence was needed in the home to care for their child.

Despite these reservations, I do endorse the report as a whole. I am particularly appreciative of the leadership exerted by you as well as the exceptional work performed by Elaine Fultz, executive director, and her staff. It has been an honor to have been associated with the work of this Commission.

Sincerely,

A handwritten signature in dark ink, appearing to read "Wade F. Horn", with a stylized flourish at the end.

Wade F. Horn, Ph.D.

## STATEMENT OF DISSENT

PAUL MARCHAND

MEMBER, NATIONAL COMMISSION ON CHILDHOOD DISABILITY

I voted in opposition to the Report to Congress regarding Supplemental Security Income for Children with Disabilities as developed by the National Commission on Childhood Disability. Although there is much to support in the Report, the Commission's recommendation number three to "Strengthen the SSI Definition of Childhood Disability", if enacted by the Congress, would do irreparable harm to the SSI program and to tens of thousands of children with severe disabilities from low income families. Indeed, depending on which of the two options on the definition would be chosen, between 110,000 and 260,000 current and future (over the next five years) children who are SSI beneficiaries would be dropped or blocked from the program. Given what the Commission learned about the strengths and the flaws of the SSI children's program and the myriad other Commission recommendations aimed at rectifying those flaws, far too much harm will come to innocent children and families who have done nothing to deserve elimination from the vital benefits available from SSI.

In regards to eligibility, the Commission concluded that there was a miniscule amount of parental "coaching" and that some types of disabilities lent themselves to possible double counting in determining limitations of function under the Individual Functional Assessment process. I heartily agree that both of these problems must be addressed and the Commission's recommendations adequately do so in other parts of the report. In my opinion, implementation of recommendation number three will disqualify far more children than is necessary to rectify the valid concerns about the program. Simply put, the Commission creates too many sacrificial lambs.

I support the remaining recommendations. However, on balance, the deleterious effects of recommendation number three thwart, for too many children, the potential good realized by all of the other recommendations. I regret having to take this action. Throughout the Commission's deliberations, I reminded myself and sometimes my fellow Commissioners of Secretary Shalala's warning and challenge to us as we began our work which was, to paraphrase her, "Do as little harm as possible to those children who are truly eligible". By my vote, I sincerely hope I have met that test.

# SAFE

## SCHOOLS ARE FOR EVERYONE

A national coalition for integration of all students with disabilities through supported education

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October 5, 1995

The Honorable James Slattery, Chairman  
National Commission on Childhood Disability  
801 Pennsylvania Avenue, N.W.  
Room 625  
Washington, D.C. 20004

Dear Mr. Slattery:

I came to this commission as an individual with three perspectives that as a parent of a child challenged with Down Syndrome, a former recipient of SSI and a professional social worker. As such I have struggled to understand the allegations of "coaching" by parents, of "gaming" the system as an SSI recipient, and the matter of not providing for children and families the preventive social services they so much need.

Much information was made available to us in order to address these concerns and others. Having studied the material provided, deliberated with my peers on the commission, and acknowledging the testimony of many individuals, including families, I cannot support the report as a whole. I make exception to what we were previously addressing as the pro family recommendations, these being items 1 through 2f of chapter 4 of the report to Congress of the National Commission on Childhood Disability. I also support chapter 7, Research For Future Policy Directions, for as explained in this chapter children with disabilities and their families have largely been neglected from research that could improve their lives.

Sharing life with families such as those that testified and having had the opportunity to address national policy which affects all of our lives confirms for me that much is still to be done to support ALL families. I hope and pray that Congress considers such advisement for if they do we will gain as a nation and not fail those who need support.

It was an honor to have had the opportunity to work with all commission members and a very competent staff led by Elaine Fultz, Ph.D.

Sincerely,



M. Carmen S. Ramirez

cc: Donna Shalala, Ph.D., Secretary, Department of Health and Human Services  
Shirley Sears Chater, Ph.D., Commissioner, Social Security Administration



October 10, 1995

Secretary of Health and Human Services Donna Shalala  
Hon. James Slattery, Chairman  
Members, National Commission on Childhood Disability  
Washington, D.C.

Re: Reservations, Understandings, and Dissent from Final Report  
of National Commission on Childhood Disability

Dear Secretary Shalala and Fellow Commissioners:

I regret that the protocol of the Commission obliges me to vote either for or against the final Report and does not permit me to indicate my support, with reservations and understandings, of most of the Report and to indicate my dissent from a portion of the Report.

Given that forced choice, I must and do dissent and vote to NOT endorse the Report.

I set out below, however, my general support, reservations and understandings, and dissent from a portion.

I. General Support

On the whole, the Report merits the support of members of Congress and the Administration.

The Report discharges the Congressional mandate. More than that, it proposes carefully considered, sufficiently justified, and narrowly tailored changes in the administration of the SSI for children program.

I believe that the changes that the Commission recommends will -- on the whole -- benefit the children and families assisted through the SSI for children program.

II. Reservations, Understandings, and Dissent

A. Reservations.

I have a reservation about the aspect of the Report (chapter three, section entitled "The Commission") that describes the "several themes" that marked the Commission's discussions and analysis.

## *Member Letters*

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The Report says that the Commission was concerned to structure the SSI program to "motivate, not deter, parents in encouraging their children to overcome their disabilities." I believe we were motivated by a desire to recommend improvements that would not create a disincentive to parents to receive appropriate interventions for their children; I do not believe that, on the whole, parents need to be motivated to seek treatment, and I do not believe that all disabilities can always be "overcome."

I also believe that the Commission was intensely focused on the issue of the eligible beneficiaries. Recommendation #3 in the Report reflects this intensity.

Finally, I believe the Commission's concerns to bring greater accountability to the SSI program masks the extensive hearings and deliberations we had about alleged gaming of the SSI application and award system. We should be explicit: we looked hard at a wealth of evidence and heard a great deal of testimony about gaming and concluded that the evidence does not match the media or somewhat limited public/Congressional concerns.

### B. Understandings.

I believe that the Commission explicitly and unreservedly approved an SSI program that awards cash to families. It did not approve any so-called voucher or other alternative medium of SSI benefits, with the exception that Medicaid benefits constitute an alternative medium. To quote from one of our Commissioners, "Cash is king" so far as the Commission is concerned.

Turning now to the Commission's recommendations for research, I had hoped that these recommendations would relate to only the SSI program and not be a comprehensive proposal for federal research related to children (or adults) with disabilities and their families. Since they appear to be more than that, I have to demur.

Also with respect to the Commission's recommendations for research, I believe that SSA-sponsored research should focus on the provider system as an indispensable variable affecting families' and children's well-being and behaviors when they receive SSI benefits. A family and child are not isolates; their well-being depends as much on their own behavior as on that of programs (governmental and nongovernmental) and policies.

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### III. Dissent

I cannot support one of the Commission's recommendations and I dissent from the entire Report because of this one recommendation.

It is the one that is, in my judgment, the most significant in its impact on the children and families, and it is the one that will have the most deleterious effects on them.

I refer to Recommendation #3, "Recommendations to Strengthen the SSI Definition of Childhood Disability."

This recommendation is cast as one to "strengthen the SSI definition of childhood disability." It consists of a statement on "Areas of Agreement" among the Commissioners; a proposal to change the statutory definition of eligible children (Option One); and a proposal to change the regulatory process for admitting children to the rolls (Option Two).

I think that it is a mischaracterization to refer to Recommendation #3 as one that "strengthens" the SSI eligibility criteria. As operationalized, each Option would significantly reduce the number of eligible beneficiaries. I hardly regard that action as strengthening.

One Option, which I opposed, would reduce the number of eligible beneficiaries by approximately 260,000 children or 20% of the current caseload over five years. That is far too great a reduction, given the Social Security Administration's recent record in monitoring admission to the rolls, the overwhelming evidence that there is no provable gaming of the eligibility-admission procedures, and the narrowly tailored and carefully crafted improvements that the Commission recommends in the administration of the program.

Another Option, which I supported because it was the only one the Commission considered as an alternative to the 260,000-child cut, would reduce the number of eligible beneficiaries by approximately 110,000 children or 8% of the current caseload over five years. Again, that itself is far too great a reduction in light of the factors I described in the paragraph above.

I cannot accept the conclusion of Recommendation #3 that a child with three "moderate" impairments (currently, that child is admissible to the rolls) is not a child with a severe disability or combinations of disabilities; and I cannot accept the conclusion that follows from that determination, namely, that the

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child and the child's family are unworthy of federal cash support to satisfy the four purposes of the SSI program as the Commission properly describes them in another recommendation.

Such a child is indeed one who -- by every noninvidious policy decision that the federal government and the state governments have made in the last 30 years -- has a severe disability, faces extraordinary difficulties in securing (much less taking advantage of) opportunities for independence, participation in and contribution to America, and integration and inclusion in the full panoply of American life.

And such a child is one who -- in my professional experience and personal history as the parent of a young man with mental retardation and autism -- is especially meritorious of our support.

Add to that child's disability-related challenges the fact that the child's family meets the federal definitions of poverty, and one has a child and family who should not be eliminated from the SSI program.

I cannot support Recommendation #3 with respect to its two reformulations of the eligible class of beneficiaries. It is intolerable for me, given all I have done and have yet to do with and for people with disabilities and their families, to accept any -- repeat: any -- proposal that reduces the number of eligible beneficiaries.

I do support the three "Areas of Agreement" described under Options for Change in Recommendation #3 (eliminating double counting, providing Medicaid, and following a presumption of admission to the rolls).

Indeed, it is because the Commission has a wide area of agreement on these and other specific improvements that I support the rest of the Report. To reiterate: given the forced choice of full support or dissent from the Report as a whole, I dissent.

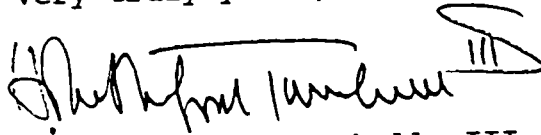
### IV. Appreciations

Because I respect the capacities, energy, and steadfastness that my fellow Commissioners brought to our difficult and highly controversial work, and because I value those prior-existing friendships that endured our work and the new ones that developed as a result of it, I say that it has been an honor to have served

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with the Commission and to have been directed in our work by Jim Slattery and assisted by such capable staff. To my fellow Commissioners and the staff, I tender my grateful and sincere appreciation.

Very truly yours,

A handwritten signature in dark ink, appearing to read "H. Rutherford Turnbull, III". The signature is stylized with a large, sweeping "H" and a long, horizontal stroke extending to the right, ending in a small "III".

H. Rutherford Turnbull, III