Public Law 104-193 requires that members of the Social Security Advisory Board (SSAB) be given an opportunity, either individually or jointly, to include their views in the Social Security Administration’s annual report to the President and Congress on the Supplemental Security Income (SSI) program. We have asked the Social Security Administration (SSA) to include in this year’s annual report the SSAB concerns regarding the SSI children’s program and request SSA conduct a comprehensive review of the program as described in this statement before implementing any changes.

Over the last year the Board has reviewed and reported on the disability programs administered by SSA with particular emphasis on the adult programs and return to work efforts. The disability programs are by far the most complex and challenging workload for the agency and as such, two-thirds of its administrative budget is spent on issues related to these programs. While the retirement and survivor programs serve a greater number of people, their decision making process is relatively straightforward and constant. In contrast, the disability decision making process involves collecting a myriad of documentation including information from the claimant, medical records, functional evaluations and expert opinions, to assess whether the person meets the statutory definition of disability and then evaluate the likelihood that the claimant will continue to meet that definition.

There are two distinct disability programs administered by SSA. The Social Security Disability Insurance (SSDI) program, funded through payroll taxes paid by both employers and employees, and Supplemental Security Income (SSI), a means tested assistance program, funded through general revenues, for low income aged, blind and disabled individuals. Both the Social Security trustees and the Congressional Budget Office project that beginning in 2016 the Disability Insurance Trust Fund will only have enough to pay approximately eighty percent of disability insurance benefits. Congress will soon have to consider whether it should simply reallocate trust fund money as it has done in the past or tie any reallocation to programmatic changes in an effort to strengthen the program which has been criticized for its subjective decision making and long delays. Although the insolvency issues facing the SSDI program are not at issue for beneficiaries receiving SSI, as their benefits have no connection to the trust fund, policy changes to the SSDI program could affect beneficiaries in the SSI program.

Within the SSI program, there is a program for low income children with disabilities; this is the focus of this statement. We believe the issues and concerns pertaining to the children’s program are unique and should be researched, evaluated and addressed separately from the SSDI program. Following is an historical overview of the SSI program including the important policy
changes that have occurred in evaluating disability for low income children as well as some discussion about how to approach any proposed changes.

The History of the SSI Program

On October 30, 1972, Public Law 92-603, the Social Security Amendments of 1972, was signed into law. At the time it was probably the longest single piece of legislation that Congress had adopted. Medicare was expanded to cover individuals with disabilities who had been receiving benefits for two years, the waiting period for disability benefits was reduced, and the new Federal SSI program for the low income aged, blind and disabled adults and children was established.

The legislative journey of Public Law 92-603 began years earlier. In the original 1935 Social Security Act, programs were introduced for needy aged and blind individuals; in 1950, a program for low income individuals with disabilities was added. These three programs were collectively called the "adult categories" and were administered by State and local governments with partial Federal funding. Over the years, the State programs became increasingly complex and inconsistent. There were several different definitions of disability, as many as 1,350 administrative agencies were involved, and benefit levels varied by more than 300 percent from State to State. These discrepancies provoked calls for program reforms.

In August 1969, President Nixon outlined a Family Assistance Plan, which included a negative Federal income tax program which would provide an income floor to the families of the unemployed and working poor on the condition that they find work or enroll in job training. This represented a big departure from then existing welfare policies. Under the Nixon proposals, eligibility requirements would no longer be based solely on income and asset levels and the program would be run through the Federal tax system rather than administered by State and local governments.

The House of Representatives began a series of public hearings on the plan and on June 22, 1971, passed H.R. 1, a modified version of the President’s recommendations. The bill moved to the Senate for consideration but languished for more than a year. Finally in late September 1972, an amendment outlining the SSI program passed and H.R. 1 followed. In conference, all family welfare provisions were dropped and all existing public assistance programs were repealed and replaced with the newly established Federal SSI program. SSI authorized cash benefits for aged, blind, and disabled individuals and introduced a new assistance program for children under 18 years old who had a disability of comparable severity to adult recipients.
The Social Security Administration was chosen to administer the new program and convert over 3 million people from State welfare programs to the new Federal SSI program. SSA had an established reputation for successful administration of existing social insurance programs and with its network of field offices and experience in processing claims and maintaining records, it seemed the most reliable choice.

**Implementation and Growth of the SSI Program for Children**

The agency had a little over 14 months to prepare for the roll out of this brand new nationwide program. The SSI disability program for adults incorporated many of the features of the SSDI program but there was no parallel children’s program and little in the legislative record to provide guidance on the purpose and goals of a program for children. In fact, there was fundamental disagreement about the basis for a children’s program.

The 1972 House Committee on Ways and Means report which accompanied the legislation that established SSI stated:

… 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.

However, the Senate Committee on Finance did not agree with the House and noted in its report:

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.1

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1The National Commission on Childhood Disability, Report to Congress, October 1995
http://www.ssa.gov/history/reports/SSIChildhoodDisabilityReport.html
A House/Senate conference ultimately reconciled the two versions of the bill. But among the hundreds of issues, the children’s program received little attention and the 67-page conference report failed to explain how the issue was resolved or define disability for a child.²

For an adult, the definition of disability was the same under the SSI program as it was for SSDI: "[The] inability to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months."³ For a child, an individual under age 18, eligibility was based on having a disability of comparable severity to that of an adult, defined as older than 18. While the evaluation for adults involved a 5 step sequential evaluation⁴ which included an analysis of their functional ability, the evaluation stopped at step three for children, meaning if they did not have an impairment severe enough to meet a listing, they were not found to be disabled.

Subsequently, Congress directed the Secretary of Health and Human Services to create eligibility standards that would establish disabling impairments in children that were of “comparable severity” to a disabling impairment in an adult. The agency began working on a listing of medical impairments that were unique to children but by 1976 the listings had not been published. The agency was criticized by Congress for delays in publishing the impairments which were necessary regulatory guidance for the State agencies. During floor debate in the Senate in 1976,⁵ one Senator noted:

> Of particular concern is the current status of children in this [SSI] program. It has been 4 years since the Congress enacted the SSI program, and there are still no adequate guidelines which would enable State agencies to determine how to apply the program to children. Individual States, receiving no direction from the Federal Government, have been adopting their own widely varying guidelines.⁶

Section 501(b) of Pub. L. 94–566 was added to the Unemployment Compensation Amendments which required SSA to publish criteria for childhood disability determinations within 120 days. The agency complied and a separate listing of impairments, designated as Part B of Appendix 1 following 20 C.F.R. § 416.985, was devised for use in determining a child’s disability.

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³ The Social Security Act §223 (d)(1); 42 U.S.C. 423(d)(1)(A) http://www.ssa.gov/OP_Home/ssact/title02/0223.htm

⁴ The Social Security Act §223 (d)(1); 42 U.S.C. 423(d)(1)(B) (2)(A) http://www.ssa.gov/OP_Home/ssact/title02/0223.htm (1) Is the individual engaging in substantial gainful activity? (2) Is the impairment severe and does it meet the duration requirement? (3) Does the impairment meet, or equal in severity, one of the medical listings? (4) Can the individual perform his or her past work? (5) Can the individual (considering his or her age, education, and prior work) perform any other work?


⁶ 122 Cong. Rec. 33301 (1976)
The Effects of Court Decisions

In the years that followed implementation of the SSI program, the evaluation of disability cases became the subject of litigation in the courts. In the *City of New York v. Heckler*, the Second Court of Appeals upheld the district court finding that SSA used an improper standard in evaluating the impairments of young workers with mental illness. After a series of hearings Congress responded by requiring SSA to rewrite the listings of mental disorders within 120 days. The House Report noted that serious questions had been raised about the old listings, observing that even "the Secretary has determined that a full scale re-evaluation of the Listings and current procedures is necessary..." The agency complied and issued new listings for analyzing mental disorders in adults. However, the children’s listing for mental disorders remained the same for almost six years, despite the similarity in the analysis between the adult’s and children’s listings for mental disorders.

Finally, in December 1990, in accordance with the Disability Benefits Reform Act of 1984, the agency issued new regulations revising the medical listings to include new medical standards for assessing mental impairments in children. The regulations incorporated functional criteria into the children’s listings and were intended to reflect medical advancements in the treatment of mental illness. Behavioral impairments such as Attention Deficit Hyperactivity Disorder, and learning disorders, were now included in the listings.

That same month, the Supreme Court issued its seminal decision in *Sullivan v. Zebley*. The case challenged the comparable severity analysis used in children’s claims. The court held that a disability analysis based solely on the medical listings was inconsistent with the statutory standard of comparable severity because there was no individualized functional analysis as contemplated by the statute and applied to the analysis in adult disability cases. The decision prompted new regulations, increased outreach efforts, and the review of thousands of prior decisions in children cases.

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7 742 F. 2d 729 (1984)
11 493 U.S. 521 (1990)
Post Zebley

To comply with *Zebley*, SSA was required to reopen denials in children’s SSI disability cases back to 1980. SSA estimated that the workload would include re-adjudicating about 550,000 claims, along with an ongoing workload of approximately 35,000 additional cases per year.\(^{12}\)

Understanding that issuing new regulations would take time interim standards were established. SSA used the *Zebley* decision as an opportunity to consider other changes and invited childhood and pediatric experts to help develop the best criteria for evaluating disability in children. One of the recommendations was an Individualized Functional Assessment which focused on behavioral problems as a type of disorder.\(^ {13}\)

SSA published the revised final rules for determining disability in children in 1993; the new standards included:

- a new step to determine if a child's impairment had more than a minimal effect on his or her ability to function (equivalent to the severity step found in the adult rules),
- a new approach to satisfying the Listing of Impairments for children, called "functional equivalence," and
- an Individualized Functional Assessment for evaluating a child's impairment beyond the medical listings to parallel the vocational steps applied in adult cases and to satisfy the "comparable severity" criterion.\(^ {14}\)

In the early 1990s, there was a spike in disability allowances for children. The review of claims denied prior to the *Zebley* decision certainly contributed to the increase, but other factors included the new listings on mental impairments, the rising number of children in poverty and SSA’s outreach efforts.\(^ {15}\) There was particular concern directed at the children that were awarded benefits because of ADHD and other impairments seen as “behavior problems.” The General Accounting Office (GAO) was asked to conduct a study concerning the growth in awards to children. They reviewed the disability decisions in the two years preceding the *Zebley*

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15 Social Security Bulletin, Vol. 70 No. 3, 2010, by Carolyn Puckett, *Administering Social Security: Challenges yesterday and Today – 1990s, Complying with Sullivan v. Zebley* - SSA worked with 150 national organizations to reach approximately 450,000 children whose claims might be affected by the court decision. The agency also placed more than 125,000 posters in English and Spanish in offices of State and local government agencies and nonprofit organizations that provided services to disabled children. [http://www.ssa.gov/policy/docs/ssb/v70n3/v70n3p27.html](http://www.ssa.gov/policy/docs/ssb/v70n3/v70n3p27.html).
decision and the two years after the Zebley decision. GAO issued its report in September 1994, finding:

While much of the attention has focused on the Sullivan v. Zebley Supreme Court decision as the cause of this growth, our analysis shows a more complicated picture. Although the new functional assessment process established by Zebley added 87,900 children to the disability rolls through 1992 who previously would have been denied benefits, this new process only accounts for about 30 percent of all awards made since it was implemented. In contrast, 70 percent of all awards went to children whose impairments were severe enough to qualify on the basis of SSA's medical standards alone, without the need for a functional assessment. Thus, most of the children who received new awards would have qualified for them even without the functional assessment process mandated by the Zebley decision.16

GAO did find that the revised and expanded medical standards for childhood mental impairments accounted for much of the growth in the program. Awards based on the mental impairments (primarily mental retardation) almost tripled while awards for children with physical impairments was nearly double during the same time period.17

During this period, there were numerous news reports, both in local and national press about children being coached by parents to misbehave in order to qualify for SSI.18 ABC’s Primetime Live aired an examination of the SSI program which featured a former SSA doctor who claimed that less than thirty percent of children on SSI really deserved benefits although no supporting evidence was provided for her claim.19


In a March 1995 report GAO addressed the allegation of parental coaching in a Report to Congress and found:

Because coaching is difficult to detect, the extent of coaching cannot be measured with much confidence. In recent studies, SSA and the HHS IG reviewed case files and identified scant evidence of coaching or malingering. In the rare instances where they found evidence of possible coaching or malingering, most of the claimants had been denied benefits anyway.20

In March 1996, GAO again considered the allegations of coaching by parents, and examined cases from two initiatives conducted by SSA to identify cases of possible parental coaching. GAO found21:

Both of these initiatives identified few cases of suspected coaching and very few of the children involved received SSI benefits….The DDS initiative identified 1,232 cases in which coaching was suspected or alleged. Only 77 of these cases resulted in awards. Most cases were included because the child's performance during psychological tests or on a comprehensive examination raised questions about the child's impairment. The quality reviewers returned very few cases to the DDSs for additional evidence or for reversal of a DDS' decision to award or deny benefits.

In response to these reports, Congress once again considered how children’s disability cases were being analyzed and in The Personal Responsibility and Work Opportunity Reconciliation Act of 1996 (PRWORA),22 Congress redefined the disability analysis in children’s cases. The comparable severity standard was replaced by the standard that a child is considered disabled if he or she has a medically-determinable impairment which results in "marked and severe" functional limitations and which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months. SSA was directed to eliminate references to maladaptive behavior in the domain of personal/behavioral function in the listing of impairments for children and to discontinue the use of Individualized Functional Assessments in evaluating a child's disability. SSA developed the final rules in 2000 with assistance from outside experts and advocates; the rules “delink” functional equivalence from


specific listings and establish a new standard of listing-level severity based on “marked” or “extreme” limitation.

Further, the rules established a “whole child” approach to disability evaluation that considers how the child functions compared to other children of the same age without impairments, 24 hours a day, 7 days a week, “at home, at school, and in the community.” They consider all indicia of a child’s functioning and any limitations, including the level of assistance the child needs within age-appropriate expectations. In addition to evidence from medical examinations, examples of such evidence include special education placement and accommodations, medications, adaptive devices, therapies, one-to-one assistance, supportive/structured settings, and information from parents, teachers, and others who know the child.

To date this new definition has withstood court challenges. However, a similar round of media reports of abuse and families “gaming the system” has cropped up.23 There has also been concern about the growth of the children’s disability program,24 and the increased number of children receiving SSI benefits due to mental impairments, which comprise a growing majority of all child beneficiaries.25

**The Current Make Up of the Program**

Given the attention to the program in media reports, congressional hearings, GAO studies and internal agency reviews, a review of the data regarding the SSI program for children may help clarify some of the issues. As the following chart shows, the percentage of children receiving SSI disability benefits is small in comparison to the total number of all beneficiaries paid by the programs administered by SSA.

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Several studies have documented the correlation between poverty and disability. Children in low-income families that live in poor areas face heightened environmental risks. Those environments, including choices and constraints induced by poverty, may result in low birth weight due to poor nutrition during pregnancy and less access to health care which could result in the development of serious disabilities and consequently increased applications for SSI disability benefits.

According to the National Center for Children in Poverty (NCCP) in 2011 the federal poverty level (FPL) for a family of four was $22,350, for a family of three it was $18,530, for a family of two it was $14,710. In 2011 there were more than 72 million children under 18 years old in the United States. 22 percent or 16.1 million of them lived below the federal poverty level (FPL) and were categorized as poor. NCCP also noted the research suggesting that families actually need an income level of twice the federal poverty level to meet the family’s basic needs and be considered a living wage.

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Therefore, families that earn up to 199% of the FPL are still not making a living wage and are categorized as low income. A living wage starts at an income equal to twice the FPL.

<table>
<thead>
<tr>
<th>Family Size</th>
<th>Federal Poverty Limit (FPL)</th>
<th>Living Wage (200 percent of FPL)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family of Four</td>
<td>$22,350</td>
<td>$44,700</td>
</tr>
<tr>
<td>Family of Three</td>
<td>$18,530</td>
<td>$37,060</td>
</tr>
<tr>
<td>Family of Two</td>
<td>$14,710</td>
<td>$29,420</td>
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</tbody>
</table>


The total percent of children that fell into the Low Income category in 2011 is about 45 percent of all the children living in the U.S.

Furthermore, the number of children that live in either poor or low-income families has been increasing over time. From 2006 to 2011, the total number of children in the U.S. increased by less than 1 percent, but there was a 13 percent increase in the number of children in families falling into the low income category and a 23 percent increase in the number of children in families with income below the FPL.

<table>
<thead>
<tr>
<th>Family Income Further Broken Down by Federal Poverty Level (FPL), 2011</th>
</tr>
</thead>
<tbody>
<tr>
<td>Above low-income 55%</td>
</tr>
<tr>
<td>less than 100% FPL 22%</td>
</tr>
<tr>
<td>100-199% FPL 22%</td>
</tr>
<tr>
<td>Low-income 45%</td>
</tr>
</tbody>
</table>

Percentage change of children living in Low-income and Poor Families, 2006–2011

<table>
<thead>
<tr>
<th></th>
<th>2006</th>
<th>2011</th>
<th>Percent Change</th>
</tr>
</thead>
<tbody>
<tr>
<td>Low Income</td>
<td>28,530,186</td>
<td>32,379,884</td>
<td>13%</td>
</tr>
<tr>
<td>(less than 200% of FPL)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Poor</td>
<td>13,078,106</td>
<td>16,105,863</td>
<td>23%</td>
</tr>
<tr>
<td>(less than 100% of FPL)</td>
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</tr>
</tbody>
</table>

According to the Census Bureau the number of children in poverty has been increasing steadily from approximately 16.2 percent in 2000 to 19 percent in 2008, and approximately 22 percent in both 2010 and 2011.
As the following charts indicate, the number of SSI applications for children for the same period has also increased substantially from 337,000 in 2000 to 498,000 in 2011. The number of total recipients has increased from 844,000 in 2000 to 1.276 million in 2011, but the overall allowance rate has declined slightly from 43.7 in 2000 to 41.6 in 2011.
What’s Next? Approaching Change in the SSI Children’s Program

The historical record of the program suggests that changes in its laws and in the standards governing SSI disability adjudications were motivated by public opinion as reflected in media reports and court decisions in cases that challenged prior decisions. Much of the history of this program has been a reaction to news reports which often contain unsubstantiated anecdotes, court decisions and congressional mandates. It is important that the decisions we make are factually based. Rather than simply developing streamlined processes for the efficient adjudication of the claims, we first need to define the mission for this particular program; a program that is supposed to serve children with disabilities, who live in poverty and are reliant on others to provide voice to their concerns and to care for their needs.

The following is a list of questions that we believe must be answered to identify the purpose and mission of the SSI children’s program. The questions posed below are the discussion points to begin a dialogue and a comprehensive review of the program. They are not proposals or recommendations; rather, they are a starting place.

1. How should we decide the criteria and where should we draw the line in determining which children should be considered disabled and deserving of public support and how should we identify those children who should be served?

2. Is the SSI disability program adequately designed to make the nuanced determinations about all types of children’s disabilities? Or should the SSI program in part or in its entirety be relocated to a different Federal agency that has more interaction and perhaps more understanding of the needs and issues related to the children’s impairments and their functional impact? Should there be a cap on SSI benefits offered for families or for any group of beneficiaries living together?

3. What cash benefits and services should be provided to children with disabilities? Should a cash benefit be paid to a parent who stays home to care for the child? Should the benefits to the child cover only whatever medical services, equipment, transportation costs or tangible goods that are directly related to the child’s disability be provided? Should SSA be responsible for determining those supports and services or should that determination be made by a different source?

4. How do we ensure that SSI children receive the services that will prepare them, if possible, for the workforce? What role if any, should SSA have in transitioning youth with disabilities to the world of work?

5. What’s the best program for a child with a disability which will both assist them with basic necessities, and enable them to learn the skills necessary to meaningfully engage in the workforce in order to become self-sufficient and productive citizens?

As the Congress considers the status of the SSI program in general, we urge that special consideration be given to the part of the SSI program that serves children with disabilities. As one of the most vulnerable segments of our population, children should have access to a program that clearly meets their needs and offers them hope for the future.

Barbara B. Kennelly, Chair (A)
Bernadette Franks-Ongoy   Jagadeesh Gokhale
Dorcas R. Hardy