FACSIMILE COVER SHEET

# AMERICAN ACADEMY OF PEDIATRICS

## *Department of Government Liaison*

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**TO:** Diana Fortuna

**FAX # TO:** 202-456-7431

**FROM:** Keri Briel, Legislative Assistant

**DATE:** April 29, 1997

**PAGES (including cover):** 3

**RE:** Copy of SSI letter that went to the President yesterday.

American Academy of Pediatrics

**Department of Government Liaison**
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April 28, 1997

The Honorable William Jefferson Clinton
The White House
1600 Pennsylvania Avenue
Washington, DC 20500

Dear President Clinton:

The American Academy of Pediatrics has worked unceasingly for children and for their health and well-being, since its beginning over 60 years. The 53,000 pediatricians who are the Academy have been tireless advocates for infants, children and youth. Our overarching goal is that they receive the comprehensive health care and other services necessary to participate fully in society.

The Supplemental Security Income Program for children (SSI) is a critical component in serving children with disabilities. The Academy recently worked closely with Congress and the Administration to strengthen this program while preserving the intent. The debate was not easy, nor are the solutions that have been reached ideal, but the Academy believes that the recently released "Interim Final SSI Rules for Children," provide a fair and reasonable interpretation of the legislation. Improvements, however, can and should be made to the rules, and the Academy offers its expertise by providing comments and suggesting modifications.

The Academy applauds your Administration's intent to maintain Medicaid coverage for children who lose SSI benefits. Those children who no longer qualify under the new, more exacting standards still have significant disabilities, and continuing health coverage may mean the difference between maintenance of current health status -- (or even improvement) or deterioration. Congress should therefore pass, and you should sign, legislation that will ensure that children who lose SSI benefits through the redetermination process shall continue to receive Medicaid health benefits.

The dangers for children are very high if the new SSI rules are not implemented "fairly and reasonably" in a consistent and accurate manner. The process is complex and eligibility must be determined on a case by case basis which will require continuous in-depth monitoring and evaluation by the Social Security Administration. The Academy believes your Administration must itself make a commitment to revise and adjust the SSI process on an ongoing basis, based on evaluation findings.

Therefore, the American Academy of Pediatrics is urging the Congress to provide the necessary funding for staffing and monitoring by the Social Security Administration. This must be done to ensure that the changes made to the SSI program are not harming needy children and families by falling short of the intended goal of keeping children with marked and severe functional limitations in the SSI program. The Academy stands ready to assist you, the Congress, and the Social Security Administration to ensure successful implementation of the new rule.

Sincerely,

Robert E Hannemann MD

Robert E. Hannemann, MD
President

BCC: DIANA FORTUNA

Social Security –
Children's Disability
Standard

COMMUNITY LEGAL SERVICES, INC.

1424 CHESTNUT STREET
PHILADELPHIA, PA 19102
215-981-3700
FAX 215-981-0434

June 12, 1997

Sylvia Mathews
Deputy Chief of Staff
West Wing
The White House
Washington, D.C. 20502

Re: SSI Disabled Children

Dear Sylvia,

We have recently obtained the enclosed SSA memordandum, explained in more detail by my also enclosed cover memo, which shows that there has been a reasonable policy available--a middle course between the old IFA test and the Listings of Impairments--to implement the SSI provisions of the new welfare law.

The SSA memo not only lays out this policy (cutting 45,000 children this year), but also critiques the "alternative" policy, since adopted in the "interim final" rules of Feb. 11, 1997, as one that does not follow the intent of the Congress and prevents "seriously disabled children" from now qualifying.

The host of Senators who have written to the President have criticized the "interim" rules on the same grounds as is found in this SSA policy memorandum.

I would appreciate your response, as I believe that this document may not have been made available to the White House when the decision on these rules were made earlier.

Sincerely,

JONATHAN M. STEIN
General Counsel

cc: Frank Raines, OMB Director
Elena Kagan, Deputy Assistant to the President

Encl.

cc: Diana (return) –

Where are we on this? Is there any chance at all – at any point – of changing our minds?

Elena

$4/5 yrs.

PHOTOCOPY
MISC. HANDWRITING

COMMUNITY LEGAL SERVICES, INC.

1424 CHESTNUT STREET
PHILADELPHIA, PA 19102
215-981-3700
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TO: Friends of SSI Disabled Children

FROM: Jonathan Stein, General Counsel

DATE: June 11, 1997

RE: SSA's Critique of Its Own SSI Child Disability Policy Adopted in the Feb. 11, 1997 Interim Final Rules

SSA prepared in late 1996 a memorandum that explained why the new SSI child disability policy published as "interim final" rules in February 1977 did not reflect the intent of Congress and would preclude "seriously disabled children" from remaining eligible under the Administration's interpretation of the SSI provision of the new welfare law. The latter eliminated the prior Individualized Functional Assessment rules, substituting in the statute a new eligibility test of "marked and severe functional limitations," and requiring the redetermination of about 260,000 IFA children under the new standard.

The document, attached, was prepared pursuant to Executive Order 12866, which requires an assessment of costs and benefits of the policy adopted and policy alternatives rejected with a rationale attached with each. The document was obtained pursuant to a Freedom of Information Act request duly filed.

The memorandum (with an April 23, 1997 cover memo explaining that the memo's "development ended on 1/27/97," two weeks before Federal Register publication of the "interim final" rules) reveals that the main policy proposed would have cut but 45,000 children among the 260,000 being redetermined this year and "save" $1.3 billion over time. (pp. 5-60) (Under this proposal close to 250,000 children would be cut or denied at application over 6 years.)

This policy was the middle course between the old IFA test and the extreme medical Listings of Impairments (e.g. requiring an IQ below 59 to qualify for mental retardation) that many Senators, including the key Senators who framed the final provision adopted, had urged the Administration to adopt. (These Senators were Chafee, Conrad, Jeffords, Harkin, Daschle, Kennedy, Rockefeller IV, Dodd, Baucus, and Mosely-Braun.)

The memo is significant in that on page 8 it offers a detailed critique of an alternative, to be adopted in the interim final rules. SSA has stated that this latter policy will cut 135,000 disabled children now, and over 6 years will cut or deny on

application close to 800,000 children. Advocates believe that this is a major undercount of children to be cut, given the extreme Listings-level disability severity threshold of the new policy. We believe that a large majority of the children to be reviewed will be terminated.

The attached SSA memorandum thus reads:

> "This alternative is based primarily on a listings-level interpretation of the intent of Congress and legislative history with an expansion of the motor domain to try to cover seriously disabled children who were not the target of the legislation. We do not recommend this option because we believe that Congress did not explicitly mandate a listings-level standard when it defined disability in terms of "marked and severe functional limitations". Also, the expansion of the motor domain will cover some of the seriously disabled children, it is not sufficient to cover all of those who were eligible under the previous rules for SSI benefits based on disability.(The word "all" emphasized in original.)
>
> "We need to be clear about the listings we use in the disability process. The listings were never intended to be more than a screening device in the evaluation process to identify many disabled individuals. They were never intended to be the sole criteria for determining disability, and they were never intended to cover all possible serious disabilities. Therefore, we determined that this alternative was not potentially effective nor reasonably feasible.

This Administration analysis above, directly comports that the views expressed by the various Senators who wrote to the President following publication of the "interim final" rules. The Senators wrote: "...{T]he Administration has misinterpreted the intent of Congress in reforming the SSI program for children with disabilities....Congress never intended and did not require this [listings or equivalent] level of severity. SSA thus ignores the law, floor debate, and the history of the program." Letter of April 14, 1997 from Sens. Chafee, Conrad, Jeffords, Daschle, Baucus, Leahy, Dodd, Kennedy, Rockefeller, and Harkin.

The Administration has not as yet responded to this letter or to the plethora of critical public comments of these rules now being employed to terminate or deny children seeking aid.

Attachment

April 23, 1997

NOTE TO THE FILES:

The attached document is an assessment of the potential costs and benefits of an alternative regulatory action which was considered in the development of the interim final rules published in the **Federal Register** on February 11, 1997, at 62 FR 6408, which were effective beginning April 14, 1997. This alternative was not adopted by SSA.

Development of this document ended on 01/27/97, and the data contained in this document does not, in some cases, reflect the final figures used for the assessment for the alternative which was adopted.

Daniel T. Bridgewater
Legal Assistant, SSA

Attachment

SUPPLEMENTAL SECURITY INCOME (SSI)
DETERMINING DISABILITY FOR A CHILD UNDER AGE 18
INTERIM FINAL RULES WITH REQUEST FOR COMMENTS

ASSESSMENT OF BENEFITS AND COSTS TO SOCIETY
AND PRESENTATION OF MAJOR POLICY ALTERNATIVES

## INTRODUCTION

The Social Security Administration (SSA) has determined that these regulations require an assessment of costs and benefits to society per Executive Order (E.O.) 12866, Regulatory Planning and Review, because they meet the definition of a "significant regulatory action." These regulations also meet the definition of a "major rule" under 5 U.S.C. 801 ff., and this assessment also fulfills the requirements of those provisions as well. In addition, SSA has determined, as required under the aforementioned statute, that these regulations do not create any unfunded mandates for State or local entities pursuant to sections 202-205 of the Unfunded Mandates Act of 1995.

E.O. 12866 includes in its definition of a "significant regulatory action" one which raises novel legal or policy issues arising out of legal mandates, the President's priorities, or the principles set forth in the E.O. Accordingly, a discussion follows of the effect of the regulations and general information on estimated costs and benefits to society.

## EFFECT OF THE REGULATIONS

These interim final rules affect the SSI program under title XVI of the Social Security Act (the Act). The SSI program provides a minimum income level for aged, blind, and disabled individuals who do not have income or resources above levels specified in the Act. SSI payments are made from the general fund of the U.S. Treasury and are intended to help provide for food, clothing, and shelter. To the extent that Medicaid eligibility is based on eligibility for SSI under title XVI, these rules also affect the Medicaid program.

These rules implement the childhood disability provisions of Public Law (P.L.) 104-193, the Personal Responsibility and Work Opportunity Reconciliation Act of 1996. Sections 211 and 212 of P.L. 104-193 provide a new definition of disability for children (i.e., individuals under age 18), mandate changes to the evaluation process for children's disability claims and continuing disability reviews (CDRs), and require that disability redeterminations be performed for 18-year-olds eligible for SSI benefits based on disability as children in the month before the month in which they attain age 18.

P.L. 104-193 provides a definition of disability for children separate from that for adults. The "comparable severity" standard in the Act has been repealed and replaced with the following standard:

> (C)(i) An individual under the age of 18 shall be considered disabled for the purposes of this title if that individual has a medically determinable physical or mental 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.
>
> (ii) Notwithstanding clause (i), no individual under the age of 18 who engages in substantial gainful activity (determined in accordance with regulations prescribed pursuant to subparagraph (E)) may be considered to be disabled.

The conference report that accompanied P.L. 104-193 further explained:

> The conferees intend that only needy children with severe disabilities be eligible for SSI, and the Listing of Impairments and other current disability determination regulations as modified by these provisions properly reflect the severity of disability contemplated by the new statutory definition. In those areas of the Listing that involve domains of functioning, the conferees expect no less than two marked limitations as the standard for qualification. The conferees are also aware that SSA uses the term "severe" to often mean "other than minor" in an initial screening procedure for disability determination and in other places. The conferees, however, use the term "severe" in its common sense meaning.

Thus, the new statutory definition of disability for children requires a child's impairment or combination of impairments to cause more serious functional limitations to be considered disabling than the old law did.

Under the new regulations, the evaluation sequence for determining initial eligibility for a child filing a claim for SSI benefits based on disability is the following:

1. Whether the child is engaging in substantial gainful activity;

2. If not, whether the child has a medically determinable severe impairment or combination of impairments;

3. If severe, whether the child(s) impairment(s) meets or medically equals the severity of a listing in the Listing of Impairments, or whether the functional limitations caused by the impairment(s) are the same as the disabling functional limitations of any listing and, therefore, are functionally equivalent to such listing.

There is no longer a provision in the sequential evaluation process affording each child whose impairment(s) does not meet or equal the severity of a listing an "individualized functional assessment" (IFA) of his or her functioning. In P.L. 104-193, Congress specifically directed that SSA discontinue use of the IFA. However, these rules clarify a number of our current functional equivalence policies to ensure that childhood disability claims are properly evaluated under the new statutory standard.

In addition to the rules required to adjudicate new and pending claims, these regulations also implement childhood disability provisions of P.L. 104-193 that affect the medical improvement review standard used to evaluate the continuing eligibility of children and provisions affecting adults (who are age 18) and who were eligible as children in the month before they attained age 18.

Further provisions concerning childhood disability adjudication are summarized below with references to the relevant sections of P.L. 104-193:

- The Commissioner of Social Security (the Commissioner) was directed to remove references to maladaptive behaviors in the personal/behavioral domain from listings 112.00C2 and 112.02B2c(2) of the childhood mental disorders listings (Section 211(b)(1)).

- The Commissioner was directed to discontinue the IFA for children in 20 CFR 416.924d and 416.924e (Section 211(b)(2)).

- Within 1 year after the date of enactment, we must redetermine the eligibility of individuals under the age of 18 who were eligible for SSI based on disability as of August 22, 1996, and whose eligibility may terminate because of the new law. The cases are to be redetermined using the eligibility criteria for new applicants. The medical improvement review standard in section 1614(a)(4) of the Act and 20 CFR 416.994a, used in CDRs, shall not apply to these redeterminations (Section 211(d)(2)).

- The medical improvement review standard for determining continuing eligibility for children was revised to conform

to the new definition of disability for children (Section 211(c)).

- Not less frequently than once every 3 years, we must conduct a CDR for any childhood disability recipient eligible by reason of an impairment(s) which is likely to improve. At the option of the Commissioner, SSA may also perform a CDR with respect to those individuals under age 18 whose impairments are unlikely to improve (Section 212(a)).

- We must redetermine the eligibility of individuals who were eligible for SSI based on disability in the month before the month in which they attained age 18 using the rules for determining initial eligibility for adults. We will do the redetermination during the 1-year period beginning on the individual's 18th birthday. The medical improvement review standard used in CDRs does not apply to these redeterminations (Section 212(b)).

- We must conduct a CDR not later than 12 months after the birth of the child for any child whose low birth weight is a contributing factor material to our determination that the child was disabled (Section 212(c)).

- At the time of a CDR, a child's representative payee shall present evidence that the child is and has been receiving treatment to the extent considered medically necessary and available for the disabling impairment. If a payee refuses without good cause to provide such evidence, we may select another representative payee, or pay benefits directly to the child, if we determine that it is appropriate and in the best interests of the child (Section 212(a)).

Although not included in these interim final rules, the law requires SSA to redetermine the eligibility of children who may be affected by the changes in the definition of disability within one year after enactment (August 22, 1997), with the provision that no child's benefit may be terminated before July 1, 1997. Under this provision of the law, many children already on the rolls will lose their eligibility for SSI benefits. Even though not a part of these rules, we also have considered this provision of P.L. 104-193 in our analysis of the costs and benefits of the changes we are making to the childhood disability program as a result of the law.

In most States, individuals who are eligible for SSI are also eligible for Medicaid, although many children can qualify for Medicaid without being eligible for SSI. Some children who lose their SSI eligibility will also lose their Medicaid eligibility. However, many of the children affected could still continue to be covered under Medicaid because they meet other Medicaid eligibility criteria. States are required to perform a

redetermination of Medicaid eligibility in any case where an individual loses SSI and that determination could affect the individual's Medicaid eligibility.

In addition, there may be redeterminations made for food stamps, Temporary Assistance for Needy Families, and other support programs for children who lose their eligibility for SSI benefits, or who cannot qualify for SSI benefits under the new disability standard. This may shift some of the burden of meeting the needs of these children to States, localities, and charitable organizations.

Program Savings

It is estimated that due to the legislation there will be reduced program outlays resulting in the following savings (in millions of dollars) to the SSI program (over $1.3 billion total in a 6-year period):

| FY1997 | FY1998 | FY1999 | FY2000 | FY2001 | FY2002 | Total |
|---|---|---|---|---|---|---|
| -$35 | -$225 | -$295 | -$315 | -$225 | -$220 | -$1,315 |

Note: Annual numbers may not add to total due to rounding.

Medicaid costs will also decrease. The decrease will be less than the effect of both of the policy alternatives.

Administrative Costs and Savings

The administrative cost of conducting the medical redeterminations of the children who might be affected by the new childhood disability standards is expected to be $140 million in FY 1997 and $85 million in FY 1998. There will be net ongoing savings of approximately $3-5 million annually.

From FYs 1999-2002, the ongoing Federal workyear savings are from fewer recipients on the rolls, i.e., from those children currently receiving benefits who will be terminated and from those children who will be denied under the stricter standards. These savings will result from fewer income and resource redeterminations, representative payee actions and maintenance of the rolls activities. The ongoing State workyear costs are for the medical reviews from the additional reconsiderations and hearings resulting from the stricter childhood disability standards.

Estimated administrative costs ($ in millions, rounded to the nearest $5 million) and workyears (rounded to the nearest 50) are:

| | FY1997 | FY1998 | FY1999 | FY2000 | FY2001 | FY2002 | Total |
|---|---|---|---|---|---|---|---|
| | $140 | $85 | -$5 | -$5 | -$5 | -$5 | $205 |
| | | | Workyears | | | | |
| Federal | 550 | -50 | -100 | -100 | -50 | -50 | 200 |
| State | 1,100 | 400 | 50 | 50 | 50 | 50 | 1,650 |
| Total | 1,650 | 350 | -50 | -50 | -50 | 0 | 1,850 |

Note: Annual numbers may not add to total due to rounding.

Reductions in SSI Recipients (in thousands)

Under this alternative, we estimate benefit eligibility for a total of 45,000 of those children receiving benefits at date of enactment will be terminated. The following figures show the estimated annual effect of the legislation on projected numbers of recipients of Federal SSI benefits.

| FY1997 | FY1998 | FY1999 | FY2000 | FY2001 | FY2002 |
|---|---|---|---|---|---|
| -5 | -40 | -50 | -50 | -40 | -35 |

POLICY ALTERNATIVES

1. Follow a Literal Interpretation of the Legislation

Under a literal interpretation of the legislation, we would only have discontinued use of the individualized functional assessment from the sequential evaluation process, deleted the "maladaptive behaviors" paragraph from the personal/behavioral area of functioning in the childhood mental disorders listings, and made only those changes mandated by the legislation, without the clarifications we have provided in the interim final rules.

We did not choose this option because we do not believe that it comports with the spirit or the intent of the law. As we explained in the preamble to the interim final regulations, the legislative history makes clear that Congress intended for us to provide benefits to needy children with severe disabilities. The Congress also singled out for special mention our policy on functional equivalence and the need to consider functional information, if reflecting sufficient severity and if it is otherwise appropriate. In an attempt to more closely reflect the spirit and the letter of the law, we decided to add a "motor" area of functioning to ensure that physical impairments are appropriately evaluated, to better explain how the policy of functional equivalence should be applied (including, the method for evaluating episodic impairments), to provide a new form for

use at the initial and reconsideration levels of our administrative review process, and to make the other clarifications throughout the interim final rules. If we had done otherwise, we would have risked excluding many of the children the law was intended to cover.

Program Savings under Alternative 1 (in millions)

It is estimated that due to the legislation there would be reduced program outlays resulting in the following savings (in millions of dollars) to the SSI program (over $6.6 billion total in a 6-year period):

| FY1997 | FY1998 | FY1999 | FY2000 | FY2001 | FY2002 | Total |
|---|---|---|---|---|---|---|
| -$165 | -$965 | -$1,290 | -$1,485 | -$1,280 | -$1,445 | -$6,625 |

Note: Annual numbers may not add to total due to rounding.

Medicaid costs would also decrease under alternative 1. The decrease would be greater than the effect of the chosen alternative and alternative 2.

Administrative Costs and Savings under Alternative 1

The administrative cost of conducting the medical redeterminations of the children who might be affected by the new childhood disability standards is expected to be $215 million in FY 1997 and $210 million in FY 1998.

From FYs 1999-2002, the ongoing Federal workyear savings are from fewer recipients on the rolls, i.e., from those children currently receiving benefits who will be terminated and from those children who will be denied under the stricter standards. These savings will result from fewer income and resource redeterminations, representative payee actions and maintenance of the rolls activities. The ongoing State workyear costs are for additional hearings, as well as medical reviews from additional reconsiderations, resulting from the stricter childhood disability standard.

Estimated administrative costs ($ in millions, rounded to the nearest $5 million) and workyears (rounded to the nearest 50) are:

| FY1997 | FY1998 | FY1999 | FY2000 | FY2001 | FY2002 | Total |
|---|---|---|---|---|---|---|
| $215 | $210 | $0 | $0 | $0 | -$5 | $430 |

| | Workyears | | | | | | |
|---|---|---|---|---|---|---|---|
| Federal | 950 | 950 | -250 | -250 | -250 | -250 | 1,000 |
| State | 1,650 | 1,700 | 300 | 300 | 300 | 300 | 4,550 |
| Total | 2,600 | 2,650 | 100 | 100 | 50 | 50 | 5,500 |

Note: Annual numbers may not add to total due to rounding.

Reductions in SSI Recipients (in thousands) under Alternative 1

Under this alternative, we estimate benefit eligibility for a total of 190,000 of those children receiving benefits at date of enactment would be terminated. The following figures show the estimated annual effect of the legislation on projected numbers of recipients of Federal SSI benefits.

| FY1997 | FY1998 | FY1999 | FY2000 | FY2001 | FY2002 |
|---|---|---|---|---|---|
| -30 | -170 | -220 | -230 | -225 | -225 |

2. Follow a Strict Interpretation of the Legislation With a Clarified Motor Domain

This alternative is based primarily on a listings-level interpretation of the intent of Congress and legislative history with an expansion of the motor domain to try to cover seriously disabled children who were not the target of the legislation. We do not recommend this option because we believe that Congress did not explicitly mandate a listings-level standard when it defined disability in terms of "marked and severe functional limitations." Also, although the expansion of the motor domain will cover some of the seriously disabled children, it is not sufficient to cover all of those who were eligible under the previous rules for SSI benefits based on disability.

We need to be clear about the listings we use in the disability evaluation process. The listings were never intended to be more than a screening device in the evaluation process to identify many disabled individuals. They were never intended to be sole criteria for determining disability, and they were never intended to cover all possible serious disabilities. Therefore, we determined that this alternative was not potentially effective nor reasonably feasible.

Program Savings under Alternative 2

It is estimated that due to the legislation there would be reduced program outlays resulting in the following savings (in millions of dollars) to the SSI program (over $4.7 billion total in a 6-year period):

| FY1997 | FY1998 | FY1999 | FY2000 | FY2001 | FY2002 | Total |
|---|---|---|---|---|---|---|
| -$120 | -$715 | -$945 | -$1,075 | -$905 | -$1,010 | -$4,775 |

This is the amount we expect to spend (in millions of dollars) on SSI childhood disability benefits:

| FY1997 | FY1998 | FY1999 | FY2000 | FY2001 | FY2002 | Total |
|---|---|---|---|---|---|---|
| $5,425 | $5,285 | $5,475 | $6,300 | $5,715 | $6,505 | $34,705 |

Note: Annual numbers may not add to total due to rounding.

It is also estimated that there would be reduced Medicaid program outlays (Federal share) resulting in the following savings (in millions of dollars) over a 6-year period:

| FY1997 | FY1998 | FY1999 | FY2000 | FY2001 | FY2002 | Total |
|---|---|---|---|---|---|---|
| -10 | -85 | -110 | -125 | -125 | -135 | -590 |

There would also be reduced Medicaid program outlays for States.

Administrative Costs and Savings under Alternative 2

The administrative cost of conducting the medical redeterminations of the children who might be affected by the new childhood disability standards is expected to be $185 million in FY 1997 and $130 million in FY 1998. For this regulation, the administrative cost of redetermining disability in SSI childhood recipients is assumed to be the same as the cost of a full medical CDR for these individuals, including the additional appellate costs.

From FYs 1999-2002, the ongoing Federal workyear savings are from fewer recipients on the rolls, i.e., from those children currently receiving benefits who will be terminated and from those children who will be denied under the stricter standards. There will be net savings of approximately $10 million annually beginning with FY99. These savings will result from fewer income and resource redeterminations, representative payee actions, and maintenance of the rolls activities. The ongoing State workyear costs are from additional hearings, as well as medical reviews from additional reconsiderations, resulting from the stricter childhood disability standard.

Estimated administrative costs ($ in millions, rounded to the nearest $5 million) and workyears (rounded to the nearest 50) are:

| | FY1997 | FY1998 | FY1999 | FY2000 | FY2001 | FY2002 | Total |
|---|---|---|---|---|---|---|---|
| | $185 | $130 | -$10 | -$10 | -$10 | -$10 | $265 |
| | | | Workyears | | | | |
| Federal | 900 | 650 | -250 | -250 | -250 | -250 | 550 |
| State | 1,200 | 1,250 | 150 | 150 | 150 | 150 | 3,050 |
| Total | 2,100 | 1,900 | -100 | -100 | -100 | -100 | 3,550 |

Note: Annual numbers may not add to total due to rounding.

Reductions in SSI Recipients (in thousands) under Alternative 2:

We expect benefit eligibility for a total of 135,000 of those children receiving benefits at date of enactment would be terminated as a result of these changes in the law. The following figures show the estimated annual effect of the legislation on projected numbers of recipients of Federal SSI benefits:

| | FY1997 | FY1998 | FY1999 | FY2000 | FY2001 | FY2002 |
|---|---|---|---|---|---|---|
| Current recipients | -10 | -95 | -110 | -95 | -80 | -70 |
| New awards | -10 | -35 | -50 | -70 | -80 | -90 |
| Total | -20 | -130 | -160 | -165 | -160 | -160 |

With the reductions in SSI recipients shown above, we estimate the average number of disabled children (in thousands) in payment status after implementation of these interim final rules would be:

| FY1997 | FY1998 | FY1999 | FY2000 | FY2001 | FY2002 |
|---|---|---|---|---|---|
| 1,010 | 950 | 955 | 990 | 1,015 | 1,040 |

Note: Annual numbers may not add to total due to rounding.

## CONCLUSION

We believe that the regulatory changes in the interim final regulations are consistent with the law and meet the intent of Congress. We carefully considered all the various policy and legal issues, and we have arrived at a childhood disability standard that is based on the level of severity represented by the Listing of Impairments. We believe that the regulatory changes meet the intent of Congress and maintain benefit eligibility for severely disabled children.

# United States Senate

WASHINGTON, DC 20510

April 14, 1997

The Honorable William J. Clinton
The White House
1600 Pennsylvania Ave., NW
Washington, DC 20500-0005

Dear Mr. President:

We are writing to express our concerns about the Social Security Administration's (SSA) interim final rules on implementing the childhood disability provisions of the new welfare reform law (sections 211 and 212 of P.L. 104-193).

The Supplemental Security Income (SSI) eligibility standard proposed by the SSA is far more severe than is required by the Personal Responsibility and Work Opportunity Reconciliation Act of 1996. It is our view that, in developing a two marked level of disability that meets or equals the Listings of Impairments, the Administration has misinterpreted the intent of Congress in reforming the SSI program for children with disabilities.

While the SSA slightly expanded the functional equals policy, it remains our view that this expansion will not adequately protect children with severe disabilities and that, in fact, a large percentage of the approximately 135,000 children who lose assistance based on the SSA's definition of disability will be disabled children who are truly in need of assistance. In fact, nationally recognized experts on the SSI program contend that your proposal will affect a far greater number than the 135,000 children you estimated.

The Senate floor colloquy between Senator Chafee, Senator Conrad, and then Senate Majority Leader Dole on September 14, 1995 -- the heart of the debate on SSI reform -- makes it clear Congress did not call for or intend for a radical overhaul of the program. In fact, during that same colloquy, Senator Dole referred to the SSI program as simply in need of a "tune up." It was based on the understanding of the need to "tune up," not dramatically overhaul, the SSI program that many Senators supported the inclusion of the phrase "marked and severe functional limitations" in the new law. It was the intent of Congress to remove from the SSI program children who are not truly disabled. Just as importantly, it was the intent of Congress that children with truly disabling conditions -- including those with one marked and one moderate condition -- retain SSI coverage. It is our fear that the level of disability the SSA is proposing to adopt will place children with disabilities at risk.

The SSA is proposing to define the phrase "marked and severe" as meaning listings levels severity or any equivalent level of severity. Congress never intended and did not require this

level of severity SSA thus ignores the law, floor debate, and the history of the program. The statutory language passed by both chambers of Congress and signed by the President is the best reflection of Congressional intent. We encourage you to instruct the SSA to reevaluate and re-target the proposed rule and establish a comprehensive functional test at a severity level that is stricter than the IFA test, but does not harm children with disabilities. In addition, we encourage you to make a commitment to undertake a complete review of the effect of these regulations on children with disabilities in consultation with experts in the field of child development

Mr. President, we appreciate your commitment to reversing the flaws in the welfare law. You have repeatedly proposed improving upon the provisions of the law which have little to do with the welfare reform goals of breaking the cycle of poverty by moving people from welfare to work. You retain the flexibility to ensure that children with disabilities are not unduly harmed by welfare reform. Cutting off assistance to low-income families who have children with marked and severe disabilities may force parents to place their children in foster care or institutions. We urge you to take your responsibility seriously and implement the new law with great care and in a manner that protects our country's most vulnerable citizens.

We appreciate your attention to this matter and look forward to hearing from you.

Sincerely,

Senator Kent Conrad

Senator John Chafee

Senator Edward Kennedy

Senator Tom Harkin

Senator John D. Rockefeller IV

Senator James Jeffords

Senator Max Baucus

Senator Patrick Leahy

Senator Christopher Dodd

Senator Tom Daschle

# SOCIAL SECURITY

Office of the Commissioner

July 9, 1997

**MEMORANDUM FOR THE HONORABLE ERSKINE B. BOWLES**

FROM : John J. Callahan
Acting Commissioner of Social Security

SUBJECT: Social Security Administration's Weekly Report -- July 14 - 25, 1997--INFORMATION

## KEY AGENCY NEWS

**Litigation Activity in Case Involving Americans with Disabilities Act (ADA):** At the request of the United States Court of Appeals for the District of Columbia Circuit, the Social Security Administration filed an amicus brief in the Michael Swanks v. Washington Metropolitan Area Transit Authority case. The district court had found that receipt of Social Security disability benefits precluded Michael Swanks, who alleged he was fired because of his disability, from seeking relief under ADA. SSA agrees with the Court of Appeals that receipt of Social Security disability benefits should not be an automatic bar to ADA relief.

## CONGRESS

**Hearing on Year 2000 Computer Problem:** On July 10, the House Committee on Government Reform and Oversight, Subcommittee on Government Management, Information and Technology (Chairman Horn) and the House Committee on Science, Subcommittee on Technology (Chairman Morella) will hold a hearing to address the first quarterly report from Federal agencies to the Office of Management and Budget on the Year 2000 computer problem. Kathy Adams, SSA's Assistant Deputy Commissioner for Systems, is expected to testify.

**Hearing on Returning Disabled Beneficiaries to Work.** On July 23, the House Committee on Ways and Means, Subcommittee on Social Security (Chairman Bunning) will hold a hearing on SSA's efforts to help disabled beneficiaries return to work. Acting Commissioner John Callahan is expected to testify for SSA and will be accompanied by Susan Daniels, SSA's Associate Commissioner for Disability. Witnesses from the General Accounting Office and the Department of Education have also been invited to testify.



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**FAX TRANSMITTAL** # of pages ▶

To Diana Fortuna / Cynthia Rice — From Gary Thorne

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## PRESS/MEDIA INQUIRIES

**ABC-TV to Air Story on the Childhood Disability Review Process:** On July 1, Ronald Claiborne, a reporter for ABC-TV in Chicago, interviewed Susan Daniels, SSA's Associate Commissioner for Disability, concerning the childhood disability reviews presently underway as a result of Welfare Reform. The story is scheduled to be aired on ABC's World News Tonight sometime in the next several weeks. The reporter also interviewed Jonathan Stein, General Counsel, Community Legal Services, Inc. (Philadelphia, PA) in connection with the story.

## ACTING COMMISSIONER'S SCHEDULE

- On July 17, Acting Commissioner Callahan will be in Seattle, WA to address a group of women business leaders. The topic will be "Social Security and Women." While in Seattle, Acting Commissioner Callahan will visit SSA's regional office and the teleservice center located in Auburn, WA.

July 10, 1997

To: Bruce, Elena, Cynthia

Fr: Diana Diane

Attached is a Time Magazine story on the upcoming cutoffs of children on SSI. It's possible we'll see more stories in the coming weeks, since the cutoffs are starting this month. I hear ABC World News Tonight may do one soon.

Our guess is 135, 000 kids will lose benefits. The data from the field so far are inconclusive as to how good a guess that was. SSA is supposed to be done with its redeterminations by August 22, but both the House and Senate propose to give them a 6-month extension, which they need.

A few things to bear in mind that this story gets wrong and others may as well:

- Kids won't lose speech training and medicine if the final reconciliation agreement includes the budget agreement's plan to grandfather Medicaid for these kids. Right now, the Senate does not include this, while the House allows but does not require states to grandfather Medicaid for these kids. But we are fighting for it. (Also, special ed would probably pay for speech training.)

- The advocates raise the spector of institutionalization, but that seems very unlikely for these kids, who are not severely disabled enough to justify being institutionalized. It's harder to dismiss the risk of foster care.

With the President having moved such a distance, what is there left to fight about? Plenty, it turns out, and in the p.r. battle, Clinton seems to have the advantage. For one thing, a narrow plurality of the public say they have more confidence in Clinton than in congressional Republicans on the tax issue, according to a CNN/*USA Today*/Gallup poll released last week. Clinton's 43%-to-40% edge is a startling turnaround in comparison with shortly after the 1994 election, when the public that had handed control of Congress to the Republicans rated the party 22 points ahead of the President on handling the issue. The change partly reflects the verdict of most independent analysts, who say Clinton's measure is a better deal for the middle-class taxpayer than what the House and the Senate are offering. And when the argument turns to the details of the various proposed tax breaks, Clinton has positioned himself as the champion of hardworking parents: while he pushes his education tax credits, for instance, the same Republicans who wanted to close the Education Department will be fighting to index capital-gains taxes so that investment profits can be insulated from inflation.

The stickiest issue to resolve between Congress and the White House is the question of whether low-income workers should get the $500-per-child tax credit. Republicans will argue that refunding these Americans more than the amount they pay in income taxes is not a tax cut but welfare. So Clinton operatives are scouring key congressional districts for real-life examples of such "welfare" recipients, lining up teachers, police officers and social workers. Clinton can also point out that the Republicans themselves, in their Contract with America, advocated giving the tax credit to the working poor. It's not hard to figure out who wins that fight.

Republicans have begun to contemplate the scenario that is their ultimate nightmare: "He could get away with vetoing a Republican bill and saying he wanted his kind of tax cuts and win," says David Mason, the conservative Heritage Foundation's leading congressional scholar. "I could get in trouble with my Republican friends for saying so, but it's true." No wonder there are few G.O.P. voices still arguing for confrontation. As a Republican strategist put it, "The fact is, we're going to have to share credit with this guy. Then again, he's not on the ballot in 1998, and Republicans in Congress are." An odd consolation for a party that rode to power in 1994 by turning a congressional election into a referendum on the President. ***—With reporting by John F. Dickerson/Washington***



# Are The Cuts Unkind?

## New rules may halt benefits to more than 100,000 disabled children. What will happen to them now?

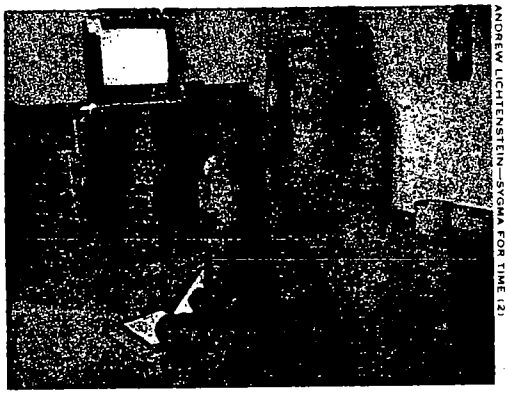
SHIRLEY ESHELMAN IS PHYSICALLY DISabled, but she manages to work small miracles for her 12-year-old son Jonathan, who is emotionally disturbed and has learning difficulties. And she does so on a family income of just $241 a week. She stretches a $30-a-month grocery budget by planting a large vegetable garden outside her home in rural Middletown, Md., and by taking Jonathan to a food pantry where they volunteer in exchange for food. She sets aside money in meticulous expense ledgers for Jonathan's outings with a local teacher who teaches him socialization skills, and a little more for his twice-monthly speech therapy. But the Eshelmans' world may be on the brink of collapse because of new federal rules that could take away Jonathan's $74-a-week disability check. "It's frightening," says Eshelman, who is worried that with her two-person household's income cut almost a third, she won't be able to meet her house payments, and she and her son will end up homeless. "I really don't know what we would do."

Jonathan is one of 264,000 low-income, disabled children nationwide whose Supplemental Security Income benefits, averaging $424 a month, are being reviewed for possible termination. The reviews are being conducted under new rules, adopted in last year's overhaul of the welfare system, that significantly tighten the program's definition of disability. So far, 42% of children whose cases have been reviewed under the new rules nationally have been found ineligible; some started losing benefits last week. Jonathan's review ended with a request for him to submit further evidence of his disability—a sign, his mother fears, that he may be on the verge of being cut off.

The move to slash children's disability is in part budget driven: the government estimates that the new eligibility rules could save $4.7 billion over six years. But the program's critics contend it has been abused by families whose children are not truly disabled. "The standards are vague and easily met," says Representative Jim McCrery, a Louisiana Republican and supporter of the new rules. "Some people regard it as just a super welfare program." The assault on children's SSI began three years ago, when a spate of news reports carried charges that parents were coaching children to act out mental disabilities. Among these was a 1994 story on ABC's *PrimeTime Live* titled "Crazy Checks," which offered anecdotal evidence of cheating in what it called "a government program gone haywire." In time the charges were largely dismissed by four separate investigations, including the Social Security Administration's own, which found "no evidence" of widespread parental prompting. But these investigations received little attention, and skepticism in Congress remained strong.

What will happen to those who lose SSI? Many will have to give up treatments ranging from speech training to medicine. Others may end up homeless, since SSI families are poor and the check is a large percentage of household income. And some families may be torn apart. Organizations like the Arc, formerly the Association for Retarded Citizens, say they have been inundated with calls from parents afraid they will have to give up their children to foster care or institutionalization. "People tell us this is what's holding their family together," says Arc spokesman Marty Ford. "If you pull this card out, the whole house falls down." ***—By Adam Cohen/Middletown***

## ON THE BRINK



ANDREW LICHTENSTEIN—SYGMA FOR TIME (2)

**THE ESHELMANS of Maryland, a disabled mother and her son Jonathan, could be made homeless by new children's disability rules. Jonathan's $74 a week in benefits is nearly a third of the family's income**

Not if we get our provision to grandfather Medicaid.

cc Cynthia Richard Green, OMB

Diana — FYI. Elena

**COMMUNITY LEGAL SERVICES, INC.**
**Interoffice Memorandum**

TO: JOHN CALLAHAN, BRIAN COYNE, ARTHUR FRIED, JUDY CHESSER SUSAN DANIELS, SOCIAL SECURITY ADMINISTRATION

FROM: JONATHAN STEIN and RICHARD WEISHAUPT

DATE: JULY 17, 1997

RE: IMMEDIATE STEPS SSA COULD TAKE TO ASSIST SSI FAMILIES WITH DISABLED CHILDREN TO APPEAL TERMINATIONS

Only 10-15% of families are appealing SSI child disability terminations, which apparently has surprised those in the Administration who had assumed (and planned) that many more families would appeal. Far fewer we believe are "opting" for benefits continuing during the appeal. The latter is an absolute constitutional right, being undermined, as we have documented, by local SSA practices of discouraging this option. (This low appeals experience confirms our own earlier predictions and the recommendations we made earlier to prevent this from happening.)

Without an appeal the family obviously cannot receive fairer treatment by having a personal hearing before an adjudicator, or preventing irreparable harm from an erroneous termination. The initial redetermination process lacks <u>any</u> personal appearance before a decision-maker prior to the termination, a scenario that you might agree is Kafkaesque.

This is a national crisis given the fact that over 50,000 children have already been terminated with many more to come. Yet it is not too late for SSA to take <u>immediate</u> steps to remediate this situation, which we suggest below:

1. <u>Personal calls/contacts to families:</u> Every family who has been or will be terminated should be personally contacted and informed that they have a right of appeal and how they can easily exercise it. Note: Past SSA Commissioner Gwen King instituted this in the late 80's for mentally ill and homeless client adverse action decisions. The current crisis demands similar action.

2. <u>Add to termination letters state/local "800" numbers of non-profit/pro bono groups and name these groups in letters:</u> We have long made this suggestion, and the American Bar Association is sending the "800" numbers available in about two dozen states. Local non-profit groups available in <u>every</u> state are legal aid and

Protection & Advocacy offices (available from the LSC or NIADA, and the Nat'l Ass'n of P. & A. Systems, all in D.C.).

3. Honoring the constitutional right to have benefits continue pending appeal and remedying documented practices of SSA employees discouraging the exercise of this right:

a. immediately instruct SSA staff to encourage exercise of this due process right and explain that a person has a statutory right to a waiver of overpayment (law says "there shall be no adjustment...") if the parent is not at fault; this is not happening now.

b. for all those appealing without benefits continued SSA should immediately write to them informing them of this right and the new, clarified waiver rights language. (We believe, given the widespread failure to advise about the waiver right, that a Federal Court would at a minimum include this in injunctive remedial relief.)

c. SSA should also immediately instruct SSA staff that "good cause" grounds to excuse 10 day late or 60 day late appeals should be liberally construed, with illustrations specific to the lives of these families. (SSA issued this clarification for drug and alcohol addiction but has not, so far, for children's cases.)

4. Share names of terminated children with state agencies now: In conformity with the excellent and caring letter of the Acting Commissioner to Governors of May 22, 1997, informing states that names of children reviewed can be shared with states, SSA should make clear and pro-actively provide to each state now the names of all children already terminated, and, concurrently with future terminations, the names of other children who will be cut. The Commonwealth of Pennsylvania, for example, has for some weeks wanted these names, so that welfare dept. staff can call each of these families to assist them with appeals and retaining their Medical Assistance.

We would be most happy to sit down with you at the earliest convenience to address these matters. Thank you for you anticipated cooperation.

cc: Ken Apfel/Franklin Raines, Office of Management and Budget
Sylvia Matthews/Erskine Bowles, Office of Chief of Staff
Elena Kagan/Bruce Reed, Domestic Policy Council
Senator John Breaux
Senator John Chafee
Senator Kent Conrad
Senator Christopher Dodd
Senator Charles Grassley
Senator Orrin Hatch
Senator Jim Jeffords

SSI for Elena

**New Definition of Childhood Disability for SSI Under Welfare Reform**
**For Internal Use Only**

On Thursday, February 6, the Social Security Administration (SSA) will announce its new standard for childhood disability for the Supplemental Security Income (SSI) program. The welfare law required SSA to set a stricter standard for this program, which provides monthly cash payments and Medicaid for low-income disabled children. As a result, 135,000 disabled children now on the rolls will lose benefits beginning this summer.

At the time the welfare law was passed, CBO and OMB estimated that it would cause 190,000 children to lose benefits. Since then, disability advocates and a small group of Senators (Daschle, Chafee, and Conrad) have pushed for a significantly more liberal interpretation of the law that would cut only 45,000 children from the rolls. The editorial boards of the New York Times and Washington Post have supported the advocates.

SSA's decision is a middle ground, but closer to the Republican leadership than to the advocates. We are likely to get a lot of criticism from advocates. The Congressional leadership may support us, but there is some risk they will charge us with backtracking on welfare reform.

**Background**
Congressional Republicans and some Democrats proposed cutbacks to this program in 1995 after anecdotal reports that parents were coaching their children to "act crazy" to get benefits, and because of the program's rapid growth after the Zebley Supreme Court decision (from 350,000 to almost 1 million children since 1990, most with mental impairments). Widespread cheating was never documented. We opposed and helped defeat proposals to block grant the program, but we ultimately accepted a Senate compromise that became law.

SSA's standard adopts the Republicans' position as a starting point, but add 3 elements to its current rules that will reduce the number of children losing benefits from 190,000 to 135,000:

- better consideration of children with physical disabilities;
- better consideration of children whose problems are episodic but very severe; and
- a new form to ensure that adjudicators follow rules that require them to look beyond SSA's list of diseases to consider how a child functions.

The advocates argue that SSA should recreate a tougher version of a test that Congress explicitly struck from the law (the "IFA"). They also charge that our decision-making is driven by budget considerations. (Even though we are announcing this decision on the day the budget is released, we should note that SSA made the decision on the merits, not based on the budget.)

Note: The number of children affected is higher than 135,000 if you include children who would have been eligible between now and 2002. The advocates tend to use the higher numbers.

**Talking Points**
**New Definition of Childhood Disability for SSI Under Welfare Reform**

Note: We should generally refer questions on this subject to SSA/Commissioner Chater. They are briefing the press on this as part of their budget briefing on Thursday at 2 p.m.

- Because disability is a complex issue, SSA had the challenging task of developing policy guidelines that meet the Congress's intent to tighten the definition of disability for children, while protecting severely disabled children.

- Out of approximately 950,000 disabled children currently receiving benefits, SSA estimates that about 135,000 children will lose monthly benefits that average about $425 per month. This number is consistent with the lower-range estimates made by the Congressional Budget Office when the bill was being debated. Most of the children affected can be broadly categorized as children with mental impairments, such as less severe learning disabilities or behavioral disorders.

- SSA notified 263,000 children and their families that their cases needed review, but only about half that number (135,000) are expected to ultimately lose benefits.

- To implement the law, SSA has added guidance to ensure careful evaluations of children with physical impairments and children with severe impairments that re-occur despite periods of remission, as well as a new form to ensure that adjudicators follow rules that require them to consider how a child functions.

- For many families with children on SSI, the most valuable part of their benefit is not the monthly cash payment, but Medicaid coverage. The President's budget proposes that children who lose SSI benefits as a result of this the law retain Medicaid coverage, so that the medical needs of needy children and families continue to be met.

- SSA will track the effects of the implementation of this law. If it discovers that revisions or improvements in the new law are needed, it will recommend such changes to the President.

- SSA is committed to implementing the new rules in a fair and consistent manner across the U.S. SSA will assist families in producing medical records needed to determine if a child is eligible. If families lack such evidence, SSA will pay for any medical exams needed to establish eligibility, as it always does.

- Families can appeal SSA's decisions and, in most cases, benefits can continue throughout the appeals process.

- Although there have been some news articles suggesting that children with severe impairments such as Downs Syndrome, severe mental retardation, autism, or certain rare diseases will lose benefits, SSA's new guidelines for evaluating severe impairments will ensure that such children remain eligible.

[Note: There have been several very compelling newspaper stories about children with very severe problems whose cases are being reviewed. The advocates tend to highlight such cases, but it appears that the vast majority of the children written about will keep their benefits. However, it will be weeks or months before decisions about individual children are made.]

**Questions and Answers:**

**Q: The welfare law called for this new standard to be published in the Federal Register by 11/22/96. Why is it taking so long to issue this regulation? When will the regulation be published?**

**A:** The regulation will be published in the next day or two. Because this new rule will have a direct impact on thousands of low-income disabled children, it was essential that SSA take enough time to ensure that the new guidelines carry out Congressional intent and ensure eligibility for severely disabled children. Working within the general framework established by Congress, SSA had to carefully examine all its eligibility criteria and, where appropriate, add functional criteria to the standards to protect SSI eligibility for children with severe disabilities.

[Note: A backlog of over 100,000 applications has built up since August, while SSA developed this new standard. These are children whose cases are in the "grey area" of the new definition.]

**Q: How many disabled children will lose monthly payments? Who are the children that will lose benefits?**

**A:** SSA estimates that, out of approximately 950,000 children currently on the rolls, about 135,000 children will no longer be eligible for SSI payments. (This number is in the low range of CBO's estimates.) The children who will be affected can be very broadly categorized as children with certain mental impairments, such as less severe learning disabilities and behavioral disorders.

**Q: When will children lose benefits?**

**A:** No one will lose benefits until the summer, and families who appeal SSA's decision will keep benefits during the appeals process.

**Q: Was the President involved in the decision of the new disability standard?**

**A:** Since the passage of welfare reform, the White House has been working with officials at all affected agencies to ensure that they implement the new law consistently and properly. SSA kept the White House abreast of policy and legal issues that arose in establishing the new standard. However, Commissioner Chater made the final decision on behalf of the President.

**Q: How much money will be saved by the new rules? Was the budget a major consideration in establishing the new rules?**

**A:** Savings of about $4.8 billion are estimated in the 6-year period starting in FY 1997. SSA was not motivated by budget considerations in establishing the new rules. SSA relied on the statute itself as well as its legislative history.

**Q: The advocates are arguing that the new standard is too strict and that Congress gave the agency much leeway in the statute to establish a more lenient standard. Why such a strict interpretation?**

**A:** It is my understanding that it is very clear from the welfare reform law and legislative history that Congress meant to establish this severity standard. These new rules meet that legislative intent while including important additional elements to protect severely disabled children.

**Q: Is the President concerned about the effect of the new law on low-income disabled children? If so, what is he going to do about it?**

**A:** Yes. That's why the Administration has taken these steps. First, while meeting congressional intent, SSA worked within the framework established by Congress to add additional criteria to the new rules that protect severely disabled children. Second, the President has proposed that Medicaid coverage continue for children who lose SSI benefits as a result of this change, so that the medical needs of families continue to be met. Third, SSA will be tracking the effects of the law. If SSA discovers that changes are needed, it will recommend such changes to the President.

**Q: Isn't this another example of the Administration backtracking on welfare reform? In addition to the increase in your food stamp/legal immigrant fix package, aren't you also reducing the savings originally expected from this change by cutting off fewer children?**

**A:** The Social Security Administration developed this regulation under its authority to implement the law, using its best efforts to interpret congressional intent. It does not reflect any change in policy. On the other hand, the welfare reform package in the budget consists of the Administration's proposed policy changes to the welfare law, including the cost of keeping Medicaid coverage for children who lose SSI. SSA believes that the Hill would concur that this is a fair interpretation of their intent.

OMB 1-pager

**Supplemental Security Income New Childhood Disability Standard**
**February 6, 1997**

The welfare law required SSA to provide a new tightened definition of childhood disability for the SSI program, which provides monthly cash payments and Medicaid for low-income disabled children. SSA was challenged with formulating a standard that both meets the intent of Congress to tighten eligibility and ensures that severely disabled children and their families are protected under the new law. SSA is announcing that standard at 2 PM today.

**SSA's Standard:**

- The Administration is confident that the standard in the regulations SSA has developed meets the letter and the spirit of the law in ensuring that needy children with severe disabilities are protected.

- *Numbers:* Of the approximately 950,000 children currently receiving benefits, CBO estimated that between 100,000 and 260,000 children would lose benefits under the new eligibility definition in the welfare law. SSA estimated last year that 190,000 children would lose benefits; **SSA estimates that under its new standard the total number of children who will be removed from the rolls is 135,000 -- in the low range of CBO's initital estimates for the law.**

- *Type of Disability.* Most of those affected under SSA's standard can be categorized as children with less severe mental impairments -- such as less severe learning disabilities or behavioral disorders. The new rules provide guidelines for evaluating more severe impairments -- such as Down's Syndrome, severe mental retardation or autism -- to ensure that such children remain eligible under the new standard. Because disability determination is a complex issue, regulations in this area are difficult and complicated. For a description of the more specific details of the regulation, the SSA Commissioner should be contacted.

**Medicaid Coverage:**

- The President is also proposing a legislative change to soften the impact of the eligibility changes. The legislative change would allow disabled children who lose their SSI eligibility under the new definition of childhood disability to retain their Medicaid health coverage -- so that the medical needs of these families continue to be met.

**Ongoing Evaluation:**

- SSA will track the effects of the implementation of this law. If they discover that revisions or improvements in the law are needed, they will recommend such changes.

Drafted/Cleared: Ken Apfel, OMB, 5-4844
KMcKiernan

Thursday, February 6, 1997
For Immediate Release

Phil Gambino / Tom Margenau
410-965-8904 Fax 410-966-9973

# News Release

## SOCIAL SECURITY

### STATEMENT OF SHIRLEY S. CHATER, COMMISSIONER OF SOCIAL SECURITY ON THE RELEASE OF NEW CHILDHOOD DISABILITY GUIDELINES TO COMPLY WITH WELFARE REFORM LEGISLATION

"Today we are announcing the release of regulations containing the guidelines we will use to determine if children with disabilities meet the new definition of disability outlined in the SSI provisions of the new welfare reform law.

Because disability is a very complex issue, formulating regulations to implement the law was an enormous task for SSA. The major challenge was to ensure that the intent of Congress was met while working within the framework established by Congress to add additional criteria to the rules to ensure continued benefit eligibility for severely disabled children and their families.

We have crafted policy guidelines that, I believe, meet the letter and spirit of the law while protecting the rights of children and families. I want to thank the many dedicated Social Security managers and employees who worked long and tirelessly to make this happen.

With the implementation of these new rules, we estimate that about 135,000 children will no longer be eligible for SSI benefits. This is consistent with the lower-range estimates made by the Congressional Budget Office.

SSA has notified about 263,000 children and their families that this change may affect them. We expect that approximately one-half of these children will continue to receive benefits when evaluated under the new rules. Although you may have seen news articles alleging that children with impairments such as Down Syndrome, severe mental retardation, autism, or many rare diseases will lose benefits, the new rules provide guidelines for evaluating severe impairments such as these to ensure that such children remain eligible for SSI benefits. In addition, these new rules include more guidance to ensure careful evaluations of children with physical impairments as well as children with severe impairments that re-occur despite periods of remission.

(MORE)

President Clinton has made it very clear that he wants to minimize any adverse consequences that this legislation might have on disabled children and their families. The President has proposed in the budget that Medicaid coverage continue for children who lose their SSI benefits as a result of this change in the definition of disability, so that the medical needs of these needy children and families continue to be met.

As this agency has always done, SSA will work with families to obtain evidence to substantiate the child's medical condition and if additional evidence is needed, SSA will pay for any consultative examinations that may be required. Also, the parents or guardians for all children have the right to appeal any decision we make. And in most cases, benefits can continue throughout the appeals process, until the child's representative has had the right to present his or her case in person before an administrative law judge.

Finally, I have asked my staff to develop plans to track the effects of the implementation of this law. If we discover that changes are necessary or desirable in the law, we will recommend revisions and improvements to the President.

We must now begin the challenging process of implementing these new guidelines in a fair and consistent manner across the country."

# # #

Date: 02/07/97 Time: 08:40
DNew rules push 135,000 disabled children off SSI

WASHINGTON (AP) Letters will begin arriving this spring informing children that they are no longer disabled enough to qualify for federal benefits.

Some 135,000 children will be dropped from the Supplemental Security Income program, or SSI, under rules released Thursday by the Social Security Administration implementing another piece of last year's welfare reform law.

The law tightened eligibility requirements for children applying for SSI, which pays about $430 per month to help parents who must stay home with their children or buy expensive equipment to help them.

The program serves nearly 1 million children at a cost of nearly $5 billion annually. In December about 263,000 families were notified that depending on the final rules, they may no longer qualify.

Under the rules announced Thursday, about half of them will lose benefits. Over the next five years, another 45,000 SSI applicants who would have qualified under old rules will not, officials said.

Disability activists said the new rules will mean mentally retarded children with IQs as low as 71 will no longer qualify for SSI.

``This is way beyond fine tuning,'' said Marty Ford, spokeswoman for the Arc of the United States, an advocacy group. ``It is devastating to these families.''

But Rep. Jim McCrery, R-La., who led the effort to rewrite the SSI rules, said Thursday, ``The main goal was to ensure that only children who were truly disabled and in need of assistance qualified for the program.''

The Social Security Administration, which had great discretion in writing the regulations, said officials studied the law and the congressional debate surrounding it to make the decision, which comes months after it was due.

``We have established a fair, a consistent manner of review ... so that children with severe disabilities ... who deserve benefits will continue to receive those benefits,'' Social Security Commissioner Shirley S. Chater said.

President Clinton's budget, also released Thursday, provides money for Medicaid benefits for about 50,000 children who are being taken off SSI and would not already qualify for Medicaid in their states.

Children have always qualified for SSI if they have a physical or mental condition included on a list of ailments. Since 1990, when the Supreme Court expanded eligibility standards, children have qualified if they have a combination of other problems that keep them from functioning normally.

The new welfare law tightened that second qualification.

A report by the congressional General Accounting Office in 1994 said that with the relaxed eligibility standards in place, the number of children on SSI soared from about 300,000 in 1989 to more than 900,000 last year.

Lawmakers and educators claimed that some parents were coaching their kids to fake behavioral and learning disabilities so they could qualify for SSI.

Disability activists had lobbied the Clinton administration to write the rules to allow as many children as possible to qualify, but they were disappointed.

``They could have written a regulation that would have hurt far fewer children,'' said Jonathan Stein, an attorney from

Philadelphia who won the 1990 Supreme Court case expanding the disability definition.

``The law is the law,'' responded Chater, who said Clinton approved the rules before they were announced.

Disabilities are labeled as moderate, marked or severe. Under the old rules, children with marked limitations in two areas or moderate limitations in three areas qualified for SSI.

For instance, a child would could not dress himself would show a marked disability, while one who just had trouble dressing himself would have a moderate problem, said Susan M. Daniels, associate commissioner for disability.

The new rules require marked disabilities in two areas, such as social and personal functioning, or extreme limitations in one area, such as the inability to walk.

``We moved the marker a little more towards severe,'' Daniels said.

McCrery said he was mostly pleased with the administration's interpretation of the law but wondered why more children were not excluded from the program under the new definition.

``In the end what we'll probably have to do is monitor this program very closely and determine if further changes are needed,'' he said.

APNP-02-07-97 0846EST

**INSIDE:**
**SOCIAL SECURITY**

# *Aid for Disabled Children Hinges on New Definition*

11/7/96

By Barbara Vobejda
Washington Post Staff Writer

In the coming days, the Clinton administration will answer a question that has prompted enormous anxiety since Congress began debating welfare legislation nearly two years ago: How many children will lose their federal disability benefits as a result of the new law?

Families and advocates for the disabled have known since the welfare law was enacted in August that eligibility would be tightened for the Supplemental Security Income (SSI) children's disability program. But Congress gave the administration wide discretion in determining which disabilities will qualify for benefits, which average about $430 a month.

If the administration adheres to a narrow definition of disability, around 200,000 of the nearly 1 million children now in the program would likely lose their benefits. If it accepts a broader definition, the number could fall below 100,000, advocates say.

With benefits for that many children at stake, those in the disabled community see these regulations as critical and have been actively lobbying the administration to cut off as few recipients as possible.

"There is a distinct risk of overkill, putting in jeopardy children even the vocal critics would not want to be terminated" from the program, said Jonathan Stein, a Philadelphia attorney and leading advocate for disabled children. "The administration should be looking for a way that harms the least children."

The decision is before officials at the Social Security Administration and could be announced within a week or two, an SSA spokesman said.

"The agency is meeting at the highest levels now, meeting with the White House" on the new rules, said Phil Gambino, an SSA spokesman. "We're at that last stage."

While much of the attention to the welfare legislation has focused on Aid to Families with Dependent Children, the law also affects several other programs, including food stamps and SSI payments to the elderly and disabled.

Sponsors of the legislation, led by Rep. Jim McCrery (R-La.), had argued that some children who were not seriously disabled were receiving benefits, including some whose parents had coached them to pretend they suffered from mental or behavioral problems.

As a result, Congress instructed the administration to tighten eligibility, but it gave little guidance on exactly how to do that.

"We want to make sure that under the new criteria, only the truly disabled qualify for this benefit," McCrery said. "That's what we're waiting to see, if the administration will indeed write regulations that carry out the intent of the law."

The law eliminates what was known as the "individualized functional assessment," or IFA, a test that was used to determine eligibility if a child's disability was not among a "listing" of conditions.

The new language says that a child "shall be considered disabled . . . if that individual has a medically determinable physical or mental impairment, which results in marked and severe functional limitations."

But that leaves enormous room for interpretation. A Congressional Budget Office estimate based on an earlier draft of the legislation indicated that as few as 10 percent or as many as 28 percent of the nearly 1 million children receiving benefits could be pushed off the rolls as a result of the law.

The language in the final legislation was less strict. At SSA, Gambino said, "we have talked about a range of 100,000 to 180,000 who could lose benefits as a result of the regulations." And advocates believe the range could be slightly larger.

After the regulations are completed, SSA must review the cases of all children who were granted eligibility through the functional assessment, or nearly 300,000 children, and determine if they meet the new criteria. That will begin early next year, with benefit cuts beginning in July.

But no one can say until the new regulations are released how many of those children, or how many new applicants, will be granted eligibility.

"We have no sense of where they might come out," said Marty Ford, assistant director for governmental affairs at The Arc of the United States, an advocacy group. "We're pushing hard because we think kids and families will be devastated by the impact if the Social Security Administration chooses too high a standard."

Under the previous law, Ford said, the standard was already very high. A mentally retarded child, for example, would have to have an IQ of 70 or below to be considered someone with a "marked" disability. An IQ of 74 was considered a moderate disability.

"It's very scary," said Patti Steinitz, a Pittsburgh mother who fears her 2-year-old daughter could lose the Medicaid benefits she receives under SSI. Steinitz said her daughter, Hunter, suffers from a severe disorder that makes it difficult for her to get enough nutrition and makes her very vulnerable to infection. She requires around-the-clock nursing, at an annual cost of more than $160,000.

Steinitz, a police officer, and her husband Mark, a businessman, are ineligible for cash benefits under SSI because of their incomes. But if they lost the Medicaid benefit that pays for Hunter's nursing care, Steinitz said, in order to care for their child, "we would have to quit our jobs and go on welfare."

Steinitz appealed personally to President Clinton for his help when he was campaigning recently in Pittsburgh and since has been writing letters to the White House.

Jonathan Stein, whose arguments before the Supreme Court in 1990 contributed to an expansion of the SSI children's program, argues that many lawmakers mistakenly believe that children who qualified for SSI because of the functional test are not seriously disabled.

Of the 300,000 children who receive SSI because of mental retardation, one-third qualified because of the functional test, he said.

"The IFA population is strewn with families who have kids with serious disabilities, and they're all in jeopardy," Stein said.

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# The President's Next Welfare Test

President Clinton will have to work with the Republican Congress to keep his promise to fix the welfare law that he signed over the protests of many Democrats. But his Administration has sole control of the implementation of a potentially punitive provision of the new law. That provision would knock children off disability rolls. How well Mr. Clinton protects those children will provide the first post-election test of his resolve to block Congress's worst impulses.

About one million poor children receive Federal money under the Supplemental Security Income program. Most recipients suffer from well-defined physical or mental handicaps that are so severe that no one disputes their eligibility. But about 300,000 of these children qualify for S.S.I. because of a combination of functional impairments, no one of which may be severe. It is this group that some members of Congress want to drive off the rolls, even though no Federal study has shown a pattern of abuse. They have accused parents of abusing the program, coaching their children to feign "maladaptive behavior" and other handicaps.

The new law eliminates maladaptive behavior as a qualifying handicap. It also vaguely calls for an overall tightening of standards. But, in a flash of good judgment, Congress left the task of issuing new guidelines — due in the next few weeks — to the Administration. That means Mr. Clinton has the authority to protect these children.

The question before the Administration is how many of these 300,000 children with a combination of functional impairments are truly disabled. Within this group, the children the Administration is most likely to rule ineligible are an estimated 50,000 who are less dramatically impaired. They qualify for S.S.I. under current rules because they suffer a combination of three "moderate" functional impairments. The Administration will be tempted to throw all these children out of S.S.I. just to appease Congress's intent to tighten eligibility.

The temptation should be resisted. Jonathan Stein, the general counsel of Community Legal Services, an advocacy group in Philadelphia, points out that these supposedly moderate handicaps can be severely debilitating. As one of many examples, he cites a 6-year-old child with a very low I.Q. of 72 and a mild case of cerebral palsy who cannot walk or talk well. By S.S.I. standards, no one of these mental or physical handicaps is severe. But the combination surely is.

A blanket rejection of aid for children with three non-severe handicaps would cruelly leave the poor parents of these severely handicapped children to fend for themselves. The Administration needs to make finer distinctions rather than simply sweep out broad categories.

The rules that the Administration will soon issue will determine how many vulnerable children are stripped of Federal benefits. Mr. Clinton's obligation, no matter how much anger he provokes on Capitol Hill, is to make sure that every child he separates from S.S.I. is undeserving. Appeasing Capitol Hill's need to find abuse where it may not exist or, worse, saving money on the backs of the disabled might be politically expedient, but it is unfair.

LOS ANGELES TIMES EDITORIALS

# Don't Penalize Disabled Kids

*Washington should seek properly broad criteria for aid*

President Clinton can begin making good on his campaign promise to fix the flawed welfare reform law by dealing with the issue of benefits for disabled children. When the Social Security Administration moves to redefine the eligibility criteria, as required under the new law, the White House should encourage a broad definition. The health of thousands of children is at stake.

One million disabled children currently receive some form of federal assistance, primarily for mental retardation, physical disabilities and, increasingly, emotional disorders. Poor disabled children also qualify for cash benefits, about $500 a month in California.

Under the new rules, narrowly tailored eligibility regulations would eliminate as many as 200,000 children from the benefit rolls, according to an analysis by the Congressional Budget Office. But this is a humanitarian issue, and a more generous standard should be adopted, one that could drop fewer than 100,000 children from this program.

Congress set tighter eligibility standards in part to remove from the rolls children who were being coached by parents to mimic emotional ailments or behavioral problems. Such fraud qualified some families for so-called "crazy money." On this point Congress was right. Fraud should not be tolerated. But most recipients are truly needy.

The new law also calls for tighter standards for children with moderate disabilities, which would preserve funds for those considered "truly disabled." Now further fine-tuning of definitions is needed, particularly in the aftermath of a 1990 U.S. Supreme Court decision that broadly extended benefits to thousands of children with mental impairments or multiple moderate disabilities.

The welfare reform law terminates federal disability benefits to legal immigrants, regardless of age or impairment, and the aid never has gone to illegal immigrants. An estimated 50,000 legal immigrant children are expected to lose benefits nationwide; as many as half live in California. Only Congress can restore the program for these children.

The welfare reform law requires the Social Security Administration to formulate new criteria by Nov. 22. President Clinton can influence that decision and should act for the benefit of disabled children. Yes, fraud is a problem. Yes, costs must be cut. But disabled children should not be counted among cost-saving measures.

THE WALL STREET JOURNAL
FRIDAY, DECEMBER 6, 1996

# *Welfare Law Leaves Clinton to Decide How Many Disabled Children Lose Aid*

By CHRISTOPHER GEORGES
*Staff Reporter of* THE WALL STREET JOURNAL

WASHINGTON – President Clinton faces his first big decision on welfare since he signed the welfare overhaul law this summer: He must choose among three competing plans that would end benefits to tens of thousands of poor, disabled children.

Advocates on both sides of the welfare debate are closely watching Mr. Clinton's choice as a signal of how far he is willing to go to cut welfare benefits. The three options, which have been presented to the president in outline form, would cut between 60,000 and about 150,000 children from the welfare rolls.

All three plans target the estimated 100,000 mildly retarded children, who are most vulnerable to losing aid. About 300,000 of the one million children receiving aid under the welfare program in question – Supplemental Security Income for Disabled Children – have some form of mental retardation.

Under the welfare law, $55 billion will be saved over six years. Congressional budget officials projected that about $6 billion would come from cutting the number of disabled children who qualify for monthly checks that average $425. Though the SSI reforms drew relatively little attention during the welfare debate over the past two years, the SSI program, along with savings from food stamps and cutting benefits to noncitizens, accounts for nearly all of the total welfare savings.

But unlike the case in other areas of welfare reform, Congress gave the president—and not the states—great leeway to decide cutoffs in the SSI program. Congress directed the administration to allow only children with "marked and severe functional limitation" to continue to receive aid, but to essentially cut off no more than 29%, or about 288,000, of the current beneficiaries.

Currently, children qualifying for SSI aid have been diagnosed with one of 60 severe illnesses, such as debilitating cerebral palsy, or show symptoms of two or three milder forms of illnesses and have been approved by medical specialists. Congressional critics, claiming fraud and abuse in this latter category, sought to shrink the rapidly growing program by disqualifying many of the 288,000 participants. Families with annual incomes of more than $30,000 don't qualify for SSI aid.

All three White House proposals would continue to provide aid to children with a listed severe illness. But the most restrictive option, developed by policy aides in the White House budget office, would make few other exceptions. This plan is projected to save about $6 billion over six years and cut off about 150,000 current recipients.

A second, less restrictive option, developed by the White House's Domestic Policy Council, expands the budget office's plan to include children with less severe disabilities. Though medical specialists would still be required to follow strict guidelines in approving children, numerical thresholds for IQ or motor-skill tests, for example, would be looser. This option is projected to save about $4 billion to $5 billion over six years and end benefits to about 100,000 current participants.

The third option, drafted by SSI advocates outside the administration, would end aid to about 60,000 of current participants who have milder symptoms of multiple illnesses. For example, an SSI child who does poorly in school and has poor vision and weak motor skills would lose aid. This option is estimated to save between $2 billion and $3 billion over six years.

Congressional Republicans have yet to review the options, and declined to comment on them. But they were skeptical that the last option could win lawmakers' support. Though Congress can't reject or modify the president's final decision, it can write a new, more restrictive law.

Mr. Clinton's choice will be incorporated into his coming balanced-budget plan, and will depend partly on the amount of savings he needs for the budget to reach balance. Regardless of Mr. Clinton's choice, no children will be cut from the SSI rolls until July 1, 1997.

Deliberations on the three plans are being conducted closely among White House policy advisers; first lady Hillary Rodham Clinton, who has said she plans to focus on welfare reform in the second Clinton term, hasn't attended the staff meetings on the issue.

THE WALL STREET JOURNAL
FRIDAY, DECEMBER 6, 1996

# Clinton Chooses Albright for State, Cohen for Defe...

## ...ake Is to Head CIA, Berger Becomes Chief Of National Security

WASHINGTON—In naming his new national security team, President Clinton simply shuffled the deck and added one new face card.

But he did make history by naming Madeleine Albright, his United Nations ambassador, as the first woman to serve as secretary of state.

*Madeleine Albright*

After weeks of deliberations, the president also chose a Republican, retiring Sen. William Cohen of Maine, to be secretary of defense. Mr. Cohen's selection was intended to bolster the administration's bipartisan congressional support. Mr. Clinton also made clear by his selections that he wasn't interested in setting a bold, new course in foreign policy. "our responsibility is to build on the strong foundation laid in the last four years," he said, in announcing his choices yesterday.

Mr. Clinton named Anthony Lake, the current national security adviser, to be director of Central Intelligence and picked Samuel Berger, Mr. Lake's deputy, to succeed Mr. Lake in the White House job.

*By Wall Street Journal staff reporters Robert S. Greenberger, Thomas E. Ricks and Michael K. Frisby in Washington.*

The Albright, Cohen and Lake nominations will require Senate confirmation, but early reaction on Capitol Hill indicated they won't face serious opposition. Sen. Jesse Helms (R., N.C.), chairman of the Senate Foreign Relations Committee and a frequent critic of Clinton diplomacy, called Ms. Albright "a tough and courageous lady" and predicted easy confirmation.

*William Cohen*

A rocky and erratic first three years have given the three returning members of the team — and their president—hard-earned but valuable experience in managing foreign policy, and they likely will work together harmoniously. In addition, Ms. Albright has been a forceful explainer of administration policy, a talent sorely lacking in top-tier cabinet slots during the last four years. Further, in picking Sen. Cohen, Mr. Clinton appears to be preparing the ground for a possible bipartisan agreement to reduce the Defense Department's budget as part of an overall effort to further reduce the federal deficit.

Moreover, the calendar for next year—a summit with Russian President Boris Yeltsin in March and one with Chinese President Jiang Zemin in the fall — suggests the administration is focusing attention on the big countries and vital U.S. interests, in stark contrast to its earlier involvement with lesser problems in places like Somalia and Haiti.

Still, a number of foreign-policy experts expressed concern that the foundation Mr. Clinton is building on consists of a thick layer of daily crisis management skills but only a thin veneer of strategic thinking. Moreover, while the new team, particularly Ms. Albright, are experts on Europe, there is a lack of working knowledge of Asia.

"They'll do a competent job if you define that as managing the daily foreign affairs of the country," says former Secretary of State Lawrence Eagleburger. "But with regard to bringing us into the 21st century with a sense of where we want to go, it won't be any more than during the last four years."

Mr. Berger, in an interview yesterday, disputed that view. "This is a group of people who have spent a good part of their lives engaged in the enterprise of American foreign policy," he said. And an aide to Ambassador Albright said her many speeches and statements over the last four years do express broad foreign-policy views.

*Anthony Lake*

During the first term, Ms. Albright was the administration's strongest supporter of using military force in Bosnia and strongly favors expanding the North Atlantic Treaty Organization by adding, among others, her native Czech Republic.

She shocked diplomats at the U.N. earlier this year, after four Cuban-American flyers were shot down by a Cuban missile, when, using the vulgarity the Cuban pilots had shouted, said Cuba's action "is not *cojones*," but "cowardice." She also alienated some members of the U.N. community by leading the administration's efforts to block U.N. Secretary General Boutros Boutros-Ghali from a second term.

But Ambassador Albright also used more delicate skills in private to pursue U.S. interests. She met regularly, for instance, with Rolf Ekeus, the U.N. official in charge of monitoring Iraq's compliance with certain U.N. resolutions, to assure him he had U.S. support while trying to find Iraq's stocks of chemical and other deadly weapons. She also communicated directly with midlevel officials, such as the State Department's desk officer for Burma, to obtain helpful information. One official said he expected Ms. Albright to continue that practice as the nation's top diplomat.

Yesterday, President Clinton sought to play down the impact of women's groups on his selection of Ms. Albright, but others in the White House suggested it may have been a crucial factor that tilted the scale in her favor. Ms. Albright actually benefited from being initially dismissed as a long-shot candidate, for it prompted leaders of women's' groups to protest she wasn't being taken seriously. And they had new clout: women voted 54% to 37% in favor of Clinton over Bob Dole, exit polls showed. She also had Vice President Al Gore in her corner.

Mr. Cohen brings other assets. At a White House news conference yesterday, the president's first sentence when introducing Mr. Cohen noted the necessity of "bipartisan support" for the nation's armed forces. Clearly, he hopes Sen. Cohen will alleviate some of his national security problems on Capitol Hill. Mr. Clinton long has been vulnerable on defense, partly because of his youthful evasion of military service, partly because of the fiasco over gays in the military early in his term, and partly because of his administration's handling of the U.S. military in Somalia.

### A Defense Intellectual

But the selection of Sen. Cohen also carries some risks. To some, it evokes Mr. Clinton's first pick for the Pentagon job, Les Aspin. Like the late Wisconsin Democrat, Mr. Cohen is an independent-thinking, Europe-oriented defense intellectual who has spent decades in Congress and lacks experience at running anything larger than a congressional staff. That lack of a management background proved troublesome for Mr. Aspin during his turbulent one-year tenure as defense secretary. The president seemed conscious of that danger yesterday when he described the job of defense secretary as "running the largest and most complex organization in the nation's government."

*Samuel Berger*

Mr. Cohen's centrist views on defense are hardly distinguishable from those of the current defense secretary, William Perry. The single greatest point of policy difference is likely to be on antimissile defenses, where Mr. Cohen has been slightly more hawkish than has the administration.

Mr. Cohen also has been far more oriented than Mr. Perry on seapower. Two of the largest employers affecting his state are **General Dynamics** Corp.'s Bath Iron Works Corp., the builder of warships, and the big Navy yard just across the state line in Portsmouth, N.H. And Sen. Cohen was a leading opponent of additional purchases of the B-2 Stealth bomber, which is built by **Northrop Grumman** Corp.

Mr. Clinton's choice of Mr. Lake to fill the top intelligence slot has raised some questions. The president said yesterday that he was glad he would have Mr. Lake "working the halls at Langley." But some critics say Mr. Lake, with his professorial demeanor, may be mugged in those halls by intelligence officials who may well resist reform. Thus he may not prove to be the strong hand many analysts think is needed at the Central Intelligence Agency, which has been plagued by traitors in its ranks and remains unsure of its mission in the post-Cold War world.

"Is he capable of doing something? I don't know, but I guess I doubt it," says Mr. Eagleburger.

Mr. Berger, who will become national security adviser, a job that doesn't require congressional confirmation, is given part of the blame for some of the administration's early overseas fiascos. But foreign-policy experts say that he has grown in his job and should be a capable coordinator of policy. Among the officials named yesterday, Mr. Berger also has the most experience with trade and Asia issues—two areas the administration regularly cites as crucial to America's future.

**WSJ from Journal Link:** For an on-line discussion about Clinton's cabinet and the full text of his remarks Thursday, see The Wall Street Journal Interactive Edition at **http://wsj.com**

The Washington Post

AN INDEPENDENT NEWSPAPER

# A Choice for the Administration

THE WELFARE bill that Congress passed and the president signed two months ago had to do with more than just welfare. Among the other programs it will affect is a special form of federal aid to needy families with disabled children. For years a kind of backwater in the budget to which no one paid much attention, the program in the 1990s suddenly more than tripled in size. The caseload shot up from 300,000 to about a million, the cost from a little more than $1 billion to about $5 billion.

Partly this expansion reflected a 1990 Supreme Court decision requiring that eligibility standards for children be eased, and partly it was the result of an earlier congressional decision to admit to the program a broader range of children with mental disorders. But critics had begun to contend that it was partly due to abuse as well. They argued mainly on the strength of anecdotal evidence that parents and others were taking advantage of the liberalized rules to obtain disability benefits for children who, while needy, were not in fact disabled, and they said the program had grown in directions that Congress never fully had contemplated.

The House version of the welfare bill therefore proposed sharp cuts in the disability benefits. Rather than give cash to eligible families, it proposed offering most of them only certain services, limiting the cost of those and narrowing the definition of disability. The Senate took a more moderate approach, which prevailed in the bill the president finally signed. The cash payments were preserved, and the disability definition was tightened less.

The new language creates a zone of discretion for the administration. A child will be deemed disabled if he or she has a "medically determinable physical or mental impairment, which results in marked and severe functional limitations." What might those be? The administration will have to say in regulations.

Just about everyone agrees that some three-fourths of the children on the rolls are disabled enough that they will meet the new test, however it is phrased. It is the others, about a quarter of a million, whose fate is up in the air, together with however many might be expected to apply in the future.

Advocacy groups say the final language in the bill was deliberately such that the administration need cut off only a minority of these. They cite, among much else, a carefully orchestrated colloquy on the Senate floor last year when this part of the bill was taking final form. Then-Majority Leader Bob Dole, who took part along with Sens. John Chafee and Kent Conrad, said at one point, "I think we can all agree that the children's SSI [as the program is called] needs a tune-up." That hardly argues for wholesale change, they say. They make the further point that the Social Security Administration has already tightened up on the program, such that the so-called allowance rate or percentage of applicants granted benefits has fallen from an artificial high of 70 percent in 1991 to 30 percent today.

Our own sense is that the administration ought to err on the side of giving the extra benefit rather than denying it. The poverty rate among children remains high, and other forms of aid to needy families with children already are being cut. Having at home a child with even a relatively modest disability can be an enormous burden and cost for even a family of some means, if only because it often deprives the household of earnings. A family member who otherwise might work is required to provide child care instead. We have no doubt that people here and there are ripping off this program, just like any other program. But most aren't, and that ought not be the presumption of policy.

No climate Δ

The Joseph P. Kennedy, Jr. Foundation

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April 11, 1997

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John J. Callahan, Acting Commissioner
Social Security Administration
900 Altmeyer Building
6401 Security Blvd., P.O. Box 1585
Baltimore, MD 21235-0001

**Re: Comments on Interim Final Rules for Determining SSI Childhood Disability, 62 Fed. Reg. 6408 (Feb. 11, 1997)**

Dear Commissioner Callahan:

I have previously communicated my concerns about the unfairness of the proposed rules to Associate Commissioner Daniels. I believe that the proposed rules will be unfair to children with mental retardation and their families, and are more stringent in regards to these children than the existing rules are for adults. Several portions of the regulations, outlined herein, appear to disfavor children with mental retardation.

It is my understanding that the Social Security Administration has accepted functional limitations two or more standard deviations below the mean as indicating marked and severe functional limitations. Three standard deviations are considered extreme disability.

In order to be fair to both children and the government, it must be recognized that, in every test, there is a range of precision(s) expressed as Standard Error of Measurement, SEM. Two SEM's in each standardized test will provide 95% confidence limits. The use of such limits, seems to us essential, in order to avoid challenges on every score in the two standard deviations range. Using your proposed regulations, many children will be denied benefits, unfairly, due to the nature of the test instrument, and the tester used, not due to the nature of their disability!

As an example, a preschool child (age 3-6) has marked and severe functional limitations in cognition if his/her performance scores are two or more standard deviations below the Mean. For example, using the WISC3 in a six year old, a score of 70 meets this requirement. However, this is not an exact measurement, so it is necessary to include two SEM's to obtain the 95% confidence limits. A Full Scale Score of less than 76, a Performance Score less than 79, and a Verbal Score less than 78 all meet this requirement.

The same strategy applies to motor and communicative scores, but in these measures, one uses standard scores, not I.Q. Standard scores less than 70 +/- 2 SEM are likewise reflective of marked and severe motor and communicative functional limitations.

Four other areas need comment: personal function, social function, deficiencies of concentration, and persistence or pace resulting in frequent failure to complete tasks in a timely manner. The best measures of personal functioning in preschool children pertains to self-care adaptive instruments. The four best measures, in the opinion of our experts, are the Vineland Adaptive Behavior Scale, the WeeFIM, the PEDI, and the AAMR scales.

Objective measures of social functioning include the various Connors Parent Teacher Rating Scales, the Child Behavior Checklists, and the Clinical Autism Rating Scale. In general, these social functioning/behavioral rating scales consist of T scores with a Mean of 50 and a standard deviation of 10. Thus, scores of greater than 70 +/- two SEM's reflect marked and severe functional social-behavioral limitations in externalize or internalized behaviors at home or at school.

Areas of concentration, persistence or pace can include reasonable comparisons to peers for certain activities. For example, taking inordinate amounts of time for basic activities can be quantitated...any child who takes more than ten minutes to drink four ounces safely has a severe feeding problem.

Another concern is the confusion that may result from the use of traditional terminology in mental retardation. When we refer to "mild" mental retardation we mean an I.Q. of 70 which is **two standard deviations** below the mean +/- two SEM's. The Draft SSI regulations call two standard deviations below the mean in other domains "marked and severe". Likewise, when we refer to moderate mental retardation, we mean an I.Q. three standard deviations below the mean. This would also cause confusion, as the Draft SSI regulations call three standard deviations in other domains,"extreme". These differences in how we label things is bound to cause confusion. The American Association on Mental Retardation definition, as you know, now carries with it an elaborate description of the needs for support, in four different dimensions.

Therefore, unless examiners in State Disability Determination Services are specifically warned of this problem, and trained to deal with these differences, a child who is mildly retarded will not be labeled with a marked and severe impairment, a child who is moderately retarded will not be labeled as having an extreme impairment.

The experts we consulted in mental retardation and communication argue that it is ill advised to combine, as they are in the proposed regulations, the categories of Intellectual Disabilities and Cognitive Disabilities into a single domain, for three reasons: 1) Scientific, 2) the importance of the communication domain and 3) the clinical implications of combined effects. The regulations for adults do not combine these domains, and to do so for children is unfair.

**1) Scientific Considerations.** Dissociation between cognition and communication are seen in many children with specific language impairments who exhibit significant deficits in language abilities, but who perform within the normal range with respect to intellectual functioning. Children with Landau-Kleffner Syndrome, for example (an acquired language deficit associated with seizure disorders) maintain normal cognitive ability despite losing communicative skills. In the case of Williams Syndrome, affected children have mental retardation but can display age-appropriate skills in some areas of language. Many children with Down syndrome have communication impairments that far exceed their level of intellectual impairment. Finally, there are many neurological impairments and brain injuries that differentially affect cognition and communication. In sum, the two categories are simply independent from each other in many areas of disease and disability and must be made separate in the final regulations to be fair to children;

**2) Communication warrants a separate domain.** Communication is the foundation for acquiring skills in many other domains and, therefore, warrants a separate domain. Individuals who lack basic communication skills find it difficult to form friendships, be integrated into educational settings, acquire vocational skills, live independently and meet daily life requirements. No other facet of human behavior has such a direct impact on daily life and efforts by persons with disabilities to be productive and independent members of society. It is a category that should stand alone in both diagnostics and assessments;

**3) Clinical Implications of Combined Effects.** A combination of Mental Retardation (i.e. I.Q. 2 S.D. below the mean +/- 2 SEM's) and a moderate to severe functional limitation in communication (2 S.D.'s below the mean +/- 2 S.E.M.'s) is extremely disabling since there is minimal ability to compensate for functional limitations by the use of assistive technology that would be helpful in the presence of cognition. Again, this speaks strongly to the need to separate the domains.

Finally, we know from long experience and research that the extent, nature, costs of caring and providing supports for individuals not properly served early in their lives increases significantly in their adult and aging years. This evidence argues for intervening early with children and families, and for interpreting the regulations more broadly, as allowed by law, than the proposed regulations.

Sincerely, and with thanks

Eunice Kennedy Shriver

Eunice Kennedy Shriver

Probs w/ stay in pd
- time
- process w/ appts
- Kids being cut off

# Consortium for Citizens with Disabilities

(3)

April 10, 1997

John J. Callahan
Acting Commissioner
Social Security Administration
PO Box 1585
Baltimore, MD 21235
(Copy by FAX: 410/966-2830)

**Re: Determining Disability for a Child Under Age 18; Interim Final Rules With Request for Comments (*Federal Register*, February 11, 1997)**

Dear Acting Commissioner Callahan:

The undersigned member organizations of the Consortium for Citizens with Disabilities Task Force on Social Security submit these comments on the Interim Final Rule regarding the childhood disability criteria for the Supplemental Security Income program.

The Consortium for Citizens with Disabilities (CCD) is a working coalition comprised of approximately 100 national consumer, advocacy, provider and professional organizations which advocate on behalf of people of all ages with physical and mental disabilities and their families. Since 1973, the CCD has advocated for federal legislation and regulations to assure that 49 million Americans with disabilities are fully integrated into the mainstream of our nation's life. The CCD Social Security Task Force monitors changes in both SSI and Social Security disability programs in Title II of the Social Security Act.

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The February 11 regulations for childhood disability determinations in the Supplemental Security Income (SSI) program are a major disappointment for several reasons. First, the eligibility standard set by the Social Security Administration (SSA) to implement the law is far more severe than was required by the Personal Responsibility and Work Opportunity Reconciliation Act of 1996 (P.L. 104-193). We believe that the new statutory definition of childhood disability gives SSA the flexibility to protect more children than will be by SSA's interim final standard. In addition, even within the eligibility standard chosen by SSA, there are a number of serious flaws which will harm children with severe disabilities.

The following comments of the CCD Task Force on Social Security (hereinafter "CCD") are addressed in three major sections: the standard itself; substantive issues within the standard; and implementation issues.

## I. NEW CHILDHOOD DISABILITY STANDARD: Listings Level Standard is Too Severe and Unnecessary

The CCD and other advocates worked very hard with Members of Congress to ensure, if the Personal Responsibility and Work Opportunity Reconciliation Act were signed into law, that the definition of disability for children in the SSI program would be fair. In fact, the new statutory language requires that a child have impairments resulting in "marked and severe functional limitations" -- the first time that the Social Security statute recognizes the importance of functional assessments for children.

We believed, and the Senators who crafted the new definition believed, that the language gave SSA room to develop a new approach to functional assessment and to tighten the eligibility criteria without a wholesale overhaul of the disability standard for children. Several Senators noted this intent in a colloquy (Senators Dole (R-KS), Chafee (R-RI), and Conrad (D-ND)) and in letters to President Clinton prior to the publication of these new regulations (Senators Chafee, Conrad, Daschle (D-SD), Cohen (R-ME), Moseley-Braun (D-IL), and Harkin (D-IA) and a letter from Sen. Wellstone (D-MN) to Secretary Shalala).

We believe that these Senators' interpretations of Senate action, the colloquy between then-Majority Leader Dole and Senators Conrad and Chafee, and the acceptability of another, less-severe standard (including a "one marked/one moderate" standard) are very critical to the children who will be adversely affected by the proposed rules. Because of their importance, we attach as an appendix a copy of these letters and the *Congressional Record* (September 14, 1995; page S 13613) with the colloquy.

It is clear that these Senators, through their own negotiations on the new definition, believed that they were not establishing a "listings level" standard for the childhood disability program. Since the critical statutory language was the result of intensive Senate negotiations which rejected the House "listings" approach, the interpretations of these Senators should be given great weight by SSA. This is especially important since there is clearly flexibility within the statutory definition for agency interpretation and there are other possible interpretations of the conference report language upon which SSA so heavily relies.

SSA's new contorted description of the meaning of "marked" and "severe" versus "marked and severe" (Sec. 416.902) provides excellent evidence that the interpretation supposedly required by the conference report language is in itself a stretch:

> *Marked and severe functional limitations*, when used as a phrase, means the standard of disability in the Social Security Act for children claiming SSI benefits based on disability and is a level of severity that meets or medically or functionally equals the severity of a

> listing in the Listing of Impairments in appendix 1 of subpart P of part 404 (the Listing). ... The words "marked" and "severe" are also separate terms used throughout this subpart to describe measures of functional limitations; the term "marked" is also used in the listings. ... **The meaning of the words "marked" and "severe" when used as part of the term *Marked and severe functional limitations* is not the same as the meaning of the separate terms *"marked" and "severe" used elsewhere in 20 CFR 404 and 416.*** ... (italics in original)

The last sentence of that definition (highlighted in bold above) illustrates the contortion and inherent failure of SSA's logic in its interpretation of Congressional intent.

Despite strong legislative history to the contrary, SSA has adopted a very high standard of disability for children which will deny benefits to almost a quarter of a million children with severe disabilities and their families over the next 6 years -- at least 135,000 children will lose current benefits after their redeterminations. This impact is wholly unnecessary and punitive to the children and their families. Many of us believe that these estimates are low, considering the high level of severity of disability that children will now have to prove to remain eligible.

RECOMMENDATION:

**SSA should re-examine its position on the new standard's required level of severity for disability. SSA should present a more accurate account of the complete legislative history and leave the door open for future agency regulation and adjustment as needed to meet changing knowledge and understanding of the nature of childhood disability. The agency should publish new regulations which more accurately reflect the legislative language and the current national knowledge-base about childhood disabilities. At minimum, SSA should include as eligible those children who have marked impairment in one area of functioning and moderate impairment in another area of functioning -- a "one marked / one moderate" standard.**

**SSA also should commit to a thorough and complete review of the effect of these regulations on children with severe disabilities, consulting with experts in children's physical, social, emotional, and mental development. The results should be made available publicly and allow observers to track how the rules affect children with different impairments and levels of severity in each of the age groups.**

## II. SUBSTANTIVE ISSUES WITHIN THE STANDARD

Given the standard chosen by SSA (essentially a "two marked", listings-level standard), there are several substantive issues that must be addressed. Without the changes we recommend, we believe that the standard is inherently unfair to children with certain disabilities and children of certain ages. Although there may be some historical logic to the distinctions, current scientific and childhood development knowledge reveal that these distinctions will have an arbitrary effect on different children.

We understand from training materials that SSA attempted to base the functional assessment requirements on the functional criteria of the childhood mental impairment regulations. However, the bulk of the work to develop those functional criteria was done in the mid-1980s. When the expert panel was convened to help develop the Individualized Functional Assessment in 1990, SSA was counseled to adjust its functional assessment process incorporating newer advances in science, child development, and disability research. As discussed below, these advances should not be abandoned in favor of strict adherence to the somewhat outdated mental impairment criteria approach (see discussion of cognition/communication and the personal area for one- to three- year olds).

1. Cognition and Communication Should Be Assessed Separately

We understand that the new standard will require a child to have a disability that actually meets the specifics of one of the "medical listings" of impairments; medically equals one of the listings; or functionally equals the limitations of one of the listings. To assess "functional equals", SSA establishes several broad areas of functioning for evaluating children's limitations by age group. They are: cognition/communication (all ages); motor (all ages); social (all ages); responsiveness to stimuli (birth to age 1 only); personal (ages 3 to 18 only); and concentration, persistence, and pace (ages 3 to 18 only). To be eligible for SSI, a child must show marked limitations in two areas of functioning (or extreme limitation in one area).

Combining cognition and communication into one area of functioning is inappropriate and will harm many children who have very severe disabilities. Because cognition (ability to learn, understand, solve problems, and use acquired knowledge) and communication (ability to communicate, including hearing and speech) are considered together as one area, children who actually have marked limitations in these two areas will be credited with marked limitations in only one area. For example, a child with marked limitations in cognitive functioning (mental retardation) and marked limitations in communication (due to speech impairments) would be considered to have a marked limitation in only one area -- the combined cognition/communication area. The impact of this standard is blatantly unfair.

Scientific research has shown that cognition and communication involve different parts of the brain, that impairments may affect each area in different ways, and that there are different manifestations of the impairments within the two different areas of cognition and communication. In addition, communication is so critical in the development of other skills and in the adaptation to other impairments that it must be considered separately. A child with an IQ of 70 who also has marked limitations in communication may have significantly different functional limitations than a similar child who does not have communication limitations.

RECOMMENDATION:

**To be scientifically accurate and fair to children with severe impairments, SSA should separate cognition and communication into two areas of functioning when assessing childhood disability. (Section 416.926a)**

One- to Three- Year Olds Should Be Assessed in the Personal Area and Concentration , Persistence, and Pace

SSA has listed only three broad areas of childhood functioning which will be assessed for children aged one to three (older infants and toddlers): cognitive/communicative development; motor development; and social development. Children must show marked impairment in two areas of functioning to be found eligible. Two critical areas of function are excluded for this age group without any explanation: personal skills and concentration, persistence, and pace.

For age 3 to 18 year olds, SSA describes the personal area as: "the ability or inability to help yourself and to cooperate with others in taking care of your personal needs, health, and safety (e.g., feeding, dressing, toileting, bathing; maintaining personal hygiene, proper nutrition, sleep, health habits; adhering to medication or therapy regimens; following safety precautions)." Certainly the assessment of a child's early efforts to acquire feeding, dressing, and toileting skills is an important indication of possible marked functional limitations.

SSA also defines "concentration, persistence, and pace" for 3 to 18 year olds as: "the ability or inability to attend to, and sustain, concentration on, an activity or task, such as playing, reading, or practicing a sport, and the ability to perform the activity or complete the task at a reasonable pace." While assessment of this area might focus on different skills for younger children, it is still an important area to consider.

For one to three year olds, these two areas of childhood development must be addressed to have a comprehensive and accurate assessment of functioning. While we understand that SSA is not establishing a "scoring" system, it is important to note that finding marked limitations in two areas out of three is qualitatively different than finding marked limitations in two areas out of four or five areas. Two out of three is certainly a description of "pervasive" functional limitations which is not required by law. "Pervasive" was removed from the statutory definition by the Senate in 1995 and it should not become a *de facto* part of the standard through regulation.

RECOMMENDATION:

**SSA must add the personal area of functioning and add concentration, persistence, and pace as areas to assess for children aged one to three. Failure to do so will result in incomplete and inaccurate assessments resulting in harsh denials of assistance for some children with very severe impairments. This result is especially troubling given the unquestioned value of early intervention in assisting children to overcome limitations to the greatest extent possible. (Section 416.926a)**

3. Measurement of IQ Must Include Room for Measurement Error

The American Association on Mental Retardation describes the measurement and use of IQ scores in *Mental Retardation: Definition, Classification, and Systems of Supports* (9th Edition, 1992), the definitive authority on diagnosis and measurement of mental retardation. AAMR cautions against strict adherence to IQ scores and urges consideration of the concept of

standard error of measurement, which is estimated to be about three to five IQ points (±3 to 5). An individual whose IQ score measures 70 should actually be considered to have an IQ in the range of at least 66 to 74 or 62 to 78 (depending on the probability of accuracy sought). Therefore it is critical that SSA not allow its disability examiners to use IQ scores to eliminate children from eligibility, rather they should look at the total child and his/her functional limitations. Children whose IQ scores are 75 or below should be considered as possibly having an impairment "two standard deviations below the norm" (SSA's definition of "marked" in areas where standard testing is available). For children with such an IQ score and the presence of a marked limitation in another area of childhood functioning, this could deny access to critical SSI cash support and medical and other supports through Medicaid. Strict adherence to numerical scores is inappropriate and could have a harsh impact on children who have severe functional limitations.

RECOMMENDATION:

**SSA should add to the functional equivalence regulations a description of the variance allowed (± 3 to 5) in appropriate use of IQ test scores and SSA must ensure that disability examiners and adjudicators understand that strict adherence to the numerical score to deny eligibility is inappropriate. When in the range of 70 to 75, the IQ scores alone should not be used as a shortcut to deny children without further exploration of the child's functional limitations. To do otherwise is to use IQ scores for the wrong purpose.**

4. Need for Better Functional Assessment for Children with Physical Limitations

Reliance on the functional factors of the "B" criteria of the childhood mental impairment regulations is not sufficient to assess children with significant physical impairments. Addition of the "motor" area of functioning does not close the entire gap. SSA needs to include another area of function which addresses non-motor aspects of physical impairment. Based upon recommendations of the National Academy of Social Insurance (*Restructuring the SSI Disability Program for Children and Adolescents: Report of the Committee on Childhood Disability of the Disability Policy Panel*, 1996) and others, this new area should include other physical functions considered a part of normal functioning such as breathing; eating, digesting, and eliminating; strength, stamina, and endurance; ability to resist disease and function in the physical world.

RECOMMENDATION

**SSA should include an additional area of functioning to address the non-motor aspects of physical impairment including at least: breathing; eating, digesting, and eliminating; strength, stamina, and endurance; ability to resist disease and function in the physical world. (Section 416.926a)**

"Other factors" Need Better Link to Functional Assessment

The existing childhood disability rules acknowledge the importance of "other factors" such as the effects of medication or treatment, adaptations, highly structured settings, and the child's ability to attend school. The proposed regulations do not change the significance of evaluating these factors when reviewing childhood claims. However, no guidance is given decisionmakers about how to incorporate consideration of these critical "other factors" into the new sequential evaluation or as part of the expanded functional equivalence determination process. We believe this is a very serious omission that should be corrected to ensure that consideration of "other factors" is not ignored in future adjudications.

RECOMMENDATION

**SSA should incorporate guidance on how to consider "other factors" in the sequential evaluation process. Previously, SSA issued such guidance in its own Program Operations Manual System (POMS). SSA should also change the proposed Evaluation Form (SSA-538) to reference "other factors" so that adjudicators consider this evidence, especially as needed for all four possible methods of establishing functional equivalence. By asking disability adjudicators to indicate how they use evidence of these other factors, SSA could help ensure that this vital information is not ignored during the adjudicative process. (Section 416.924c)**

6. Need To Utilize Available, Appropriate Tests to Measure Function When Evidence is Incomplete

For some children, available evidence in the file may not be complete or thorough enough to indicate actual functional limitations. State DDS examiners are required to seek appropriate consultative examinations for a complete assessment of the child's limitations. The National Academy of Social Insurance urged increased use of the standardized tests which exist to measure the impact of mental impairments. Eunice Kennedy Shriver of the Joseph P. Kennedy, Jr. Foundation provided a description of some of these tests in her comments to Associate Commissioner Susan Daniels dated March 14, 1997. We have not been able to learn whether SSA regularly provides DDS examiners with guidance on the type of up-to-date tests to request and purchase to best assess functional limitations for different age groups.

RECOMMENDATION

**SSA should amend the regulations to indicate that state agencies will purchase tests to assess function, where relevant. SSA should regularly provide guidance to DDS examiners regarding which tests are currently available and considered reliable to assess function for different age groups.**

7. Need to Evaluate "All Relevant Evidence", Not Just All "Medical" Evidence

Section 416.926 defines medical equivalence for children. It is flawed in that it indicates that SSA will "compare the symptoms, signs and laboratory findings about your impairment(s), as shown in the medical evidence we have about your claim,..." While "medical evidence" is later defined to include "all relevant evidence in your case file", the controlling sentence still indicates that only "symptoms, signs and laboratory findings" will be examined. These references should be changed to clarify that all relevant evidence will be considered at every stage of the evaluation process. Since some of the medical listings include functional criteria, it is most important that all evidence, including functional evidence, be considered throughout the entire sequential process.

RECOMMENDATION

**SSA should clarify Section 416.926 to refer to all relevant evidence rather than just "symptoms, signs and laboratory findings" and all relevant medical evidence.**

III. IMPLEMENTATION ISSUES

There are several issues regarding implementation of the new regulations which we believe SSA must address. Brief descriptions of these issues are as follows:

8. SSA published these rules as interim final regulations, effectively immediately. However, the agency requested public comments and presumably might make some changes before publishing final regulations. **If changes are made, fairness demands that SSA set aside or "flag" the potentially affected cases and hold any denial decisions.** Children should not be denied on the basis of regulations with a short life-span which SSA intends to amend. Otherwise, the process will be viewed as arbitrary and capricious.

9. Case reviews of the children whose eligibility needs to be redetermined are just beginning now. Without relevant school records, the vast majority of the redeterminations will have incomplete evidence. **SSA should instruct the state disability agencies to postpone completion of cases during the summer if school records are not available.**

10. **The Evaluation Form (SSA-538) used in assessing children under these regulations should be made public and available to families and advocates through all field offices and through publication in the *Federal Register* and on SSA's internet home page.**

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The undersigned organizations urge the Social Security Administration to publish new regulations incorporating the changes suggested above.

Thank you for the opportunity to submit comments on these regulations. If you have any questions on the above, please contact Marty Ford (The Arc, 202/785-3388) or Rhoda Schulzinger (Bazelon Center for Mental Health Law, 202/467-5730).

Sincerely,

Marty Ford
The Arc of the United States

Rhoda Schulzinger
Bazelon Center for Mental Health Law

Tony Young
United Cerebral Palsy
Associations, Inc.

Paul Seifert
International Association of Psychosocial
Rehabilitation Services

Co-Chairs, CCD Task Force on Social Security

ON BEHALF OF:
American Academy of Child & Adolescent Psychiatry
American Association of University Affiliated Programs
American Association on Mental Retardation
American Network of Community Options and Resources
American Psychological Association
American Rehabilitation Association
Association of Maternal and Child Health Programs
Autism Society of America
Bazelon Center for Mental Health Law
Brain Injury Association
Council for Exceptional Children
Division for Early Childhood of the Council for Exceptional Children
Epilepsy Foundation of America
International Association of Psychosocial Rehabilitation Services
Joseph P. Kennedy, Jr. Foundation
Learning Disability Association of America
National Alliance for the Mentally Ill
National Association of Developmental Disabilities Councils
National Association of Protection and Advocacy Systems
National Association of School Psychologists
National Council for Community Behavioral Healthcare
National Easter Seal Society
National Mental Health Association
National Parent Network on Disabilities
Paralyzed Veterans of American
Spina Bifida Association of America
The Arc of the United States
United Cerebral Palsy Associations, Inc.

no longer be protected by
mmunity for reporting. Only
th reports will be protected.
ally, we have clarified the defini-
of child abuse or neglect to pro-
additional guidance and assistance
States as they endeavor to protect
children from abuse and neglect.

Let me briefly mention the other programs authorized in the 1995 CAPTA amendments: the new Community-Based Family Resource and Support Grants represent the result of nearly a full year's effort to consolidate the Community Based Prevention Grant, Respite Care Program, and Family Resource Programs; the Family Violence Prevention and Services Act which provides assistance to States primarily for shelters; the Adoption Opportunities Act which supports aggressive efforts to strengthen the capacity of States to find permanent homes for children with special needs; the Abandoned Infants Assistance Act which provides for the needs of children who are abandoned, especially those with AIDS; the Children's Justice Act; the Missing Children's Assistance Act and section 214 of the Victims of Child Abuse Act.

Mr. President, I would like to thank the members for their attention. These are important programs and they will affect many children and families. I urge the adoption of the 1995 CAPTA amendments.

STUDENT AID

Mr. MACK. Mr. President, with regard to title V of H.R. 4, the Work Opportunity Act, I am interested in clarifying an issue regarding the applicability of the term "assistance * * * for which eligibility is based on need" to various student loan programs. As I understand this legislation, eligibility for needs-based public assistance will either be subject to a deeming period or will be forbidden for a period of five years for most non-citizens. At this time, there seems to be an erroneous public perception that all student financial aid programs will be subject to these provisions. This is not the case. In the interests of responsible legislating, I think it is important to clarify that unsubsidized student loans are not needs-based and should therefore not be subject to the requirements of title V.

Mr. SIMPSON. Mr. President, Senator MACK is correct. Although the term "assistance * * * for which eligibility is based on need" in title V of H.R. 4 would apply to most forms of student financial aid, the unsubsidized student loan program is indeed a financial aid program which is not based upon need. Therefore, this particular program would not be subject to the deeming period or 5-year ban established in title V of this bill.

Mr. DOLE. Mr. President, I would like to offer my support of the comments made by Senators MACK and SIMPSON on this issue.

CHILDREN'S SSI

Mr. CONRAD. Mr. President, I have a series of clarifications concerning the children's SSI program that I would like to discuss with the majority leader.

But first, let me express my appreciation to Senator DOLE for his leadership in helping us reach a compromise on this issue. The SSI agreement is not everything I had hoped to achieve when Senator CHAFEE and I introduced the Children's SSI Eligibility Reform Act, but it is clearly an improvement over the House bill.

In addition, I believe the agreement includes a number of extremely important provisions to both address criticisms that have been leveled against the Children's SSI program and protect children with severe disabilities. I am extremely pleased we were able to reach a bipartisan compromise on this issue, and thank Senator DOLE, Senator SANTORUM, Senator DASCHLE, Senator CHAFEE, Senator SIMPSON, Senator JEFFORDS, and others who were so deeply involved.

Mr. President, I would like to clarify for the RECORD the intent surrounding several of the provisions in the amendment. First, the amendment deletes the word "pervasive" from the definition of child disability that was included in the welfare reform bill reported in May by the Finance Committee. This is an important change, and one that I fully support. Would the majority leader clarify his understanding of the intent of this change?

Mr. DOLE. I want to thank the Senator from North Dakota for his leadership and hard work on this issue. Children with disabilities are certainly among those most at risk in our society, and we want to make sure we are doing the right thing by them. He and Senator CHAFEE have worked extremely hard to bring the Senate to this point.

As for the Senator's question, I understand that the Senator from North Dakota was concerned that the term "pervasive" included in the earlier definition implied some degree of impairment in almost all areas of a child's functioning or body systems. That was not the intent of the earlier proposed change to the statute. It is expected that the children's SSI program will serve children with severe disabilities. Sometimes children will have multiple impairments; sometimes they will not.

Mr. CONRAD. I also understand that the amendment is designed to facilitate expert analysis of the SSI program for children by the National Academy of Science, to ensure that program changes, including determination of disability, are based on the best possible science.

Mr. DOLE. Yes. I think we can all agree that the children's SSI needs a tune up. The provision for a study by the National Academy of Sciences of the disability determination procedures used by the Social Security Administration will help accomplish this goal, and help us obtain a realistic picture of how an impairment affects each child's abilities.

No doubt about it, the children's SSI program is extremely important for some children with disabilities. But as the Senator from North Dakota made mention, there have been widespread allegations that some children on SSI are not truly disabled, or money is spent in ways that do not benefit the child. I hope this study—in addition to the changes we have made in the law—will help restore confidence in this program.

Again, it is my expectation that this program will continue to serve children with severe disabilities, and that includes properly evaluating children too young to test, children with multiple impairments, and children with rare or unlisted impairments which nevertheless result in marked and severe functional limitations.

Mr. CONRAD. Is it expected that the Social Security Administration and the Congress will rely heavily on the expert advice of the National Academy of Science when engaging in future regulatory activity and deliberations regarding impairments of children in the SSI program?

Mr. DOLE. Yes. But I also hope we hear from many others as well with good information to offer, including other experts, parents, and advocates.

Mr. CHAFEE. If I might also ask the majority leader a question. The leadership amendment and the Finance Committee proposal are both silent about the purpose of children's SSI. However, unlike the House proposal, both retain the cash benefit nature of the program. This is a concept that Senator CONRAD and I thought was extremely important when we introduced the Childhood SSI Eligibility Reform Act, and I am pleased that the majority leader's proposal retains flexibility within the SSI program by retaining the cash nature of the program. It is important for the SSI program to reflect the impact a disability has on families faced with a variety of circumstances. SSI often provides important assistance to families by replacing a portion of the income that is lost when a parent must care for a disabled child. The flexible nature of SSI is indispensable for many parents who are rendered unable to work because they must stay at home to provide care and supervision to their children with disabilities. Does the majority leader share our assessment?

Mr. DOLE. No doubt about it, for some families with a severely disabled child, SSI can be a lifesaver. It allows them to care for their child at home—who might otherwise be institutionalized at much greater cost to the government—or obtain services they could not otherwise afford. If a small payment can help a disabled child stay with his family, or grow into a productive adult, it is better for the child and better for society. SSI benefits provide the greatest flexibility, and the least amount of bureaucratic redtape.

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different purpose—to help poor
ies with the extra costs of having
child with a disability. It seems the
program has expanded without much
congressional attention. In my view,
we need to revisit the purpose of the
SSI program. The Finance Committee
has not tackled this problem yet, but it
should and I believe it will. But the
Senate decision to retain the cash ben-
efit is clearly an important difference
from the House.

Mr. CONRAD. I would like to join in the comments of both of my colleagues regarding the cash benefit nature of the SSI program. This provision is critically important, and I commend the Majority Leader for including it in the amendment. If I might address one additional question to the majority leader, it is the intent of this Senator and other supporters of this amendment on both sides of the aisle that this amendment is the position of the Senate, and that it will be vigorously defended in conference with the House of Representatives. Will the majority leader insist on this provision during conference with the House?

Mr. DOLE. This is a bipartisan compromise with broad support, and in my view it should be a position to which the Senate should firmly hold in conference.

Mr. CONRAD. Base on these assurances, I am pleased to support the compromise we have developed on children's SSI. This is not everything I had hoped to achieve, but it is critically important that the Senate enter conference with a solid, unified position.

Mr. WARNER. Mr. President, I am pleased to rise as one of the original cosponsors of the Republican leadership welfare reform bill.

We have entered this historic debate because the 30-year War on Poverty remains a war, but the nation is losing. According to recent analysis, aggregate government spending on welfare programs over the last 30 years has surpassed $5.4 trillion, an expenditure that exceeds our national debt.

Despite this spending, America's national poverty rate remains at about the same level as 1965, the year that President Johnson launched the War on Poverty.

Despite the best of intentions, we have a welfare system that "traps" children and families in a cycle of dependency, and that encourages behavior leading to indefinite reliance on welfare. It fosters a lifestyle that is in direct opposition to the motivators that propel others to get up and go to work every day.

The Republican leadership's bill emphasizes work, families and genuine hope for the future while giving the States greater responsibility—and flexibility—for managing welfare.

This measure has been a long time coming, and I do not just mean this summer. Our distinguished colleague from Colorado, Senator HANK BROWN, did an outstanding job in 1993 and 1994 as chairman of the Republican Welfare Reform Task Force. Health Care Reform diverted the Senate, but it did not diminish the value of their work. Much of what we are considering today is built directly on the strong foundation of Senator BROWN's early proposals.

I also think back to the 1986 State of the Union Address of President Ronald Reagan. That year he proposed Welfare Reform. This was another step. The Reagan welfare reform plan, the Family Security Act of 1988, was guided to enactment by the fine hand of the then Finance Committee Chairman, Senator MOYNIHAN of New York, who is now serving with such distinction as the co-manager of this bill.

The Family Security Act of 1988 served as a laboratory for S. 1120. In 1988, we first dealt with the issues of workfare versus welfare, the dilemmas of teen pregnancy and illegitimacy, the high costs of work requirements, and the need for broad federal waiver authority. It is the State and local levels of government which administer the American welfare system, not the Department of Health and Human Services.

I am proud that under the waiver authority established by the Family Security Act, the Commonwealth of Virginia has been in the vanguard of welfare reform initiatives.

While we are struggling to come together in the Senate to pass S. 1120, my State has already enacted and is now implementing what we call the Virginia Independence Program or "VIP" for short.

VIP is the visionary welfare reform program brought to the people of Virginia under the outstanding leadership of Gov. George Allen. It was no easy task to battle a sometimes hostile state legislature, dominated by the other political party, as well as the mountain of redtape required in securing the necessary Federal waivers. He succeeded splendidly, however, in achieving his goals, and now Virginia is in the careful, watchful, early stages of actual reform.

Governor Allen, with his great courtesy, personally journeyed to Washington on September 13 to deliver a thoughtful and, in my judgment, immensely helpful letter on what he believes the Senate should accomplish in welfare reform.

Mr. President, I ask unanimous consent that my letter from Governor Allen be printed in the RECORD at this point for the benefit of all of my colleagues.

There being no objection, the letter was ordered to be printed in the RECORD, as follows:

COMMONWEALTH OF VIRGINIA,
OFFICE OF THE GOVERNOR,
*September 13, 1995.*

Hon. JOHN W. WARNER,
*U.S. Senate,*
*Washington, DC.*

DEAR JOHN, As the United States Senate continues to debate welfare reform this week, I believe that our experiences in the Commonwealth of Virginia can be instructive.

I hope you will consider Virginia's plan to be a model for the nation. The comprehensive Virginia plan is based upon the principles of the work ethnic and personal responsibility. Our experiences support the need for an overall block grant approach, that will give States the flexibility to appropriately design programs that address the individual needs of the citizens of their State, return AFDC to a program of temporary assistance for those in need, and require work for all able-bodied recipients.

I understand that there will be attempts to amend S. 1120 by attaching new chains on the block grants to the States. As a staunch proponent of federalism and self-determination, I oppose such choke chains, *whether they are "conservative" or "liberal" ones*, and respectfully encourage and request that you to do likewise for Virginians.

Experience shows that the States are perfectly capable of taking this responsibility and exercising it wisely for our citizens. Virginia's landmark welfare reform legislation is a prime example. Our plan applies to the entire AFDC caseload, with a work requirement for 48,000 of our 74,000 cases. It incorporates common-sense principles into the welfare system by rewarding responsible behavior and providing compassionate, but temporary, assistance for those in need.

In addition to providing opportunity and support to recipients, the program is expected to save the taxpayers more than $130 million over the first five years. Already, we have had a significant drop in our caseload. Restrictive maintenance-of-effort requirements rob States of the ability to share in these savings and the incentives to achieve them. They should be opposed.

As you know, Virginia received a waiver to begin implementing this landmark welfare reform plan on July 1 of this year. You also should be aware that, before this waiver was granted, we spent the better part of two months fending off efforts by the Clinton Administration to completely rewrite our plan. The administration proposed literally hundreds of changes or conditions in the waiver process. Many of them involved very fundamental things; if agreed to, they would have raised the cost of the program significantly and changed essential provisions.

We had a tough fight in our state legislature—with a final bill clearing the General Assembly only in the last hour of the 1995 legislative session. At issue were questions such as whether we would have a real work requirement and a real time limit; whether there would be a child cap and strong requirements for paternity establishment; and whether we would require minor recipients to stay in school and live at home with a parent or guardian.

This spirited debate was expected, given the fundamental nature of the changes and reforms we were proposing. We did not expect, however—after the legislative process was completed at the state level and we had decided what state law and state policy were going to be—that we would have to turn around and refight all those battles with the federal bureaucracy through the waiver process. A good example was the time limit. We went to the wall with HHS over the issue of whether we in Virginia would be able to define the circumstances that would allow

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September 17, 1996

The Honorable Bill Clinton
President of the United States
The White House
Washington, DC 20500

Dear Mr. President:

Your administration has a key role to play in the implementation of the children's Supplemental Security Income (SSI) provisions that were included in the welfare reform bill enacted last month. While we are all interested in ensuring that only children who are truly disabled receive SSI benefits, we are equally concerned that those children who are, in fact, severely disabled remain eligible for the program. The Social Security Administration (SSA) has the difficult responsibility of striking a balance between these two goals.

The statutory language was intended to give SSA substantial discretion in drawing the eligibility line for this program. Clearly, the new law cannot be read to allow SSA to continue the current level of severity which drew so much criticism. At the same time, the new definition was never intended to "gut" the program and, in fact, affirms the importance of functional assessment as part of an effective evaluation of childhood disability.

The debate over this issue was heated at times, but, ultimately, we reached a compromise on the definition of childhood disability in September, 1995. That definition became part of the overall Congressional compromise on SSI, and was included in the first two versions of welfare reform approved by Congress and then finally in the bill enacted in August. The compromise is notable in two ways. First, it preserves a broad functional approach, beyond the "Listings of Impairments," in measuring childhood disability. Second, it specifically does not establish the listings level of severity, or any equivalent level of severity, as the measure to be used in assessing childhood disability.

The enclosed Senate colloquy between those of us involved in this compromise is important in understanding the meaning of the new definition. This colloquy was not entered into lightly. Rather, it was the subject of much negotiation and was key to the final language of the definition regarding "physical and mental impairment, which results in marked and severe functional limitations" after dropping the requirement that the effect of the impairment also be "pervasive".

It is certainly appropriate for SSA, as the regulatory agency, to adopt a disability test that is stricter than the old Individualized Functional Assessment (IFA), but which is not at the very strict level of the "Listings." The proposal put forward by several disability advocates and organizations with considerable expertise – a one marked/one moderate level – is an acceptable and reasonable approach that fulfills the statutory demand for a test that allows benefits only for marked and severe functional limitations, but does not require that these limitations be pervasive.

The Congressional Budget Office (CBO) has also acknowledged that SSA would have a great deal of flexibility in meeting the requirements of the new law. The enclosed Senate Finance Committee report shows that CBO estimated that the new definition of childhood disability could bar anywhere from 10-28 percent of children from the program, depending upon the regulatory interpretation of the new definition.

I know that you will do everything in your power to ensure that children with severe disabilities who are truly deserving are not harmed by the changes in the new welfare law. Thank you in advance for your attention to this matter. Please do not hesitate to contact me if I may be of any further assistance.

Sincerely,

John H. Chafee

John H. Chafee

JHC:bd

cc: Secretary Shalala
Commissioner Chater

# United States Senate

WASHINGTON, DC 20510-2403

September 4, 1996

President Bill Clinton
The White House
1600 Pennsylvania Ave NW
Washington, DC 20500-0005

Dear Mr. President:

I am writing regarding the Supplemental Security Income (SSI) provisions of the new welfare law. As you know, there are approximately 1 million children on SSI. For this reason, it is imperative that the Social Security Administration (SSA) implement the new law with great care and in a manner which ensures that disabled children are not harmed.

The SSA has significant latitude in interpreting the new law which for the first time in the history of the 25 year old program requires the implementation of a broad functional limitations test to evaluate children, retaining the central tenants of the earlier Functional Assessment test. Over 275,000 of the 1 million children on SSI will soon be subjected to new reviews under this law. The Congressional Budget Office has told Congress that with the discretion afforded the SSA under the new law, policies could either cut close to 30 percent of the total 1 million, or cut well below 10 percent -- depending on the SSA's interpretation of the law.

The Senate debate and the legislative history of the final SSI reforms make it clear Congress did not call for or intend for a radical overhaul of the program. In fact, in a colloquy with Senator Chafee and me on September 14, 1995, Senator Dole referred to the SSI program as simply in need of a "tune up."

The intent of Congress in mandating reforms was to remove from the SSI program children who are not truly disabled. I thus urge you to instruct the SSA to carefully develop policies that do not harm disabled children who rely on SSI, but only impact the much smaller group intended by Congress. Additionally, I encourage you to pay careful consideration to the recommendations of nationally recognized experts of this program, such as the Community Legal Services of Philadelphia, The Arc (formerly Association of Retarded Citizens), and the Judge David L. Bazelon Center for Mental Health Law, in developing a comprehensive functional test at a severity level that impacts the fewest number of disabled children.

On a related matter, Congress did not explicitly make the new law retroactive to claims pending on the date of enactment. Consequently, I urge that you clarify that the new law is prospective. That is, families who properly received benefits under existing rules prior to passage of the new law should not now be asked to repay these benefits as a result of this change.

Also, for families at risk of termination, I request that you instruct the SSA to provide parents with the following: (1) adequate information and appropriate assistance regarding the medical and functional evidence of disability required to receive benefits; and (2) appropriate assistance in finding legal representation to appeal their cases. It is also important that the SSA continue benefits in cases of appeal until the Administrative Law Judge hearing and decision are final – an essential protection given the lives and health of children are at stake and the risk of error is great in mass reviews under a complex, new law.

I appreciate your attention to these matters and look forward to hearing from you.

Sincerely,

KENT CONRAD
United States Senate

KC:wmah

cc: Carol Rasco, Director
Domestic Policy Council
Shirley Chater, Commissioner
Social Security Administration

United States Senate
Office of the Democratic Leader
Washington, DC 20510–7020

October 4, 1996

The President
The White House
Washington, D.C. 20500

Dear Mr. President:

You have an opportunity to implement the recently enacted welfare reform legislation in a manner that treats low-income disabled children fairly. In crafting a new definition of disability for children under the Supplemental Security Income (SSI) program, Congress provided the executive branch with great latitude to interpret the statute. Knowing of your long-standing commitment to these children, I know you will use that latitude wisely.

My staff and I were deeply involved in crafting with Senator Dole, Senator Chafee and Senator Conrad the compromise language that ultimately became the basis for the new law. We made a conscious and sustained effort to ensure that the Social Security Administration was granted considerable discretion to implement regulations that would tighten the program without dropping truly disabled children from the rolls. This understanding is confirmed by the views of the Congressional Budget Office (CBO) at the time; CBO told Congress that the new policies could cut between 10 to 28 percent of the children from the program, depending upon SSA's regulatory interpretation.

A great deal of effort went into forging a bipartisan compromise over reforming this program. In the end, we reaffirmed that a functional assessment of a child's abilities was critical in evaluating childhood disability. The legislative history makes clear that, to accomplish this, SSA should establish a functional assessment beyond the "Listings of Impairments." The new definition of disability, requiring that qualifying impairments be "marked and severe functional limitations," explicitly does not establish the listings level of severity, or any equivalent measure, as the basis for determining childhood disability. For SSA to interpret the statute otherwise would be a tragic mistake with potentially devastating consequences for thousands of this nation's most vulnerable children.

Certainly, the new statute requires SSA to eliminate the old Individualized Functional Assessment. It does not, however, compel SSA to adopt the very strict level of the listings. A better approach, which we envisioned when crafting the compromise language, would require one marked and one moderate disability in order to qualify. This approach is supported by several respected organizations representing children with disabilities with whom we consulted in the process of developing the new definition. Such an approach meets the statutory requirement that the test determine eligibility only for "marked and severe functional limitations" without requiring the listings level of severity.

I trust that you will do everything you can to strike a balance that ensures only those children who are severely disabled receive SSI benefits, without denying those who are truly deserving. Thank you for your consideration of this legislative history in interpreting the new law in the best interest of America's most vulnerable children.

With best wishes, I am

Sincerely,

Tom Daschle
United States Senator

cc: The Honorable Carol Rasco
The Honorable Shirley Chater

LEY-BRAUN
INOIS

COMMITTEES:
BANKING, HOUSING, AI
URBAN AFFAIRS
FINANCE
SPECIAL AGING

# United States Senate

WASHINGTON, DC 20510 1303

September 25, 1996

The Honorable Bill Clinton
President
The White House
1600 Pennsylvania Avenue, NW
Washington, D.C. 20500

Dear Mr. President:

I am writing regarding the Supplemental Security Income (SSI) provisions of the new welfare law. As you know, the Social Security Administration has a key role in the implementation of the children's SSI provisions. While I fully support efforts to ensure that only children wh are truly disabled receive SSI benefits, I hope that there will be adequat safeguards to ensure that those children who are, in fact, severely disabled, will not be unduly harmed by the new rules.

The Congressional Budget Office has told Congress that the new welfar law could result in anywhere from a ten percent to a twenty-eight percent reduction in SSI caseloads. This demonstrates the considerable discretior that the SSA will have in implementing the broad functional limitations test used to evaluate children.

In developing policies to implement the new SSI provisions, I encourage you to carefully consider the recommendations of several nationally recognized experts of this program, including the SSI Coalitior located in Chicago. The proposal put forth by the SSI Coalition is simila to that put forward by several other disability advocates--that is, a "one marked/one moderate" functional disability test. This standard is an acceptable and reasonable approach which fulfills the statutory demand to: a test that allows benefits only for marked and severe functional limitations, but does not require these limitations to be pervasive.

Mr. President, I know that you, too, are keenly interested in implementing the welfare bill in a way that will adequately protect children with severe disabilities. I appreciate your thoughtful consideration of this matter and look forward to hearing from you.

Sincerely,

Carol Moseley-Braun
United States Senator

CMB:arc

cc: Shirley Chater

United States Senate
SPECIAL COMMITTEE ON AGING
WASHINGTON, DC 20510-6400

October 8, 1996

The Honorable Bill Clinton
President of the United States
The White House
Washington, DC 20500

Dear Mr. President:

The recently enacted welfare reform legislation included changes to the eligibility standard for low-income children who receive Supplemental Security Income (SSI). The legislation eliminated the Individual Functional Assessment, an eligibility standard formulated for children as a result of the Supreme Court decision in Sullivan v. Zebley. The Social Security Administration (SSA) is now in the process of carrying out a directive to draft a new definition that will permit a child to receive benefits if he or she has a "medically determinable physical or mental impairment, which results in marked and severe functional limitations."

As Chairman of the Senate Special Committee on Aging, I have worked to ensure that the SSI program is not vulnerable to false claims for disability benefits from disabled adults, immigrants, and children. However, I am concerned that as SSA carries out its mandate to revise the disability criteria, children with severe disabilities may be denied eligibility unfairly.

Congress intended that the new eligibility guidelines should be more strict than the Individual Functional Assessment; however, Congress recognized that the revised standard should continue the use of criteria which take into account functional limitations. In addition, there was no explicit directive that the new standard equal the level of severity generally found in the Listing of Medical Impairments.

Evidence of congressional intent can be found in a colloquy between Senator John Chafee and Senator Bob Dole (Cong. Rec. S13613). My colleagues noted that a definition requiring a "marked, severe, and pervasive impairment" was rejected by the conferees. When this language was proposed, the Congressional Budget Office (CBO) calculated that the number of children who would be affected could be anywhere from 10 to 28 percent of the children currently on the program. Upon further consideration, the term "pervasive" was

all areas of a child's functioning or body systems. With the deletion of the term "pervasive," it is clear that Congress is not demanding a drastic change in the level of severity required to demonstrate eligibility for benefits. In choosing a more lenient definition, it is also clear that the number of children who ultimately lose benefits will be lower than the range cited by CBO.

The SSI program provides critical health services and financial support for families with disabled children. While the program has experienced problems, I believe that SSA has initiated steps to implement safeguards which protect against potential abuses. I know that you will do whatever you can to encourage a standard that will promote confidence in the program and will direct help to those who need it most.

With best wishes, I am

Sincerely,

William S. Cohen
Chairman

cc: Carol Rasco, Director
Domestic Policy Counsel
Shirley Chater, Commissioner
Social Security Administration

# United States Senate

COMMITTEE ON LABOR AND
HUMAN RESOURCES
WASHINGTON, DC 20510-6300

December 9, 1996

The President
The White House
Washington, D.C. 20500

Dear Mr. President:

The recently enacted welfare reform legislation requires, among other things, that the Social Security Administration reformulate the Supplemental Security Income (SSI) standard used for determining whether children with disabilities are eligible. Knowing of my interest in disability policy, I urge you to ensure that the new standard reflect congressional intent, as evidenced by recent correspondence to you from Senators Daschle, Chafee, and Conrad, who were key players in reaching the bipartisan consensus language that was included in the final legislation.

A colloquy between Senators Dole, Chafee, and Conrad reflects key understandings that should guide the decision making process:

-children with disabilities are among those most at risk in our society;

-.the children's SSI program is extremely important and for some families with a severely disabled child SSI can be a lifesaver;

-the SSI program allows parents to care for their child at home or obtain services they could not otherwise afford;

- the SSI program for children needs a tune-up, not an overhaul; and

-we want to make sure that we are doing the right thing by children with disabilities.

Again, I urge you to give serious consideration to the comments made by the key Senators who were involved in the bipartisan agreement and adopt a policy that does the right thing for children with disabilities and their families.

Sincerely,

Tom Harkin
United States Senator

COMMITTEES:
ENERGY AND NATURAL RESOURCES
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SMALL BUSINESS
INDIAN AFFAIRS
VETERANS' AFFAIRS

# United States Senate

WASHINGTON, DC 20510-2303

November 12, 1996

Ms. Donna E. Shalala
Secretary
Department of Health and Human Services
200 Independence Avenue, S.W.
Washington, D.C. 20201

Dear Secretary Shalala:

I am writing to express my concern for children with disabilities and their families who may be hurt when the new eligibility standards for children in the Supplemental Security Income Program (SSI) are issued by the Department of Health and Human Services. One of the reasons I voted against the Welfare Reform bill was the change in the SSI program for children. I believed that too many children could unnecessarily be hurt by the elimination of the Individual Functional Assessment (IFA).

Parents, advocates, social workers, and teachers have all contacted my office, worried that 3,200 children in Minnesota could lose their SSI benefits. These families need SSI to cover the additional costs of raising a child with a disability. There are no other programs that pay for adaptive clothing, special diets, increased laundering, travel to specialists, certain equipment, specially trained baby sitters, etc. Families already experiencing stress from day to day care may crumble under the weight of the full financial burden. In Minnesota, children who lose their SSI may also lose their Medicaid and thus their families would no longer receive in-home family supports and other medical care.

The loss of the IFA, the category for maladaptive behavior, and the new requirement that a child's condition to be "marked and severe" could mean that some children with the following conditions could lose their SSI benefits: autism, cerebral palsy, mental retardation, attention deficit disorder/attention deficit hyperactivity disorder, emotional behavioral disorders, arthritis, pulmonary tuberculosis, burns, schizophrenia, and a combination of mild disabilities. Many of these conditions, singly and combined, have a great impact on children's lives. Children with autism may be able to dress and feed themselves, but must be watched every moment they are awake so as not to cause harm to themselves. Children with mild mental retardation may be able to keep up with their peers, but if epilepsy and cerebral palsy are also present they would require a great deal more care.

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In addition, I would hope that in issuing its new eligibility standards, the Department of Health and Human Services would recognize that the medical and education communities are currently reluctant to place labels on young children. However, under strict new eligibility standards, it would not be surprising to see children with functional limitations being given severe labels and psychiatric diagnoses in order allow them to obtain needed services.

I urge the Department to set its eligibility standards in such a way that would allow children who are truly dependent on SSI to continue to receive benefits. It is ironic that the IFA was targeted in the Welfare Reform bill since functional assessments are much more reliable than medical listings, and there are great functional variations among people who carry the same medical listing. Additionally, diagnostic processes used to determine a medical listing use functional assessments.

My greatest concern is that we not reduce our commitment to keep children, particularly children with disabilities, in their family homes. In the 1970's, Congress made an assumption that the best place for a child to be raised is with his or her family. A number of commitments were made to provide financial assistance to families and an education to children with disabilities so that they could be raised at home. This has worked incredibly well. In 1965, 91,000 children lived in state institutions but now only 3,000 children remain in them. In 1977, 90,000 children lived in residential facilities, but now only 40,000 live in these facilities. In short, the number of children receiving SSI benefits have increased, but the number of children in out-of-home placements has decreased.

Again, I hope that you will take great care in establishing these standards. I firmly believe that we must not reduce our commitment to children. Thanks for your attention to the issues I have raised. I look forward to hearing from you.

Sincerely,

Paul Wellstone

Paul David Wellstone
United States Senator

PDW:sa