NLWJC - Kagan
DPC - Box 057 - Folder-002

Social Security - Children's Disability Standard [3]

COMMUNITY LEGAL SERVICES, INC.

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

Social Security —
Children's Disability
Standard

June 4, 1997

Dear Elena,

Enclosed is further background information I do hope you can read on SSI children's disability policy. It is crucial that the White House is better informed about this often misunderstood program now affecting 1 million children.

Thus enclosed is:

1. A full description of the alternative proposal of "one marked and one moderate" that better reflects the law and intent of Congress here. (See Nov. 1996 memo of the SSI Coalition in Chicago.)

2. Our comments on the interim final rules.

3. Comments of the Consortium of Citizens with Disabilities, representing several dozen national disability and medical groups.

4. Copies of the recent letter of 10 U.S. Senators, and two of the Fall 1996 letters to the President, from Sens. Chafee and Daschle, making clear that Listings-level severity was never to be the new test, and urging "one marked and one moderate" as a middle course that fulfills congressional intent.

Please feel free to call for any clarifications which I understand it is appropriate for the Administration to do in the post-comment period on rules.

Sincerely,

JONATHAN M. STEIN
General Counsel

Encls.

Please feel free to share with others.

THE SSI COALITION
FOR A RESPONSIBLE SAFETY NET

SUPPLEMENTAL SECURITY INCOME FOR LOW INCOME ELDERLY AND PEOPLE WITH DISABILITIES

205 West Monroe Street ◆ Chicago, IL 60606-5013
Telephone 312.223.9600 ◆ FAX 312.263.3846

November 20, 1996

pre-regulation issuance

ISSUES CONCERNING THE NEW CHILDREN'S SSI DISABILITY STANDARD

["One marked - one moderate"]

HOW DOES THE SSI COALITION PROPOSAL DIFFER FROM THE INDIVIDUALIZED FUNCTIONAL ASSESSMENT TEST?

The SSI Coalition proposal differs from the discarded IFA test in the following ways:

- The SSI Coalition proposal sets a disability threshold that is higher than that contained in the IFA. Under the IFA, a child with only three moderate functional limitations could generally lead to a finding of disability. Conversely, the SSI Coalition Proposal raises the threshold by requiring a higher threshold for a moderate limitation ("good solid moderate") and by eliminating the provision that a child with three moderate limitations is generally found disabled.

45,000 cut in present =
250,000 denied or terminated over 6 years

- The SSI Coalition proposal makes clear that double-counting of functional limitations is not permitted.
- Evidentiary development will be emphasized in many areas, to ensure that decisionmakers document in a reliable manner the underlying medical diagnoses, to provide longitudinal evidence of the history of level of functioning, including ensuring that results of standardized testing are consistent with evidence of functional limitations.
- The SSI Coalition proposal does not permit consideration of maladaptive behavior in assessing personal/behavioral functioning, either at the third step (the Listings) or the new fourth step (the "marked and severe functional limitations" test).

HOW DOES THE SSI COALITION PROPOSAL ADDRESS THE CONCERNS OF CONGRESS?

As set forth below, Congress raised four concerns with the old childhood disability standard.

- ◆ The old IFA test was deficient because it allowed nearly all children with three moderate impairments to be found disabled (leading to disability findings for children who were not truly disabled).
    - ● The IFA test was too liberal because it generally, although not invariably, allowed children with moderate functional limitations in three areas to be found disabled. Conversely, the SSI Coalition proposal makes clear that children may be found disabled only if they have three good, solid moderate functional limitations.
- ◆ There was concern that some functional limitations caused by medical impairments were double-counted in assessing loss of functioning in various areas.
    - ● The SSI Coalition proposal makes clear that decisionmakers cannot double-count the impact of functional limitations in determining disability.
- ◆ There were inadequate safeguards to ensure that adequate and reliable evidence was developed to ensure that children truly had certain impairments (i.e., the children were not malingering, cheating, being coached).
    - ● The SSI Coalition proposal makes clear that evidence must be reliable and accurately reflect a child's actual level of functioning before it is relied upon in making a finding of disability.
- ◆ It was inappropriate to consider evidence of maladaptive behavior in assessing a child's functional limitations in the area of personal/behavioral functioning.
    - ● The SSI Coalition proposal does not permit consideration of maladaptive behavior in assessing personal/behavioral functioning at the "marked and severe functional limitations" step.

WHY ARE OTHER PROPOSALS THAT RELY ON THE LISTINGS INSUFFICIENT?

An approach based on satisfying the listings (either through meeting their criteria, or showing impairments that are medically or functionally equivalent) is not acceptable for the following reasons.

- ◆ The listings and their functional equivalents were consciously written at a highly restrictive level. This is shown by examples of conditions that SSA considers functionally equivalent to the Listings (examples set forth at 20 C.F.R. § 416.926a(d)):

- documented need for organ transplant;
- frequent need for a life-sustaining device (e.g. central venous alimentation catheter), at home or elsewhere;
- any physical impairment, or combination of physical and mental impairments causing complete inability to function independently outside the area of one's home within age-appropriate norms;
- requirement of for 24-hour-a-day supervision for medical or behavioral reasons; and
- gastrostomy in a child who has not attained age 3.

- The Listings, including functional equivalence, fail to set forth, or provide sufficient guidance on assessing:
  - children who suffer from a physical impairment, or a combination of physical and mental impairments that cause loss of functioning in:
    - cognition;
    - communication;
    - personal/behavioral functioning;
    - gross and fine motor functioning;
    - physical stamina; or
    - concentration, persistence, or pace; and
  - children who suffer from a combination of mental impairments only that cause limitations in all relevant areas of functioning, including those set forth above.
- The Listings do not include many childhood disorders. SSA has repeatedly acknowledged that the childhood Listings of impairments, like the adult Listings, are flawed as a sole test of disability because of their incompleteness. They only "evaluate the more common impairments." 42 Fed. Reg. at 147006 (1977). There are over 5,000 known rare diseases, and the disproportionate presence of rare disorders among children demonstrates how a Listings-only or Listings-equivalent evaluation can never fairly evaluate childhood impairments.
- The Listings focus on extreme pathology and gross failures of treatment. The Listings measure severity by using proxy measurements--how often a child has been

hospitalized, whether she or he uses crutches or braces, or whether she or he has become malnourished or experienced severe growth impairment. However, there are children who "avoid recurrent hospitalizations" or other extreme measures of treatment because their parents put extraordinary amounts of time into monitoring their health and avoiding the need for hospitalization.

- The Listings, conversely, exclude coverage of impairments such as asthma and seizure disorders whenever the child cannot show that she or he has a regular treating doctor, or that a treatment regimen has been tried for at least three months. Thus, children, who for whatever reason including the lack of available health care, can be denied at the Listings step because they do not have a regular doctor, or because they have not been in a treatment regimen for at least three months.

- SSA will have great difficulty in getting its decisionmakers to apply the equivalence standards in a uniform manner to the variety of impairments, either alone or in combination, that could cause marked and severe impairments. Although the present equivalence tests have been used since 1991, the statistics show that few decisionmakers rely on them to make disability determinations. The functional equivalence test, which is the only way in which functioning is considered at the Listings step, was utilized in only 7.2% of all allowances.

COMMUNITY
LEGAL
SERVICES, INC.

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

April 2, 1997

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

Re: Protecting Disabled Children from Improper Loss of Benefits--Comments on Interim Final Rules for Determining SSI Childhood Disability, 62 Fed. Reg. 6408 (Feb. 11 , 1997)

Dear Mr. Callahan:

This unfortunate rule making will have the harshest of consequences for children with disabilities, especially children diagnosed with mental retardation, who number close to 40% of children to be reviewed and at risk of termination under these rules. We strongly believe that the Congress and President never intended this harm to children to emanate from the recently enacted Personal Responsibility and Work Opportunity Reconciliation Act of 1996. These comments then are offered with the purpose of returning these policies to what was legislated and the realities of the current program.

The consequences for children, whom everyone would conclude have serious disabilities, are so dire in terms of jeopardizing their life, health and safety that we call upon SSA not only to heed the call for multiple changes in the regulations but also to recognize the serious failings in the regulatory process itself.

It is undisputed here that the agency merely eliminated one test in a blunt strike without formulating a reasoned new test. Simply dusting off a prior "functional equals" test in existence since 1991 and presenting it as a "clarified" new test, is an abdication of Executive Branch responsibility to faithfully execute the law. The agency should announce now that it will be going back to the drawing board to craft new rules while these rules are continued as a temporary, truly interim stop-gap during which time children are not terminated from SSI. This essential question of a fair and reasoned regulatory process is one included in our first section on how these rules fail to comply with the law Congress passed and the President signed.

A. The SSI Child Disability Rules Contravene the Provisions of the Welfare Legislation

Section 211 of the welfare legislation established a new test of allowing eligibility for children showing "marked and severe functional limitations" at the same time as it eliminated the prior individualized functional assessment ("IFA") test. See Sec. 211(a)(4) and 211(b)(2), amending 42 U.S.C. Sec. 1382c(a)(3). The congressional enactment was something of a mixed message because as it rejected, for reasons unexplained in the legislative history, the old test, it explicitly continued a broad functional test. Indeed, for the first time in the history of the SSI childhood disability program, Congress specifically mandated that a functional analysis be utilized to evaluate childhood disabilities.

The law also left in place key regulations that were intrinsically part of the former IFA test, namely "functioning in children", 20 C.F.R. § 416.924b (utilizing concepts of age-appropriate activities, developmental milestones, domains or areas of functioning, e.g. cognition, and communication, activities of daily living), and "other factors" used in the IFA, 20 C.F.R. § 416.924c (embracing many real-life factors, like effects of structured settings and school absences, impacting on functioning). That Congress wanted to insure accurate and fair assessments of childhood disabilities is best reflected in the Senate colloquy of former Majority Leader Bob Dole, who helped craft the final enacted language, that Congress wanted the program to "obtain a realistic picture of how an impairment affects each child's abilities." Cong. Rec. S 13613 (Sept. 14, 1995) (3d col.). In the same statement, Senator Dole described the new law as providing for a "tune-up" of the program, id., a description far short of the radical overhaul of the program reflected in SSA's rules.

The agency has simply opted, without any consultation or input from the medical or disability communities outside SSA, to end the fourth step, the IFA test; not to replace it with a refined or reformulated "functional limitations" fourth step, as one might anticipate from the legislation; and then to retain the first three steps of the existing childhood sequential evaluation process, making relatively inconsequential changes in the functional equivalence provision of the third "meets or equals" step. Thus with one swing of a regulatory blade, SSA apparently assumes that it has fulfilled its Executive Branch responsibilities of faithfully executing this statute.

In this abdication of administrative responsibility to utilize its expertise and experience of 25 years in administering this program, and failure to solicit public input before issuing an "interim final" rule, the agency's regulation not only will deprive disabled children of "realistic" assessments of their disabilities, but will also prove to be far more stringent that the "marked and severe" standard Congress contemplated.

As will be shown below, the great majority of IFA children will lose SSI under these rules. If Congress had intended this result it would have rather easily and clearly legislated this result, as it did ending SSI eligibility for most immigrants, and had earlier enacted, ending SSI for substance abusers. In lieu of a massive termination option, Congress in line with Senator Dole's "fine-tuning" admonition, established an individualized review process for all IFA children. That process will, contrary to congressional intent, now result in the massive loss of benefits for IFA children.

1. The Functional Equals the Listing Test Is Basically The Same Test Applied By SSA Prior to the New Welfare Law

To give some colorable appearance of implementing the new statutorily mandated "functional limitations" test, SSA has placed sole reliance on a policy of an impairment being "functionally equal" to the Listings of Impairments. But review of the new sequential evaluation regulation, 20 C.F.R. § 416.924 et seq., shows that SSA has not significantly redefined the concept of functional equivalence. As the table attached as Exhibit A illustrates, SSA has not, with two small exceptions, made any changes in functional equivalence![1]

---

[1] Thus, the "new" functional equivalence, as set forth in 20 C.F.R. § 416.926a, is different from SSA's prior functional equivalence, as set forth in 20 C.F.R. § 416.926a and the POMS, in the following ways:

- in assessing whether a child is disabled under the "broad areas of development or functioning" test, SSA will explicitly consider limitations in gross and fine motor skills in determining functional equivalence (motor skills were not explicitly considered under the old "broad functional limitations" equivalence test); and

- maladaptive behavior is not considered in the personal development or functioning area for children ages 3 to 18.

Indeed, the Administration states in its training materials that:

> Step 3 also <u>remains the same</u> – We consider whether the impairment(s) meets, or medically or functionally equals, a listing.... The <u>policy of functional equivalence has not changed</u>, but we have clarified it because of its new importance.

SSA Office of Disability, Childhood Disability Training Student Manual, Pub. No. 64-075 (March 1997) at TAB A--Outline, p. 5. (emphasis added)[2]

In addition, the clarification of functional equivalence, set forth at 20 C.F.R. § 416.926a(b), which identifies four categories of functional equivalence, is essentially identical to the three categories of functional equivalence previously used by SSA and set forth in its Program Operations Manual Systems ("POMS"). <u>See</u> Table B for comparison of old and new functional equivalence categories.

Thus, it is fair to state that SSA's "new" childhood disability standard is essentially the "old" first three steps of the childhood disability sequential evaluation applied prior to August 22, 1996 (the date of enactment of Pub.L. No. 104-193).

2. The New Standard Is Much More Restrictive Than That Test Contemplated By Congress When It Passed The Welfare Act

In enacting the "marked and severe functional limitations" test, Congress gave SSA great latitude to determine the specific disability standard to be applied to children seeking SSI. Indeed, the Congressional Budget Office estimated that, because of the broad room for regulatory interpretation, some number of children less than 10 percent to a maximum 28 percent of the total number of child SSI beneficiaries could be cut off the rolls.

---

[2] <u>See</u> <u>also</u> 62 Fed. Reg. at 6413 (Feb. 11, 1997) ("... we are retaining our prior policies on determining functional equivalence.")

The legislative history of the Conference Report on the welfare act is vague, and at bottom, non-determinative of the key issue of the severity threshold of the new test. While it provided that, "[i]n those *areas of the Listings* that involve domains of functioning, the conferees expect no less than two marked limitations as the standard for qualification," it nowhere states that "two marked" is also the standard outside the Listings, nor that the Listings or equivalence to the Listings must be used as the sole childhood disability standard. Indeed, the Conference Report sanctions use of other determination standards beyond the Listings: the conferees state that they "expect SSA to continue to use criteria in its Listings of Impairments *and in the application of other determination procedures*, such as functional equivalence, to ensure that young children … are properly considered for eligibility of benefits." (emphasis added). H.R. Conf. Rep. No. 725, 104th Cong., 2d Sess. 328 (July 30, 1996). (SSA has chosen to ignore this language emphasized above in its selective recitation of the legislative history, see 62 Fed. Reg. at 6409.)

Prior versions of the welfare legislation's SSI childhood disability provisions that Congress considered and rejected, offer further relevant history for interpreting the new standard. (SSA appears to be oblivious to this critical history.) The House of Representatives version would have defined the childhood disability standard as a medical impairment(s) that met or equalled the Listing of Impairments set forth at 20 C.F.R. pt. 404, subpt. P, app.1--the present third step of the childhood standard and the standard adopted in these interim final regulations. Compare H.R. 4, § 602(A)(1)(ii)(II), 104th Cong., 2d Sess. (1996) with 62 Fed. Reg. at 6410 (Feb. 6, 1997) (3d col.)(the standard in the newly enacted law "is a level of severity that meets or medically or functionally equals the requirements of a listing").

The Senate rejected the House's use of "meets or equals" the Listings as the sole SSI childhood disability standard, and this rejection prevailed for final enactment. Initially, the Senate version defined childhood disability as a "medically determinable physical or mental impairment ... that results in marked, pervasive, and severe functional limitations .... " H.R. 4, § 311(a)(4). In addition, the Senate version deleted the reference to maladaptive behavior in the "B" criteria of the children's mental impairment listings and discontinued use of the individualized functional assessment (IFA). Id. However, the Senate later, upon final passage of the welfare act and to avoid too stringent a test, deleted the word "pervasive" from the new statutory standard. 141 Cong. Rec. S 13613 (Sept. 14, 1995)(2d col.). In a key Senate floor colloquy, former Senate Majority Leader Bob Dole stated:

> [T]he 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.

Id. Senator Dole's statement rejects a Listings-level severity standard because Senator Dole was describing impairments of Listings-level severity, as these generally are so severe as to have "pervasive" impacts rendering the child almost or totally dysfunctional.[3] Senator Dole's statement also rejects Listings-equivalency levels of severity because, similarly, the functional equivalency regulations tied to the Listings also embody "pervasive" impacts of extreme disability such as a child needing an organ transplant, ventilator dependence, or a child requiring 24 hour medical supervision. 20 C.F.R. § 416.926a(d). SSA's interim final rules embody the same "pervasive" type impairments as examples of functional equivalency. 20 C.F.R. § 416.926a(d), 62 Fed. Reg. at 6428 (Feb. 11, 1997).

In the end, the House stepped away from its "meets or equals" Listings test, and accepted the Senate's less stringent childhood disability standard. This reflected Congress' intention, in the words of Senator Dole, to "tune up" (but not drastically change) the children's SSI program.

Most importantly then, the prevailing Senate version rejected sole reliance on the third, "meets or equals," step of the sequential evaluation--the standard that SSA adopted in these interim final regulations. This reading of the legislative history

---

[3] See, e.g., Hypoglycemia Listing § 109.12 (child in convulsions or a coma); Hypertensive cardiovascular disease Listing, § 104.03 (requiring impaired renal function, cerebrovascular damage or congestive heart failure); Neurological Motor dysfunction Listing, § 111.06 (persistent disorganization or deficit of motor function involving two extremities which interferes with major daily activities and results in disruption of fine and gross movements or gait and station); Juvenile diabetes Listing, § 109.08 (despite prescribed therapy child has recent, recurrent hospitalizations with acidosis or recent, recurrent episodes of hypoglycemia).

was further confirmed in letters to the White House from the bipartisan Senate floor leaders of the finally enacted provision.[4] SSA, in an extraordinarily deficient recitation of the legislative history, chose to totally ignore both House and Senate's ultimate rejection of the "meets or equals" version of the legislation, the Senate floor colloquy, the dropping of the "pervasive" language in the Senate, and the letters of these Senators who fashioned the final language. Without this honest addressing of the complete legislative history, SSA's total reliance upon ambiguous conference report language then is highly suspect and misplaced.

3. Estimates of Numbers of Children Who Will Lose SSI Eligibility Are Not Realistic And, Thus Do Not Justify SSA's Statement That The Standard In The Interim Final Regulations Is Less Restrictive Than The Listings Of Impairments.

SSA, in its rationalizing assessment of the impact of these interim final regulations, published concurrently with

---

[4] In one such letter, Sen. John H. Chafee (R-R.I.) stated that the congressional compromise on children's SSI "is notable in two ways. First, it preserved a broad functional approach *beyond* the 'Listings of Impairments,' in measuring childhood disability. Second, it specifically <u>does not</u> establish the listings level of severity, or any other equivalent level of severity, as the measure to be used in assessing childhood disability." Letter of Sen. John H. Chafee to President Clinton (Sept. 17, 1996).

Likewise, Sen. William Cohen (R-Me.) stated that, even though "Congress intended that the new eligibility guidelines should be more strict than the [IFA] … there was, [however], no explicit directive that the new standard equal the level of severity generally found in the Listings of Medical Impairments." Letter of Sen. William Cohen to President Clinton (Oct. 8, 1996).

Similarly, Senate Minority Leader Tom Daschle (D-S.D.) noted that, while "the new statute requires SSA to eliminate the old [IFA] ... it does not compel SSA to adopt the very strict level of the listings." Letter of Sen. Tom Daschle to President Clinton (Oct. 4, 1996).

Finally, Senator Kent Conrad (D-N.D.) stated that "[t]he Senate debate and the legislative history of the final SSI reforms make it clear that Congress did not call 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.'" Letter of Sen. Kent Conrad to President Clinton (Sept. 4, 1996). These contemporaneous descriptions of the legislation are probative of Congressional intent.

issuance of the rules, falsely creates a fiction for White House and public consumption that pretends to chart a middle course. The "middle" turns out to be the number of children to be axed by these rules:

> We expect benefit eligibility for a total of 135,000 of those children receiving benefits at date of enactment will be terminated as a result of these changes in the law. (emphasis added)

See 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, p. 6 (Feb. 1997)(issued pursuant to Executive Order 12866). About 266,000 children will be reviewed under these new rules, and almost exactly half are projected to be terminated.

In large part, SSA relies on this estimate that "only" 50% of children will be terminated from SSI as justification for the "new" disability standard, a grisly variant of the Solomonic story of splitting the child in half.[5] In so doing, SSA concedes that the welfare act did not require it to rely solely on the listings step to define childhood disability.

SSA provided no explanation of why only 135,000 current child SSI recipients will be terminated from SSI eligibility and has not responded to date with any data supporting this number. However, SSA states that this 135,000 estimate is a middle ground and thus complies with welfare act. In contrast to the 135,000 termination estimate, SSA, in the same Assessment, posited two other "Policy Alternatives" rejected by SSA.

In the first Alternative, SSA estimated that 190,000 SSI child recipients would be terminated under a "literal interpretation" of the legislation. SSA defined a literal interpretation as essentially ending the IFA and continuing the prior "meets or equals" the Listings step without "clarification" of functional equivalence. Id. at p. 7.

---

[5] The story of Solomon and the baby to be split in half should be on the reading list for those White House and SSA policy makers fashioning this "compromise" who believe here that fairness and legality always reside in the middle.

What SSA hides here--but states clearly elsewhere--is that its functional equivalence policy, absent the relatively insignificant addition of consideration of fine and gross motor skills for children age 3 to attainment of age 18, "has not changed." SSA Office of Disability, Childhood Disability Training Student Manual, Pub. No. 64-075 (March 1997) at TAB A--Outline, p. 5. Put another way, the only way that SSA's estimate of 190,000 terminations is correct is that, but for consideration of limitations in gross and fine motor skills for children age 3 to age 18, 65,000 children would be terminated from SSI disability under the upcoming childhood disability review process. There is no rational way for the "motor skills" addition to favorably affect so many children.[6]

In the second Alternative, SSA estimated that 45,000 SSI child recipients would be terminated if it had added an additional step in the sequential evaluation beyond the listings that provided that a child would be considered disabled with a "marked" limitation in one area of functioning and a "moderate" limitation in another area of functioning. This was the interpretation urged by the bi-partisan group of Senators who had framed the final version of the SSI child provisions. See fn. 4, supra. (This interpretation would still have dropped the more liberal part of the IFA test by ending eligibility based on "three moderate" impairments.)

SSA contends that use of a one "marked" and one "moderate" test "would have retained the IFA, albeit in a narrower version, in violation of § 211(b)(2)" of the welfare act. SSA's argument is specious as it assumes that any disability standard that looks like any part of the old IFA test must be illegal. Under such reasoning, functional equivalence is likewise suspect, as is the new rule's reliance on "areas" of functioning, which uses the same "domains" of functioning used in the IFA test. Compare 20 C.F.R. §§ 416.926a(b)(2) & (c) (interim final regulations) with 20 C.F.R. § 416.924d(c) (1996).

---

[6] At the end of 1994, the total number of IFA allowances for all physical impairments, totaled just 32,900. Report to Congress of the Nat'l Comm'n on Childhood Disability, 1991-1994, App. 7E (Oct. 1995). And "motor skills" at Listings level equivalency is a far more severe test than under the IFA.

Neither estimate contains any explanation as to how the numbers of terminations were calculated. And, the analysis fails to come to grips with the central problem with SSA's estimate that "only" 135,000 SSI child recipients will be terminated from SSI. Because the functional equivalence standard is essentially the same as that applied by SSA prior to enactment of the welfare act, and all the IFA children had already failed to qualify at the step three "meets or equals" step, SSA's estimate that only half of those children whose claims will be reviewed will be terminated is not credible. Thus SSA's representation to the White House and public in the policy Assessment of charting a middle course is disingenuous.

Thus all these IFA children were presumably reviewed previously under virtually the same functional equals test, and all lost at step 3, leading to the step 4, IFA allowance. (SSA has failed to provide any credible evidence that step 3 was "skipped over" for anywhere like 135,000 children.) These rules have set in motion a disaster in the making for the great majority, not just 50% of the 266,000 children now being reviewed.

4. The Closed Process in Developing The Interim Final Rules Taints These Regulations

Unlike the effort after the court's Zebley decision at formulating childhood disability rules, the agency failed in the six months from August 1996 to February 1997 to establish any kind of consultation process with national experts from the mental retardation, mental health, and pediatric professional communities, nor from the nationally recognized child disability consumer organizations. Given the impact that these rules will have on one million currently disabled children on SSI, this lapse is shocking and unprecedented.

In 1990 the agency convened a work group of national pediatric experts to advise it on developing new evaluation rules. Since that time various other experts have also been identified outside SSA who were available for similar consultation. Yet for some unarticulated reason, expert input was not sought for these rules. This lack of input is reflected not only in deficiencies as enumerated in the following comments, but more broadly in the larger concept of these new rules, i.e. rescission of the IFA with no satisfactory replacement except a return to a pre-existing policy that totally failed to properly evaluate these children.

This extraordinary lapse in agency decision-making needs to be remedied by the creation of a group or groups to advise the agency on rules to replace these interim rules, and for this effort to be placed on a fast-track with a set time table. Too much is at stake for the lives and health of children to have such important rules take final effect, as they have already done, without this necessary input.

B. Specific Remediable Problems with the Interim Final Regulations

As a general note, especially for the Commissioner and General Counsel, a number of remedies for deficiencies in the rules involve more explication and elaboration to provide greater clarity and understanding of the rules. We anticipate a response that the Office of Disability has already put forth, that greater detail is or will be provided in the POMS. But, the POMS are either unavailable or deemed irrelevant by Administrative Law Judges, Appeals Council Members and Regional Counsel and U.S. Attorneys who look solely to the regulations for interpretation. Thus, reliance on the POMS as a cure virtually insures a dual system of law at SSA, and differential treatment of the same children by different levels at SSA.

As guardians of due process and equal protection, the Commissioner and General Counsel should not allow references to POMS provisions, current or future, to let the agency avoid its responsibility to have the regulations themselves be adequate to the task at hand--especially here where "functional equivalency" is such an inherently complex and often unfathomable policy upon which to rest the lives and health of so many children.

If we were to prioritize concerns among the following critical comments we would emphasize:

--the need to better define and give necessary, working flexibility to the key term "marked," including the weighing of combined impairments and where two impairments exist in one "area";

--incorporation of the Standard Error of Measurement ("SEM") into the definition for tests such as I.Q. tests to allow children within the SEM of 2 standard deviations to be "marked";

--separate the cognitive/communicative "area";

--provide additional "areas," especially a personal one, for evaluating children aged 1 to 3;

--add "areas" for fairer evaluations of physically disabled children; and

--expand, clarify, and make "other factors" a usable adjudicative tool for evaluation and adjudication.

Detailed comments to the interim final regulations are set forth below under headings for each regulation.

1. Section 416.911--Definition of disabling impairment; and 416.924--How we determine disability for children

For the reasons set forth in section A, we believe that the standard for childhood disability, set forth in the rules is considerably more restrictive than mandated by the welfare law. We urge SSA to adopt a new standard that incorporates the one "marked" one "moderate" impairment concept discussed above, and urged by the bi-partisan group of Senators who crafted the enacted standard.

2. Section 416.919n--Informing the examining physician or psychologist of examination scheduling, report content, and signature requirements.

In subpart (c)(6), the regulations provide that the consulting examining physician's report should:

> describe the opinion of the consultative physician or psychologist about your functional limitations in learning, motor functioning, performing self-care activities, communicating, socializing, and completing tasks (and, if you are a newborn or young infant from birth to age 1, responsiveness to stimuli).

This description of the areas of childhood functioning lacks sufficient detail. For example, the word "socializing" does not adequately explain the social area, as defined at 20 C.F.R. § 416.926a(b)(4)(iii). Instead, this section should cross-reference the areas of functioning set forth in 20 C.F.R. § 416.926a(b)(5), and require reports to analyze a child's functioning by comparison to the areas of functioning set forth by age group. In addition, this section should cross-reference the guidelines on consideration of age in 20 C.F.R. § 416.929a, functioning in children in 20 C.F.R. § 416.926b, other relevant factors in 20 C.F.R. § 416.926c, and consideration of pain and other symptoms in 20 C.F.R. § 416.929.

Often, doctors, including doctors employed by state disability determination services, are not aware of these provisions concerning evaluation of childhood disability claims. Requiring consideration of these factors will help to ensure that childhood disability claims are fully and fairly developed.

In subsection (g), SSA provides that it will require completion of the Form SSA-538, Childhood Disability Evaluation Form for all cases at the initial level and for all cases at the reconsideration level, except for cases in which a disability hearing officer makes the decision. However,

> [d]isability hearing officers, administrative law judges, and the administrative appeals judges on the Appeals Council (when the Appeals Council makes a decision) will not complete the form, but will indicate their findings at each step of the sequential evaluation process in their determinations or decisions.

Because SSA acknowledges that functional equivalence is now the "last point of adjudication in a child's claim [and is] critical to the outcome of many [sic] cases," 62 Fed. Reg. at 6413, SSA should require <u>all</u> decisionmakers, including disability hearing officers, administrative law judges, and administrative appeals judges at the Appeals Council to complete the Form SSA-538. Such a requirement will ensure that all decisionmakers go through the appropriate analytical process in assessing functional equivalence. Use of the form will help to ensure that decisionmakers do not omit parts of the functional equivalence determination, including, but not limited to, consideration of the four different types of functional equivalence.

In addition, completion of this form will provide greater uniformity in decisionmaking, a perennial problem at SSA that would be exacerbated by this differentiated requirement. Indeed, SSA should treat the functional equivalence determination as it does mental impairment determinations in which the Psychiatric Review Technique Forms are completed. 20 C.F.R. § 416.920a requires that SSA decisionmakers complete a standardized document to ensure that mental impairments are properly evaluated. In justifying its requirement that such a standardized document be completed by all decisionmakers, including disability hearing officers, administrative law judges, and administrative appeals officers at the Appeals Council, SSA states that use of the document assists in "[o]rganizing and presenting the findings in a clear, concise, and consistent manner." Id.

The same reasoning applies to functional equivalence determinations, particularly where SSA has pointedly focused on the need to "clarify" the functional equivalence determination to "reflect the increased importance of the functional equivalence policy under the new law." 62 Fed. Reg. at 6413. Unless standardized instruments are used to ensure the "clarified" procedure is applied, there is a significant risk that disability hearing officers, administrative law judges, and administrative appeals officers at the Appeals Council will not properly apply the "clarified" functional equivalence standard.

In addition, while not part of the regulation, Form SSA-538 needs to be redrafted to ensure that all factors relevant to the disability process are considered. For example, the "other factors" are hardly mentioned, and with no means or direction on the form as to how to employ them. And although "marked" is defined as two standard deviations from the norm, the definition fails to take account of the margin of error of standard tests.

3. Section 416.924a--Age as a factor of evaluation in childhood disability.

As is argued later in the discussion concerning functional equivalence, SSA should cross-reference or integrate the rules concerning age as a factor of evaluation in childhood disability in 20 C.F.R. § 416.926a, and into Form SSA-538.

4. Section 416.924b--Functioning in children.

This section defines three important concepts: "developmental milestones" used generally to assess children from birth to attainment of age 3, "activities of daily living" used generally to assess children from age 3 to attainment of age 16, and "work-related activities" used generally to assess children from age 16 to attainment of age 18.

These three concepts need to be integrated, by cross-reference, into 20 C.F.R. § 416.926a, the functional equivalence regulation, and into Form SSA-538.

5. Section 416.924c--Other factors we will consider.

The "other factors" policy was left untouched by the new welfare law which gave tacit approval to its contents. Yet, this section generally fails to provide adjudicative guidance to decisionmakers about <u>how</u> these "other" factors should be used in the disability determination process. In subsection (a), the regulation provides generally that:

> When we evaluate whether your impairment(s) ... causes marked and severe functional limitations, we will consider all the factors that are relevant to the evaluation ... such as the effects of your medications, the setting in which you live, your need for assistive devises, and your functioning in school.

However, § 416.924c fails to provide any guidance on how consideration of these factors is done in the childhood sequential evaluation. This omission is repeated in 20 C.F.R. § 416.926a, the functional equivalence section, and in Form SSA-538.

To avoid "other factors" continuing to be a largely ignored policy in adjudications, SSA should give more specific guidance in the regulation as to <u>how</u> it should be used in the very concrete contexts of the critical "marked" and "moderate" adjudicative terms. Thus SSA should prescribe in accordance with the clear intent of, for example, the structured setting "factor," § 416.924c(d), 62 Fed. Reg. at 6423, that a "moderate" level of functioning in a supportive setting may in fact be a "marked" level outside of the setting. SSA should bring into the rules the more helpful discussion of the "other factors" from the POMS § DI 25214.001.A.2 (Draft, Mar. 5, 1997), but this cannot substitute for guidance on how they affect "marked"/"moderate" and the ultimate finding.

Also the "other factors" policies lack express linkages to the critical "areas of functioning" that determine eligibility in functional equivalence. Each of the "other factors" should cross-reference or cite those areas impacted upon by the "other factors", e.g. school attendance or lack thereof relating to social functioning and cognitive functioning.

The critical need is to explain how, when such factors are present, the adjudicator actually uses them to make a decision. The rules are bereft of this guidance. When one looks at the singular Evaluation Form, SSA-538, for example, "other factors" is never mentioned in the first three of the four "methods" for assessing functional equivalence, and barely mentioned in the fourth ("Broad Functional Limitations"). And the entire form lacks necessary guidance on what you do when they are present, e.g., how a "moderate" can become a "marked" with other factors present.

SSA would do well to incorporate superseded POMS provisions which set forth procedures to follow in assessing whether the "factor" was relevant for the disability determination. See POMS § DI 25214.015.C (CD-ROM, Jan. 1997). Without this direction this will be a forgotten or not understood policy among many decisionmakers at a time when "functional equivalence" must be as all-encompassing as possible.

Finally, SSA should use this opportunity to assess the adequacy of the "other factors" listed, which the medical community has viewed as too limited. As the original SSI Childhood Workgroup unanimously recommended in 1990, the rules need to take into account widely acknowledged risk factors, such as biological ones like anemia and recurrent infections, health care related ones, like less than optimal treatment available, and family and environmental ones like malnutrition, history of abuse and toxic environment. These objectively observable risk factors are considered by the professional communities to be indispensable in the evaluation of pediatric impairments, particularly if one is attempting to make longitudinal judgments.

6. Section 416.926--Medical equivalence for adults and children.

This section defines medical equivalence for children, by combining it with the adult medical equivalence definition. Our concern with this definition concerns the types of evidence that may be used to support a finding of medical equivalence.

As drafted, the regulation provides that medical equivalence findings may be based only on medical evidence. To wit, the sentence "[w]e will compare the symptoms, signs and laboratory findings about your impairment(s), as shown in the medical evidence we have about your claim, with the corresponding medical criteria shown for any listed impairment[.]" is consistent with the sentence that follows, "[w]hen we make a finding regarding medical equivalence, we will consider all relevant evidence in your case record" only if relevant evidence is defined to encompass only "symptoms, signs, and laboratory findings."[7]

SSA should clarify these two sentences to make clear, at least in determining medical equivalence for children, that "all relevant evidence," and not just "symptoms, signs, and laboratory findings" must be considered in making medical equivalence determinations. Thus, we propose that this section be rewritten as follows:

> (A) How medical equivalence is determined. We will decide that your impairment(s) is medically equivalent to a listed impairment in appendix 1 of subpart P of part 404 of this chapter if the medical findings<u>, as evidenced by all relevant evidence in your case record,</u> are at least equal in severity and duration to the listed findings. We will compare the symptoms, signs, and laboratory findings about your impairment(s), as shown in the medical evidence we have about your claim<u>, and by all other relevant evidence concerning your impairment(s) in your case record,</u> with the

---

[7] The draft POMS language provides the same. POMS DI § 25215.0010A.2.b.

> corresponding medical criteria shown for any listed impairment. ~~When we make a finding regarding medical equivalence, we will consider all relevant evidence in your case record.~~...

Finally, SSA should provide some examples of medically equivalent impairments, as it has done for functional equivalence. See 20 C.F.R. § 416.926a(d). Equivalence, now as the last step in the process, is unusually important, and medical equivalence is still a cloudy area for most decisionmakers. Many decisionmakers, and medical and psychological consultants would benefit from examples of medical equivalence.

7. Section 416.926a--Functional Equivalence

There are several problems with the manner in which the Administration has defined functional equivalence, including the following:

a. Failure To Adequately Integrate, By Reference To Other Regulatory Sections, Consideration Of Issues Concerning Age, Functioning In Children, Other Factors, And Symptoms Such As Pain

i. Failure To Incorporate Age As A Factor Of Determining Functional Equivalence

The broad areas of functioning for children birth to attainment of age one and from age one to attainment of age three should cross-reference 20 C.F.R. § 416.926(b) concerning correcting chronological age of premature infants. In addition, the broad areas should contain an explanation and examples of how correction of chronological age might affect evaluations under these broad areas of functioning.

The broad areas of functioning for children from birth to attainment of age 6 should cross-reference 20 C.F.R. § 416.924a(c)(3) concerning age and the impact of severe impairments on younger children. Particularly important for decisionmakers is the guidance provided by 20 C.F.R. § 416.924a(c)(3) concerning a child's development between birth and age 6. In addition, the broad areas should contain an explanation and examples of how deficits in development in one area can delay development or functioning in other areas.

The broad areas of functioning for children from age 12 to 18 should cross-reference 20 C.F.R. § 416.926a(c)(4) concerning the difference in loss of functioning caused by impairments occurring at various age levels, and the effects of degenerative disorders.

This is also a problem in the Form SSA-538.

ii. Failure To Incorporate Terms of Functioning In Functional Equivalence Determination

This section defines three important concepts: "developmental milestones" used generally to assess children from birth to attainment of age 3, "activities of daily living" used generally to assess children from age 3 to attainment of age 16, and "work-related activities" used generally to assess children from age 16 to attainment of age 18. These three concepts need to be integrated, by cross-reference, into 20 C.F.R. § 416.926a, the functional equivalence regulation.

This is also a problem in Form SSA-538.

iii. Failure To Incorporate "Other Factors" In Functional Equivalence Determination

20 C.F.R. § 416.924c provides an important discussion of some "other factors" that may have impact on child's functioning, including, but not limited to, chronic illness, effects of medication, effects of highly structured settings, adaptations, time spent in therapy, and school attendance. These concepts need to be integrated, by cross-reference, into 20 C.F.R. § 416.926a, and concrete advice given as to how they are considered in the functional equivalence determination.

iv. Failure To Incorporate Evaluation Of Pain And Other Symptoms In Functional Equivalence Determination

20 C.F.R. § 416.929 provides an important discussion of how pain and other symptoms may impact on child's functioning. The language regarding pain and other symptoms need to be integrated, by cross-reference, into 20 C.F.R. § 416.926a. Again, the regulations need to make it clear how pain gets factored into the equivalence determination.

This is also a problem in Form SSA-538.

Thus, we propose that a new subparagraph (5) be added to 20 C.F.R. § 416.926a(b) that provides as follows:

> (5) In considering the methods under which you may have an impairment(s) that is functionally equivalent to a listed impairment, we will consider the following factors, which are discussed elsewhere in these regulations:
>
> - corrected chronological age (20 C.F.R. § 416.926a(b));
> - your ability to adapt to an impairment(s) (20 C.F.R. § 416.926a(c)(1));
> - the interactive and interdependent impact of severe impairments on you if you are a younger child (20 C.F.R. § 416.926a(c)(3));
> - the impact of degenerative disorders on you if you are an older child (20 C.F.R. § 416.926a(c)(4));
> - the importance of developmental milestones for you from birth to attainment of age 3 (20 C.F.R. § 416.926b(b)(2));
> - the importance of activities of daily living for you from age 3 to attainment of age 16 (20 C.F.R. § 416.926b(b)(3));

- the importance of work-related activities for you from age 16 to the attainment of age 18 (20 C.F.R. § 416.926b(b)(4));
- the importance of the factors of chronic illness, effects of medication, effects of highly structured settings, adaptations, time spent in therapy, and school attendance (20 C.F.R. § 416.926c); and
- consideration of your pain and other symptoms (20 C.F.R. § 416.929).[8]

b. Failure To Provide Examples Of Various Types Of Functional Equivalence, And Conversely, To Explain Why The Twelve Examples Listed Are Functionally Equivalent.

SSA, when it defines the four functionally equivalent impairment categories at § 416.926a(b)(1)-(4), i.e., limitation of specific functions, broad areas of development or functioning, episodic impairments, and limitations related to treatment or medication effects, should provide examples by type of functionally equivalent impairments. Without such examples, SSA decisionmakers will not properly apply these sections.

Thus, SSA should make the following additions to subsections (b)(1), (3) and (4):

(1) Limitation of specific functions. * * * Limitation(s) of specific function(s) is expressed in several of the listings. For example:

---

[8] Arguably, SSA has done this at 20 C.F.R. § 416.926a(c)(2). However, that paragraph is limited to consideration of broad areas of development or functioning. The factors set forth are applicable in consideration under the other three methods of showing functional equivalence. Second, not enough detail is contained in 20 C.F.R. § 416.926a(c)(2) about these factors and their role in the disability determination. Finally, there is no cross-reference to 20 C.F.R. § 416.929, which concerns evaluation of pain and other symptoms.

- Listing 101.03A (Deficit of musculoskeletal function - "walking is markedly reduced in speed or distance despite orthotic or prosthetic devices";

- Listing 104.05C (Cardiac arrhythmia, with "labored respiration on mild exertion");

- Listing 111.07B (Cerebral palsy with "... motor dysfunction and ... IQ of 70 or less; or ... interference with communication; or ... emotional disorder"); or

- 111.09A (Communication disorder with documented neurological deficit, with "speech deficit which significantly affects the clarity and content of speech").

(3) Episodic impairments. * * * Episodic impairments are described in several listings. For example:

- Listing 103.03B. (Asthma, in spite of prescribed treatment, "and requiring physician intervention, occurring at least once every 2 months or at least six times a year.");

- 107.05A. (Sickle cell disease, with "recent, recurrent, severe, vaso-occlusive crises.");

- Listing 111.02A. (Major motor seizures despite treatment, with "nocturnal episodes manifesting residuals which interfere with activity during the day.");

- Listing 12.03C. (Schizophrenic, Paranoid, and Other Psychotic Disorders, "characterized by ... repeated episodes of deterioration or decompensation."); and

- Listing 14.08N. (Human Immunodeficiency Virus (HIV) with repeated manifestations of HIV infection or other manifestations resulting in significant, documented symptoms or signs.").

Conversely, SSA should explain why the 12 examples, set forth at 20 C.F.R. § 416.926a(d), are functionally equivalent. This is a comment we made to the previous set of regulations. If functional equivalence has been underutilized, as SSA maintains, it should take every possible step to remedy that problem. SSA should include the explanations included in its Childhood Disability Training - Student Manual at Tab B in the regulations to provide guidance to decisionmakers on why the examples are functionally equivalent. All decisionmakers, especially ALJ's, Appeals Council members and Regional Counsel, will not be accessing this student manual into the future.

c. Failure To Adequately Define "Marked" And "Extreme" Functional Limitations.

To avoid the likely consequence of terminating the great majority of the 266,000 children to be reviewed, and to comply with the recent legislation, the question of what constitutes "marked" is probably one of the most important rules to reconsider and revise.

i. Need to Allow for Combining Impairments to Constitute or Equal a "Marked"

Federal statutory law binding on SSA has long required that multiple impairments must be fairly and accurately weighed by the agency: "The Secretary shall consider the combined effect of all of the individual's impairments without regard to whether any such impairment, if considered separately, would be of such severity.... [T]he combined impact of the impairments shall be considered throughout the disability determination process." 42 U.S.C. § 1382c(a)(3)(F).

The new interim rules definition of "marked limitation" does include language that this limitation "may arise when several activities or functions are limited...," yet there is no more guidance for situations when there are multiple impairments and problems, each of which may be well-documented, strong but "moderate" limitations. It is apparent logically and in medical practice for the combination of lesser problems adding up to a "marked" or two "marked" level of functioning, yet the rules skirt this reality.

What is far worse is that in the March 1997 Student Training Manual, the agency has in Tab F, Question 30 asked: "Can 3 "moderates" add up to 1 "marked"? What about a child with "moderate" limitations in cognition and "moderate" limitations in communication unrelated to cognition? Response: "Moderate limitations cannot be "added-up" to equal a "marked" limitation." (emphasis added).

There is no justification either in medical practice or in the recent law enacted for this extreme and harsh position. Certainly the regulations as written don't require this response. More importantly the rules need to make abundantly clear that combining impacts to reach a "marked" limitation is fully in keeping with prior and existing law, 42 U.S.C. § 1382c(a)(3)(F) above, and the new law's broad reach to assess all "functional limitations" that may constitute in totality the level of "marked and severe functional limitations" this new law anticipated.

ii. Establish Needed Flexibility in What Constitutes Two "Marked" Limitations by Recognizing that Two Separate Impairments that Affect the Same "Area" of Function Satisfies the New Statutory Test

SSA has always recognized that a person could be markedly impaired in a particular domain or area even if they were restricted in only a few functional activities encompassed in a broad domain or area. Thus, the interim rules state that a "marked limitation may arise when several activities or functions are limited or even when only one is limited as long as the degree of limitation is such as to interfere seriously with the child's functioning." 20 C.F.R. § 416.926a(c)(3)(i)(C) (emphasis added). This is a sound approach that recognizes that loss of a key function can be devastating to overall ability. However, SSA does not follow this policy to its logical conclusion. Two separate impairments can affect particular functions in the same domain or "area" but they will not be separately weighed because they fall within the same broad "area." Thus if a child has a physical impairment that affects his ability to walk and that inability is correctly categorized as "marked" in the motor "area," then there is no way to also evaluate and give additional adjudicative weight to another separate motor impairment--say, for example, a child who also lost several fingers due to an accident, which might also be properly considered as causing a separate "marked" problem in fine motor skills. Similar problems can, of course, arise in any of the broad areas of function, be they motor, cognition/communication, personal, social or concentration, persistence or pace.

The problem is exacerbated by the interim decision to combine the disparate functions in the cognitive and communicative areas into one large area. For example, a child with an IQ in the marked range might have a speech problem separate and apart from her retardation, yet a marked inability to communicate would not lead to a finding of disability because it was in the same area. Perversely, a "marked" limitation in the personal area would lead to a finding of disability, solely because it was in a different area.

Similar problems arise when the regulations classify virtually _all_ non-motor area physical impairments as personal care limitations or classify physical stamina problems as limitations in concentration, persistence or pace. A child, for example, may have a physical impairment of asthma and a mental impairment of depression, _both_ seriously impacting _but_ counting as only one "marked" in concentration, persistence or pace. This doubling up within "areas" only exacerbates what is already a significant problem.

As we have suggested elsewhere in these comments below, the cognitive and communicative areas must be separated and a separate category established for physical impairments other than motor impairments. However, even if this were done (and especially if it is not done) SSA must make it explicit that impairments leading to different functional limitations in the _same_ broad "functional" area should be separately counted as two marked limitations to lead to a conclusion of disability regardless of how the "areas" are grouped.

In the alternative, two marked limitations in the same functional "area" should be considered an "other factor" under 20 C.F.R. § 416.924c that, when combined with a moderate limitation in another area, will be considered disabling.

iii. The Two Standard Deviations Below Mean Standard for "Marked" Needs to Be Further Defined in the Rules to Provide for Standard Error of Measurements

Our comments adopt the sound recommendations of Mrs. Eunice Kennedy Shriver, Executive Vice-President of the Joseph P. Kennedy, Jr. Foundation who submitted comments to Associate Commissioner Susan Daniels on March 14, 1997 (letter attached as Exhibit "C"). Mrs. Shriver, based on extensive consultation with leading national experts in the field, explained that the use of the Standard Error of Measurement ("SEM") was essential to fairly apply the two standard deviations test. To obtain 95% confidence limits, it is necessary to include two SEM's.

Thus, as Mrs. Shriver wrote with regard to the IQ test, the WISC3, "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." Mrs. Shriver goes on to other objective measurements of childhood functioning where the same principle should be applied, e.g. for motor and communicative scores, "standard scores less than 70 +/- 2 SEM are likewise reflective of marked and severe motor and communicative functional limitations;" similarly where social functioning/behavioral rating scales are used (consisting of T scores with a Mean of 50 and a standard deviation of 10), "scores of greater that 70 +/- two SEM's reflect marked and severe functional social-behavioral limitations...."

It is thus essential to revise the definition of "marked" to explicitly provide that this pivotal term embrace children whose scores are less than 70 <u>plus or minus 2 SEM's</u>.

iv. The Definition of "Marked" Needs to Include a Requirement that Standardized Tests Should in All Cases be Obtained or Purchased by the State Agencies

Mrs. Shriver's letter dated March 14, 1997 to Associate Commissioner Daniels also makes reference to a number of key standardized tests beyond IQ tests for areas of social functioning, personal functioning and other areas. These are all amenable to the two standard deviations +/- two SEM scoring. SSA has never had a set policy on the use of these tests, and they are often not used or purchased through Consultative Examinations. The current laissez-faire practice that leaves it up to state agencies is not conducive to obtaining the best and most objective evaluations of children, and worse, almost guarantee non-uniform and subjective assessments of what functional equivalence is.

The Report of the Committee on Childhood Disability of the National Academy of Social Insurance, Restructuring the SSI Disability Program for Children and Adolescents, (eds. Prof. Jerry L. Mashaw, Dr. James M. Perrin, and Virginia Reno, 1996) urged increased use of standardized tests to assess the functional consequences of mental disorders (at p. 27). This Report, requested by the Chairman of the House Ways and Means Committee, urged these tests to be used to "improve the quality of evidence used to determine a claim," and that many of these tests could be administered by trained lay interviewers or technicians while relying on doctors or psychologists to interpret the results. Id. (See p. 27, n. 31 for tests cited by Academy consulting experts, as well as those cited in Mrs. Shriver's letter of March 14, 1997.) The regulations should make it clear that such tests should be purchased by SSA in most cases amenable to testing.

v. The Definition Section of "Marked" Needs Examples To Promote Understanding and Uniform Application

Unlike the prior adjudicative guidelines section of the regulations, former sec. 416.924e, these rules use no examples to illustrate what "marked" means in the real world of adjudications. The agency should provide in the rules, not only in POMS unavailable to adjudicators outside state agencies, case illustrations of what limitations "interfering seriously with the child's functioning," means in § 416.926a(c)(3)(i)(C). This now is essential as functional equivalence using the two marked level is the last step in the evaluation and must be well understood to avoid mass termination of children.

vi. Clarify the Meaning of "Extreme" Limitations

There is an internal inconsistency with the definition which says "extreme" for an infant is "one-half chronological age or less" and for an older child, 3-18 years of age it is "no meaningful functioning." § 416.926a(c)(3)(ii)(C). One half of functioning is certainly more than "no" meaningful functioning. To make this consonant we suggest "minimal" should be substituted for "no" before "meaningful functioning."

d. Children Aged 1 To 3 Must Not Be Confined To Just Three Areas of Functioning

There is an inherent discrimination in these rules that is not required by the new law that confines young children aged 1 to 3 to just three areas (cognition/communication, motor and social), in contrast to infants who are evaluated in four areas and older children in five areas. It is much more difficult to show marked limitation in 2 of 3 areas, as opposed to 2 of 4 or 2 of 5. This conflation of areas assessed for these young children is inconsistent with how SSA evaluates these other children.

Personal development should be added as an area of functioning for children aged 1 to 3. When Congress ordered changes in the program, it did not at all seek changes in the types, content or number of "domains" or, as they are now called, "areas" of functioning. Indeed, Congress left in place the general "Functioning in Children" regulation which established the general constructs for these areas, including the "personal/behavioral" and the "cognitive" and "communicative" as separate areas. See the continuing regulation formerly enumerated as sec. 416.924b.

The agency well knows that a personal development area is relevant and appropriate for children aged 1 to 3. Under prior rules this area was defined for young children as: "your ability to help yourself and to cooperate with others in taking care of your personal needs, in adapting to your environment, in responding to limits, and in learning new skills." See prior rule sec. 416.924d(f)(5). The agency should restore this area which the pediatric community understands and uses to assess these children.

The inappropriate further conflation of the cognitive and communicative areas is applicable to all children and is addressed below.

e. Children With Physical Impairments Other Than Motor Deficits Must Be Evaluated in Another, Additional Area of Functioning

The addition of a motor skills area to the mental disorder functional areas of the Listings incorporated into the functional equivalence test does nothing to cure the existing deficiencies of the IFA test, which inadequately evaluated children with physical problems using the same set of domains, as areas were then called. SSA must honestly admit that the mental disorder "B" functional criteria were never intended to evaluate the physical disabilities of children. And it simply is not fair to these children to assume as the rules do that all manifestations of physical impairments will be fairly assessed in the personal or concentration, persistence or pace (or motor skills) areas.

The interim rules fail to heed the call of the National Academy of Social Insurance Report cited above which found the functional criteria in use then (and now continued on), "use essentially the same criteria for assessing function as the mental disorder listings" and consequently they are not appropriate for children with physical impairments and children who have both physical and mental impairments. (Report at pp. 27-28.) The Report urged that "appropriate criteria" be established for these children including neurological, stamina and endurance, medical fragility and vulnerability to disease, and the need for special equipment in order to function. (*Id*. at 29.)

We therefore suggest an additional area of functioning to capture the non-motor "marked and severe functional limitations" of children with physical impairments or both physical and mental impairments defined as:

> Other physical functions considered a part of normal functioning such as breathing; eating, digesting and eliminating; strength, stamina and endurance; and ability to resist disease and function in the physical world, etc.

Congress certainly did not ask the agency to build upon or continue deficiencies of the prior functional test. By failing to re-examine how fairly the agency evaluates physically disabled children, and failing to heed the call of informed observers such as the National Academy of Social Insurance, the agency will ultimately fail to meet the new statutory test which in now way ordered the physically impaired child to be measured by mental disorder criteria.

f. The Rules Need to Recognize the Separateness of the Communication and Cognition Areas of Functioning and View Them as Two Distinct Areas

The conflation of the two areas of cognition and communication into one combines area is in conflict with the uniform and long-standing body of medical and scientific findings and literature. Surely SSA understood this when it recognized the separateness of these two domains in the prior rules. The new legislation, in primarily addressing the apparent need for a new severity level <u>while</u> continuing a broad "functional limitations" test and indeed, ratifying this concept for the first time in the statute, never directed the agency to subtract or conflate areas of functioning. Given the major body of medical and scientific literature behind these analytical categories of functioning, Congress could not have done so. Congress, remember, left intact the "Functioning in children" regulation which clearly set forth the separate "major spheres of activity--i.e. physical, cognitive, communicative...." 20 C.F.R. § 416.924b(b)(5). Yet these new rules, to the surprise of all, managed, perhaps unintentionally, to "cut and paste" the formulation as it appeared in the child mental disorder listings.

According to experts consulted by the Kennedy Foundation in the fields of mental retardation and communication, there are a number of reasons why it is ill advised to combine these two areas into one. Mrs. Shriver, in her second letter to Susan Daniels of March 20, 1997 (attached as Exhibit "D"), has set forth:

> **"1. Scientific Considerations.**
>
> Disassociation between cognition and communication is 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.

2. Communication warrants a separate domain.

Communication is the foundation for acquiring skills in many other domains and, therefore, warrants a separate area. 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. In fact, perhaps no other facet of human behavior so directly impacts 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 in the normal range."

There is thus every reason to keep these very separate areas of functioning separate in the rules.

8. 20 C.F.R. § 416.929--How we evaluate symptoms, including pain.

Pain and subjective symptoms can be easily overlooked. Thus, the policy concerning how pain and other symptoms is to be considered should be cross-referenced in 20 C.F.R. § 416.924a (other factors we will consider) and 20 C.F.R. § 416.926a, the functional equivalence regulation.

In addition, pain and other symptoms should be included in the first section of Form SSA-538 concerning factors that must be considered in assessing functional equivalence.

9. 20 C.F.R. § 416.987--Disability redeterminations for individuals who attain age 18.

This regulation should incorporate language from 20 C.F.R. §§ 416.924d(j) and 416.924e(d), concerning how SSA will evaluate young adults who generally have no work experience, under the adult disability standard. That language, deleted by SSA as a result of the welfare act, provides an excellent discussion of how persons age 18 and older satisfy the adult standard, and thus provides vital guidance to deciding young adult cases. This is extremely important if the transition from child to adult is a smooth one in terms of SSI eligibility.

10. 20 C.F.R. § 416.990--When and how often we will conduct a continuing disability review

In subsection (11), which concerns continuing disability reviews for children found disabled due to low birthweight, the regulation should cross-reference 20 C.F.R. § 416.924a(b) and provide that the corrected chronological age is used as the trigger date for a continuing disability review. This means that a child born weeks prematurely who is found disabled due to low birthweight need not have his or her disability status reviewed until his or her corrected chronological age of one is reached--which will be reached when the child's chronological age is 14 months in this case.

C. Implementation Issues to Address and Remedy

We have numerous concerns about implementation of these welfare act changes. Below, is a partial list of questions we have concerning this implementation.

Interim Rule Changes

Will SSA apply changes in the interim rules to cases already decided to prevent inequities and discrimination, and in light of the fact that no benefits can be terminated before July 1, 1997? Failure to apply changes to reviewed cases would subject the agency to litigation from children prejudiced by unequal treatment.

Appeal Procedures

Will SSA issue instructions to field office staff that require good cause for late filing of appeals be granted liberally for parents and caregivers who are filing appeals for children receiving termination notices?[9]

Outreach To Other Agencies

Will SSA do outreach to other federal agencies (e.g. HHS, DOE), state agencies, and local governmental agencies to advise them of the changes in the children's SSI program?

Will SSA work with the Health Care Financing Administration and state Medicaid agencies to capture Medicaid encounter data to be used in development of medical records for children whose disability status is under review?

Casefile Development

Will SSA require that old casefiles be obtained and made part of the case record for all cases reviewed in the redetermination process, the continuing disability review process, and the 18 year old review process? This will be key to affording due process to those reviewed.

BDD Procedures

Will SSA provide adequate funding to state disability determination agencies to ensure that all needed consultative examinations, and especially pediatric assessment tests, can be obtained?

Will SSA ensure that state BDD agencies have sufficient numbers of pediatricians and child psychologists to review casefiles to meet statutory and regulatory mandates? (*See* 42 U.S.C. §1382c(a)(3)(H).) This is particularly important because state BDD doctors will be

---

[9] We hope that SSA uses good cause policies at least as liberal as thus used with persons terminated from disability as a result of the DAA changes contained in the Contract with America Advancement Act of 1996.

required to learn a new evaluation system (i.e. functional equivalence has been "clarified") and, in addition to having more children's casefiles to review, will probably need to take additional time reviewing those casefiles and completing the new form (Form SSA-538).

Will SSA ensure that state BDD agencies collect all relevant records in children's cases before they make new disability determinations, and postpone completion of cases during summer months beginning in May when schools begin to shut down?[10]

Quality Review

What steps will SSA take to review the quality and accuracy of childhood disability determinations applying the new standard? We believe that SSA should carefully track statistical data concerning application of the new childhood disability standard, as well as ensure that its Office of Disability staff are involved in a continuous review policy so that policymakers are reviewing actual decisions and casefile records to assess how such decisions are actually being made. (*See* Exhibit to Thomas Yates' SSI Coalition comments for an attached a list of relevant statistics that SSA should track on a monthly basis. What plans does SSA have for making those statistics available to the public.

Secondly, what are SSA's plans when more than 50% of children redetermined are being terminated from SSI? Will the White House and public be immediately informed that prior "Assessment" estimates were dramatically understated? Will SSA revisit the regulations or take other steps to warm the "adjudicative climate?"

---

[10] This is particularly important because many state BDD agencies will be making these decisions during the summer of 1997. In making these decisions, review of school records is essential. However, many school districts maintain skeleton staff levels during the summer months when schools are closed. BDD'S will have extreme difficulty obtaining school records for children attending public schools during the summer of 1997. And, records will be, in many cases, critically important in assessing childhood disability.

* * * * *

Thank you for this opportunity to provide comments. Should you have any questions or want additional information, please feel free to contact us. Our direct dial telephone numbers are (215) 981-3742 and 981-3773.

Sincerely,

JONATHAN M. STEIN
General Counsel

RICHARD P. WEISHAUPT
Project Head
Health & Human Services Unit

jmp

cc: President Bill Clinton
Franklin Raines, OMB Director
Erskine Bowles, Chief of Staff
Senator Arlen Specter
Senator Rick Santorum
Representative Tom Foglietta
Representative Chaka Fattah
Representative Jon Fox

FUNCTIONAL EQUIVALENCE COMPARISON

Standard Prior to 8-22-96	**Standard Set Forth in Interim Final Regulations**
SPECIFIC FUNCTIONS Impairments that cause a marked limitation in one or two basic age-appropriate functions are functionally equivalent to the listings. POMS § 25215.010D.2.a.	LIMITATIONS OF SPECIFIC FUNCTIONS A child's impairment(s) is functionally equivalent in severity to a listed impairment because of extreme limitation of one specific function, or of limitations in more than one specific function (e.g. limitations in walking and talking).
LIMITING FUNCTIONAL CONSEQUENCES Impairments are disabling if they have "consequences not necessarily related to a single, specific age-appropriate function, but having such a marked impact on functioning that they preclude the full range of age-appropriate activities. There are two types of limiting functional consequences: ▪ Impairments that are "episodic, or occur with specified frequency despite treatment, depending on the listing" where "[t]he child may be able to function well between episodes." POMS § DI 25215.010D.2.b. ▪ Impairments that "require treatment that is itself debilitating or contributing to functional limitations" including, but not limited, to conditions requiring extended and invasive treatments, and side effects of medication. POMS § DI 25215.010D.2.b.	EPISODIC IMPAIRMENTS If a child has a chronic impairment(s) that is characterized by frequent illnesses or attacks, or by exacerbations and remissions, SSA will compare the child's functional limitations to those in any listing for a chronic impairment with similar episodic criteria. LIMITATIONS RELATED TO TREATMENT OR MEDICATION EFFECTS Some impairments require treatment over a long time (i.e., at least a year) and the treatment itself (e.g., multiple surgeries or the side effects of medication) causes marked and severe limitations.

EXHIBIT A

BROAD FUNCTIONAL LIMITATIONS	BROAD AREAS OF DEVELOPMENT OR FUNCTIONING
Using the paragraph "B" criteria of the childhood mental impairments listings (or, if applicable, the paragraph "B" or "C" criteria of the adult mental listings), a child is considered disabled if:	A child's impairment is functionally equivalent if the effects of the impairments in broad areas of development or functioning, is equivalent to functioning in Listing 112.12 (birth to age 1), or Listing 112.02 (age 1 to age 18).
for a child aged 1 up to 3, she or he has one "extreme" impairment (functioning at no more than one-half the child's chronological age) or two "marked impairments (functioning between one-half and two-thirds of the child's chronological age); or for a child age 3 up to 18 years, she or he has "two" marked impairments. *	A child is considered disabled if she or he has an extreme limitation in one area of development or functioning, or marked limitations in two areas of development or functioning.
The paragraph "B" criteria were:	The areas of development or functioning to be considered are:
for children from birth to age 1: a) cognitive/communication development; b) motor development; c) social development; and d) responsiveness to stimuli.	for children from birth to age 1: a) cognitive/communication development; b) motor development; c) social development; and d) responsiveness to stimuli;
for children aged 1 to age 3: a) gross or fine motor development; b) cognitive/communicative function; c) social function; and	for children aged 1 to age 3: a) gross or fine motor development; b) cognitive/communicative function; c) social function; and
for children age 3 to age 18: a) cognitive/communicative function; b) social functioning; c) personal/behavioral functioning; and d) concentration, persistence, or pace.	for children age 3 to age 18: a) cognitive/communicative function; b) social functioning; c) personal/behavioral functioning; and d) concentration, persistence, or pace.

---

* A child aged 3 up to age 18 with one extreme limitation would undoubtably satisfied the first type of functional limitation--specific function—. and been found disabled.

EXHIBIT B

The Joseph P. Kennedy, Jr. Foundation

1325 G STREET, N.W., SUITE 500
WASHINGTON, D.C. 20005-4709
(202) 393-1250

SUBJECT FILE
SF

March 14, 1997

The Honorable Susan M. Daniels, Ph.D.
Associate Comissioner, Social Security Administration
Office of Disability
6401 Security Boulevard
Baltimore, MD 21235

Re: Comments on 20 CFR Parts 404 and 416 Supplemental Security Income: Determining Disability for a Child Under Age 18; Interim Final Rules with Request for Comments

Dear Dr. Daniels:

I enjoyed speaking with you last week. Our discussion was of great assistance in understanding the issues confronting the Social Security Administration. As promised, I am enclosing the analysis we discussed relative to 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.

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

EXHIBIT C

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. I have enclosed the WISC 3 cutpoints as an example. All standardized instruments have manuals with similar tables.

The same strategy applies to motor and communicative scores, but in these measures, one uses standard scores, not IQ. 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.

Unless specifically warned 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.

We appreciate your willingness to examine these issues, and look forward to another discussion as to how we can provide additional information or clarification. As promised, we will provide specific information on the need to provide separate cognition and communication domains in lieu of the combined domain in the proposed regulations. We will have other comments, as well, on the regulations in the next two weeks.

Please advise, and thank you.

Sincerely,

Eunice K Shriver

Eunice Kennedy Shriver

I hope this information is useful and informative in special ways

The Joseph P. Kennedy, Jr. Foundation

1325 G STREET, N.W., SUITE 500
WASHINGTON, D.C. 20005-4709
(202) 393-1250

March 20, 1997

The Honorable Susan M. Daniels, Ph.D.
Associate Comissioner, Social Security Administration
Office of Disability
6401 Security Boulevard
Baltimore, MD 21235

Re: Comments on 20 CFR Parts 404 and 416 Supplemental Security Income: Determining Disability for a Child Under Age 18; Interim Final Rules with Request for Comments

Dear Dr. Daniels:

As promised, I am providing the analysis of the cognition/speech domains we discussed relative to children with mental retardation.

The experts we consulted in mental retardation and communication argue that it is ill advised to combine 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.

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;

EXHIBIT D

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.

Finally, we know from long experience and research that the extent, nature, costs of caring and providing supports for individuals not served early in their lives increases significantly in their adult and aging years.

Please advise, and thank you.

Sincerely, & with warm good wishes

Eunice Shriver
Eunice Kennedy Shriver

I hope all this information is helpful to you and to our Special [illegible]

cc: Jonathan Stein
Dr. Robert Cooke

JUDGE DAVID L.
BAZELON
CENTER
FOR
MENTAL
HEALTH
LAW

Civil Rights and Human Dignity

April 11, 1997

John J. Callahan
Acting Commissioner
Social Security Administration
PO Box 1585
Baltimore, MD 21235

BY FAX 410/966-2830

Dear Acting Commissioner Callahan:

We write to express deep concern about the interim final regulations for the children's Supplemental Security Income (SSI) program that were published in the Federal Register on February 11, 1997.

The Judge David L. Bazelon Center for Mental Health Law is the leading national legal advocacy organization representing people with mental disabilities. Through precedent-setting litigation, public policy advocacy and technical support for local lawyers and other advocates, the Bazelon Center works to define and protect the rights of adults and children who rely on public services and ensure their equal access to health and mental health care, income support, education, housing and employment.

The Bazelon Center has a long history of advocating on behalf of children with mental and emotional disabilities who are eligible for SSI. We worked with the Social Security Administration (SSA) to revise and improve the childhood mental impairment regulations and participated in the agency's effort to develop new children's rules after the Zebley decision. Most recently, we worked to ensure that the program continue to provide cash assistance to families who want to raise their children with significant disabilities at home.

The final interim regulations are a major disappointment to us because they establish an eligibility standard that is far more severe than that 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 establish a standard that will protect more children.

The very high standard of disability chosen by SSA requires proof of marked limitations in two areas and will limit eligibility among children who have severe disabilities -- many of them with mental and emotional disabilities -- causing great hardship to them and their families. Our understanding is that the childhood SSI regulations were revised because of concerns about alleged fraud among a small group of beneficiaries. By raising the eligibility standard, the interim final

1101 Fifteenth Street NW, Suite 1212, Washington DC 20005-5002, 202/467-5730, TDD: 202/467-4232, fax: 202/223-0409
World Wide Web: http://www.bazelon.org, e-mail: hn1660@handsnet.org

regulation may not accomplish this goal, but will result in families and children with legitimate needs for assistance losing benefits.

We urge you to leave the door open for future agency regulation and adjustments as needed to meet changing knowledge about childhood disability. At a 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.

Our major concerns with the specifics of the regulations are detailed in the comments submitted by the Social Security Task Force of the Consortium for Citizens with Disabilities and attached here as an appendix. Among our recommendations are the following:

1. Assess cognition and communication separately to allow proper assessment of children with marked limitations in both areas of functioning.
2. Assess children ages one-three in the additional areas of personal skills and concentration, persistence and pace to avoid holding them to an even higher standard of severity.
3. Allow room for measurement error when using standardized tests to adhere to best practice.
4. Provide greater guidance to decisionmakers about the importance of evaluating "other factors" when reviewing childhood claims.
5. Provide greater guidance to disability adjudicators on the availability of appropriate tests for functional assessments for different age groups.
6. Clarify that "all relevant" evidence must be evaluated to assess medical equivalence, not just "medical" evidence.

In addition to these substantive concerns, there are a number of implementation issues that we believe SSA must address:

First, SSA published these rules as interim final regulations, effective immediately. However, the agency requested public comments and we urge you to make improvements before publishing final regulations. If changes are made, fairness demands that SSA set aside cases that are denied prior to the issuance of final regulations. Failure to do so makes the process arbitrary and capricious, resulting in unequal treatment for children similarly situated.

Second, we have tremendous concern about SSA's ability to obtain relevant school records prior to summer recess. Without these records, some assessments of children will be incomplete and perhaps, inaccurate. SSA should instruct the state disability agencies to postpone completion of cases during the summer if school records are not available.

Third, SSA now requires disability adjudicators to use a new evaluation form when assessing children. This form should be made public and available to families and advocates through all field offices, through publication in the Federal Register and on SSA's Home Page.

We urge you to publish new regulations incorporating the changes suggested above. If you have any questions, please contact Rhoda Schulzinger of my staff at 202/467-5730.

Sincerely,

Robert Bernstein, Ph.D
Executive Director

Attachment: Comments from CCD Social Security Task Force

Consortium for
Citizens with
Disabilities

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.

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)

2. 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)

5. "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. <u>Need to Evaluate "All Relevant Evidence", Not Just All "Medical" Evidence</u>

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.

<u>RECOMMENDATION</u>

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. <u>IMPLEMENTATION ISSUES</u>

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.**

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

Marty Ford
The Arc of the United States

Rhoda Schulzinger
Bazelon Center for Mental Health Law

Tony Young

Tony Young
United Cerebral Palsy
Associations, Inc.

Paul Seifert

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.

neglect will no longer be protected by CAPTA's immunity for reporting. Only good-faith reports will be protected.

Finally, we have clarified the definition of child abuse or neglect to provide additional guidance and assistance to 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.

But I think there may be some difference of opinion about the purpose of the program. The SSI program was originally started to provide a small cash income to individuals who cannot work because of age or disability. But the children's SSI program had a somewhat different purpose—to help poor families with the extra costs of having a 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 benefit 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 comanager 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

JOHN H. CHAFEE
RHODE ISLAND

CHAIRMAN, COMMITTEE ON
ENVIRONMENT AND PUBLIC WORKS

COMMITTEE ON FINANCE

JOINT COMMITTEE
ON TAXATION

SENATE ARMS CONTROL
OBSERVER GROUP

United States Senate
WASHINGTON, DC 20510-3902

WASHINGTON OFFICE:
WASHINGTON, DC 20510
(202) 224-2921
TDD: (202) 224-7746

PROVIDENCE OFFICE:
10 DORRANCE STREET
SUITE 221
PROVIDENCE, RI 02903
(401) 528-5294

TOLL FREE NUMBER
IN RHODE ISLAND
1-800-662-5188

INTERNET ADDRESS:
senator_chafee@chafee.senate.gov

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, <u>beyond</u> the "Listings of Impairments," in measuring childhood disability. Second, it specifically <u>does not</u> 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

KENT CONRAD
NORTH DAKOTA
202-224-2043

COMMITTEES:
AGRICULTURE, NUTRITION, AND FORESTRY
FINANCE
BUDGET
INDIAN AFFAIRS

United States Senate
WASHINGTON, DC 20510-3403

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

WILLIAM S. COHEN, MAINE, CHAIRMAN

LARRY PRESSLER, SOUTH DAKOTA
CHARLES E. GRASSLEY, IOWA
ALAN K. SIMPSON, WYOMING
JAMES M. JEFFORDS, VERMONT
LARRY CRAIG, IDAHO
CONRAD BURNS, MONTANA
RICHARD SHELBY, ALABAMA
RICK SANTORUM, PENNSYLVANIA
FRED THOMPSON, TENNESSEE
JOHN W. WARNER, VIRGINIA

DAVID PRYOR, ARKANSAS
JOHN GLENN, OHIO
BILL BRADLEY, NEW JERSEY
J. BENNETT JOHNSTON, LOUISIANA
JOHN B. BREAUX, LOUISIANA
HARRY REID, NEVADA
HERB KOHL, WISCONSIN
RUSSELL D. FEINGOLD, WISCONSIN
CAROL MOSELEY-BRAUN, ILLINOIS
RON WYDEN, OREGON

MARY BERRY GERWIN, STAFF DIRECTOR/CHIEF COUNSEL
THERESA M. FORSTER, MINORITY STAFF DIRECTOR

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 dropped from the definition because the term implied some degree of impairment in almost 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

CAROL MOSELEY-BRAUN
ILLINOIS

COMMITTEES:
BANKING, HOUSING, AND 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 who are truly disabled receive SSI benefits, I hope that there will be adequate 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 welfare law could result in anywhere from a ten percent to a twenty-eight percent reduction in SSI caseloads. This demonstrates the considerable discretion 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 Coalition, located in Chicago. The proposal put forth by the SSI Coalition is similar 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 for 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

Carol Moseley-Braun
United States Senator

CMB:arc

cc: Shirley Chater

TOM DASCHLE
SOUTH DAKOTA

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

NANCY LANDON KASSEBAUM, KANSAS, CHAIRMAN

JAMES M. JEFFORDS, VERMONT
DAN COATS, INDIANA
JUDD GREGG, NEW HAMPSHIRE
BILL FRIST, TENNESSEE
MIKE DEWINE, OHIO
JOHN ASHCROFT, MISSOURI
SPENCER ABRAHAM, MICHIGAN
SLADE GORTON, WASHINGTON

EDWARD M. KENNEDY, MASSACHUSETTS
CLAIBORNE PELL, RHODE ISLAND
CHRISTOPHER J. DODD, CONNECTICUT
PAUL SIMON, ILLINOIS
TOM HARKIN, IOWA
BARBARA A. MIKULSKI, MARYLAND
PAUL WELLSTONE, MINNESOTA

SUSAN K. HATTAN, STAFF DIRECTOR
NICK LITTLEFIELD, MINORITY STAFF DIRECTOR AND CHIEF COUNSEL

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

PAUL D. WELLSTONE
MINNESOTA

MINNESOTA TOLL FREE NUMBER:
1-800-642-6041

United States Senate
WASHINGTON, DC 20510-2303

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

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.

☐ 717 Hart Senate Office Building
Washington, DC 20510-2303
(202) 224-5641

☐ 2550 University Avenue, West
Court International Building
St. Paul, MN 55114-1025
(612) 645-0323

☐ Post Office Box 281
105 2d Avenue, South
Virginia, MN 55792
(218) 741-1074

☐ 417 Litchfield Avenue, SW
Willmar, MN 56201
(612) 231-0001

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

United States Senate
WASHINGTON, DC 20510

10 Senators

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,

Kent Conrad
Senator Kent Conrad

Ted Kennedy
Senator Edward Kennedy

Jay Rockefeller
Senator John D. Rockefeller IV

Max Baucus
Senator Max Baucus

Chris Dodd
Senator Christopher Dodd

John Chafee
Senator John Chafee

Tom Harkin
Senator Tom Harkin

Jim Jeffords
Senator James Jeffords

Patrick Leahy
Senator Patrick Leahy

Tom Daschle
Senator Tom Daschle

[illegible]
SOUTH DAKOTA

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

JOHN H. CHAFEE
RHODE ISLAND

CHAIRMAN, COMMITTEE ON
ENVIRONMENT AND PUBLIC WORKS

COMMITTEE ON FINANCE

JOINT COMMITTEE
ON TAXATION

SENATE ARMS CONTROL
OBSERVER GROUP

United States Senate
WASHINGTON, DC 20510-3902

WASHINGTON OFFICE:
WASHINGTON, DC 20510
(202) 224-2921
TDD: (202) 224-7746

PROVIDENCE OFFICE:
10 DORRANCE STREET
SUITE 221
PROVIDENCE, RI 02903
(401) 528-5294

TOLL FREE NUMBER
IN RHODE ISLAND
1-800-662-5188

INTERNET ADDRESS:
senator_chafee@chafee.senate.gov

CHAFEE

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

Social Sec – Children's Disability

5-25-97 Disability Meeting

Prob: choice of li std – shouldn't be 2-marked / instead: 1 marked/1 mod.

Stein: Cm Legal Services memo

Tougher std than Cong – listings level severity –

not a middle course, but extreme interp of law.

EG – IQ of 71 – moderate, not marked.

So lots of kids w/ mental retardation will get kicked off.

Cerebral palsy – only if at marked or listings level – braces or wheelchair

10 US Senators sent letter – we didn't intend listings level severity,

tho not IFA.

should be: plus minimum X

Dr – Having definite cut (eg IQ 70) makes no sense. "IQ as an absolute"

Lumped cognitive & communication – makes no sense in terms of brain activity

2 lumped as 1 criterion. Categs anyway.

Kids between 1 & 3 – only 3 areas, not 5 as in older children.

Stein: 6-7 suggestions: see memo.

See example of child w/ IQ in 50s – e.g. of how cog/com are separate – thus should be two marked, whereas now only counted as one.

Need to cash no diff. btw 2-marked kids and 1 marked/1 mod kid.

Warren: No widespread fraud or abuse

Dole: "fine-tuning"

Shriver: Over 5-6 years – 800,000 children

over 6 years

If all changes made – 250,000 children still would be cut off. Wouldn't be rendering statute meaningless

45,000 each year

Social Security –
Children's Disability Standard

Elena --

Here is background for the Shriver meeting. You already have the huge package Mrs. Shriver sent over. For more readable background, attached is briefing material we prepared when SSA announced its regulation last February.

- Shriver is bringing other advocates with her, including Jonathan Stein, the chief litigator of the Zebley case that started all this, Marty Ford from the Arc, and a pediatric neurologist associated with a Kennedy foundation whom I don't know. There is no doubt Stein will sue us on all of this, if he hasn't already.

- Stein and Ford approach this issue pretty contentiously, so we have to decide whether we say we are just there to listen, or whether we should agree to follow up on their concerns with SSA and even consider whether to say we will consider revising SSA's reg. We don't want to go too far on the latter.

- I would recommend that our message be: "The Administration is very concerned about the implementation of this reg and the law, since it affects so many disabled children and their families, and so it is very useful to have your perspective. We will review this with SSA as we monitor the implementation of the law." But there is a limit to this, since for the most part they just want to replay the debate we went through before the reg was issued.

- The advocates strongly opposed our interpretation of the welfare reform law on this issue, but we didn't feel we had wiggle room either legally or politically, certainly not enough to support the advocates' interpretation.

- We expect that SSA's final interpretation, announced in early February, will remove 135,000 children from the SSI rolls. There are now about 900,000 children on the rolls.

- One good thing we can emphasize is that the budget agreement grandfathers Medicaid coverage for the 135,000 children losing SSI.

- They will allege that SSA's regulations are too strict, that many more than 135,000 children will lose SSI, and that SSA should immediately engage in a consultative process to revise them. We haven't dealt with this issue internally since February, and SSA is about a month away from having information on the types of children who are losing coverage -- so we don't yet know if our 135,000 estimate is solid. (It may be longer than that, since appeals can drag on for months or years.)

- One new item: SSA has just begun to notify families that their children will lose benefits, and Stein has attached information on a child with mental retardation that he says has been cut off unfairly. We can't really respond to a specific case in the meeting, but they will contend that SSA is not doing a good job of this. SSA is trying to get me more info on the merits of this case. Kids with mental retardation and other mental impairments are disproportionately affected by these cuts.

—Diana

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 [illegible] 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

CHILDREN'S SSI CUTS

Background

- Program geared to families with income under 190% of poverty; maximum monthly payment of $460 a month declines as income increases
- SSI also makes you eligible for Medicaid
- Tremendous growth in program due to Supreme Court decision, outreach, better recognition of mental impairments -- now 1 million children, up from 300,000 children in 1989, at a cost of almost $5 billion a year
- Supreme Court decision led SSA to lower its standard -- "IFA" test -- and emphasize child's functioning, not just disease
- Media stories of coaching children to "act crazy" never documented beyond a tiny number; more likely resentment sprang from marginal cases -- learning disabilities, behavioral problems, ADHD -- many of which SSA probably rejected

Legislative Change

- House initially wanted to block grant, or cut grants to all children; Senate resisted and crafted this compromise, which we ultimately endorsed
- New definition: child must have "marked and severe functional limitations"; IFA repealed
- We and Congressional leadership assumed strict interpretation at the time, including cost estimates (savings of $8 billion over 5 years)
- Advocates worked quietly with Daschle, Conrad, and Chafee to add some legislative history to support their current contention that SSA could add back a new version of the IFA test (most Dems were silent, however)
- Conference report supports strict interpretation; Republican leadership would have charged us with bad faith if we endorsed advocates' plan
- We chose middle ground interpretation that will cut off 135,000 children.

Implementation

- Law required SSA to issue new definition by Nov. '96, but reg issued Feb. '97.
- By next August, SSA must redetermine eligibility of the approximately 300,000 children who got on current rolls through IFA test; families received notices
- Now that decisions are starting to be made, there are likely to be inaccurate stories about children who will lose their benefits, but decisions about individual children will not be made until summer.

How SSA Determines If a Child is Disabled

- o We had to use SSA's current framework for making this decision -- it would take up to 2 years to design a new approach (not practical given the backlog built up since August)

- o Children are eligible for SSI if:

  1. their disease/impairment is on SSA's list; or
  2. they have functional limitations in certain "domains" (e.g., personal, cognitive, social, motor)

- o IFA allows children with "3 moderate" or "1 marked and 1 moderate" impairment.

- o Eliminating the IFA would raise that standard to "2 marked" impairments.

Option 1: Republican leadership position -- Strict Interpretation. Cut off 190,000 kids. No cost to budget. Eliminate "IFA" test, strict standard of "2 marked" impairments.

Option 2: Advocates' Proposal. Cut off 45,000 kids. Cost to budget: $6.4 billion over 5 years. Build back new IFA test that allows children with "1 marked and 1 moderate" impairment to qualify; eliminate only those with "3 moderates." Supported by Sens. Daschle, Chafee, Conrad, Cohen; Gov. Dean; Mayor Rendell.

Option 3: Middle Ground Adopted by Administration. Cut off 135,000 kids. Cost to budget: $2.4 billion over 5 years. Eliminate "IFA" test and strict standard of "2 marked", but soften with modifications.

- o add new motor domain, to take better account of children with physical disabilities

- o ensure that adjudicators consider a child's functioning by requiring them to fill out a special form

- o require special consideration of chronic/episodic impairments, that come and go (AIDS, schizophrenia)

- o grandfather Medicaid for all children now on rolls (50,000 are otherwise expected to lose Medicaid) -- may be most important part of benefit

Pro's: o While a significant change from our previous position, did not alienate Republicans; will restore public confidence in program

Con's: o While probably right middle ground to strike, advocates view as defeat
- o Hard to be confident SSA's system is picking up most severely disabled
- o Poor families are facing other changes in welfare system
- o Few speak out to support us (except American Academy of Pediatrics)
- o While program has few supporters, stories of children losing aid could change this

Note: SSA is guessing at the number of children affected by each proposal; also, SSA has considerable administrative power in implementing any definition

PROFILE OF CHILDREN

- Difficult to estimate because so many children who entered program via IFA would actually qualify under toughest standard
  - Appears that most stories the press has picked up are children who would still qualify
- Not a question of what diseases or impairments, but degree of impairment
- Difference between marked and moderate often question of frequency: "occasional pain" vs. "frequent pain"
- Most of the children in question have mental impairments:

Even Advocates Agree to cut:

- Children with less severe behavioral problems, such as conduct disorder, ADHD, learning disabilities, or mild mental retardation -- many of which were the impetus for changes to the program.

Advocates want to preserve benefits for:

- Children with significant impairments, such as asthma, cerebral palsy or mental retardation, whose problem does not spill over into other areas of the child's functioning (social, activities of daily living)

Middle Ground Option would preserve benefits for:

- many children with physical disabilities
- children with episodic illness

Strictest Option would be unfair to:

- children with physical disabilities
- children with chronic physical problems

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.

(M O R E)

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.

THE NEW YORK TIMES **EDITORIALS/LETTERS** MONDAY, NOVEMBER 11, 1996

The New York Times

Founded in 1851

ADOLPH S. OCHS, *Publisher 1896-1935*
ARTHUR HAYS SULZBERGER, *Publisher 1935-1961*
ORVIL E. DRYFOOS, *Publisher 1961-1963*
ARTHUR OCHS SULZBERGER, *Publisher 1963-1992*

ARTHUR OCHS SULZBERGER JR., *Publisher*

JOSEPH LELYVELD, *Executive Editor*
GENE ROBERTS, *Managing Editor*

Assistant Managing Editors
SOMA GOLDEN BEHR
GERALD M. BOYD
DAVID R. JONES
CAROLYN LEE
JACK ROSENTHAL
ALLAN M. SIEGAL

HOWELL RAINES, *Editorial Page Editor*
PHILIP M. BOFFEY, *Deputy Editorial Page Editor*

JANET L. ROBINSON, *President, General Manager*
JOHN M. O'BRIEN, *Executive V.P., Deputy Gen. Mgr.*
WILLIAM L. POLLAK, *Executive V.P., Circulation*
PENELOPE MUSE ABERNATHY, *Senior V.P., Planning and Human Resources*
DANIEL H. COHEN, *Senior V.P., Advertising*
RICHARD H. GILMAN, *Senior V.P., Operations*
RAYMOND E. DOUGLAS, *V.P., Systems and Technology*
DONNA C. MIELE, *V.P., Human Resources*
CHARLES E. SHELTON, *V.P., Distribution*
DAVID A. THURM, *V.P., Production*

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 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.

Soc Sec —
Ch Disabil Std

**Consortium for
Citizens with
Disabilities**

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.

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)

2. 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)

5. "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.**

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
Marty Ford
The Arc of the United States

Rhoda Schulzinger
Rhoda Schulzinger
Bazelon Center for Mental Health Law

Tony Young
Tony Young
United Cerebral Palsy
Associations, Inc.

Paul Seifert
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.

neglect will no longer be protected by CAPTA's immunity for reporting. Only good-faith reports will be protected.

Finally, we have clarified the definition of child abuse or neglect to provide additional guidance and assistance to 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.

But I think there may be some difference of opinion about the purpose of the program. The SSI program was originally started to provide a small cash income to individuals who cannot work because of age or disability. But the children's SSI program had a somewhat different purpose—to help poor families with the extra costs of having a 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 benefit 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 comanager 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

JOHN H. CHAFEE
RHODE ISLAND

CHAIRMAN, COMMITTEE ON
ENVIRONMENT AND PUBLIC WORKS

COMMITTEE ON FINANCE

JOINT COMMITTEE
ON TAXATION

SENATE ARMS CONTROL
OBSERVER GROUP

United States Senate
WASHINGTON, DC 20510-3902

WASHINGTON OFFICE:

WASHINGTON, DC 20510
(202) 224-2921
TDD: (202) 224-7746

PROVIDENCE OFFICE:

10 DORRANCE STREET
SUITE 221
PROVIDENCE, RI 02903
(401) 528-6294

TOLL FREE NUMBER
IN RHODE ISLAND
1-800-662-8168

INTERNET ADDRESS:
senator_chafee@chafee.senate.gov

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

KENT CONRAD
NORTH DAKOTA
202-224-2043

COMMITTEES:
AGRICULTURE, NUTRITION
AND FORESTRY
FINANCE
BUDGET
INDIAN AFFAIRS

United States Senate
WASHINGTON, DC 20510-3403

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

TOM DASCHLE
SOUTH DAKOTA

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

CAROL MOSELEY-BRAUN
ILLINOIS

COMMITTEES:
BANKING, HOUSING, AN
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 discretion 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 Coalition 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 for 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

Carol Moseley-Braun
United States Senator

CMB:arc

cc: Shirley Chater

WILLIAM S. COHEN, MAINE, CHAIRMAN

LARRY PRESSLER, SOUTH DAKOTA
CHARLES E. GRASSLEY, IOWA
ALAN K. SIMPSON, WYOMING
JAMES M. JEFFORDS, VERMONT
LARRY CRAIG, IDAHO
CONRAD BURNS, MONTANA
RICHARD SHELBY, ALABAMA
RICK SANTORUM, PENNSYLVANIA
FRED THOMPSON, TENNESSEE
JOHN W. WARNER, VIRGINIA

DAVID PRYOR, ARKANSAS
JOHN GLENN, OHIO
BILL BRADLEY, NEW JERSEY
J. BENNETT JOHNSTON, LOUISIANA
JOHN B. BREAUX, LOUISIANA
HARRY REID, NEVADA
HERB KOHL, WISCONSIN
RUSSELL D. FEINGOLD, WISCONSIN
CAROL MOSELEY-BRAUN, ILLINOIS
RON WYDEN, OREGON

MARY BERRY GERWIN, STAFF DIRECTOR/CHIEF COUNSEL
THERESA M. FORSTER, MINORITY STAFF DIRECTOR

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 dropped from the definition because the term implied some degree of impairment in almost 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,

Bill Cohen

William S. Cohen
Chairman

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

NANCY LANDON KASSEBAUM, KANSAS, CHAIRMAN

JAMES M. JEFFORDS, VERMONT
DAN COATS, INDIANA
JUDD GREGG, NEW HAMPSHIRE
BILL FRIST, TENNESSEE
MIKE DEWINE, OHIO
JOHN ASHCROFT, MISSOURI
SPENCER ABRAHAM, MICHIGAN
SLADE GORTON, WASHINGTON

EDWARD M. KENNEDY, MASSACHUSETTS
CLAIBORNE PELL, RHODE ISLAND
CHRISTOPHER J. DODD, CONNECTICUT
PAUL SIMON, ILLINOIS
TOM HARKIN, IOWA
BARBARA A. MIKULSKI, MARYLAND
PAUL WELLSTONE, MINNESOTA

SUSAN K. HATTAN, STAFF DIRECTOR
NICK LITTLEFIELD, MINORITY STAFF DIRECTOR AND CHIEF COUNSEL

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

PAUL D. WELLSTONE
MINNESOTA

MINNESOTA TOLL FREE NUMBER:
1-800-642-6041

United States Senate
WASHINGTON, DC 20510-2303

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

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.

☐ 717 HART SENATE OFFICE BUILDING
WASHINGTON, DC 20510-2303
(202) 224-5641

☐ 2550 UNIVERSITY AVENUE, WEST
COURT INTERNATIONAL BUILDING
ST. PAUL, MN 55114-1025
(612) 645-0323

☐ POST OFFICE BOX 281
105 2D AVENUE, SOUTH
VIRGINIA, MN 55792
(218) 741-1074

☐ 417 LITCHFIELD AVENUE, SW
WILLMAR, MN 56201
(612) 231-0001

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

The Arc of the United States
Governmental Affairs Office
1730 K Street, NW, Suite 1212
Washington, D.C. 20006-3868
(202) 785-3388 • FAX (202) 467-4179 • TDD (202) 785-3411-4179
E-mail: arcga@radix.net

Soc Sec –
Ch Disabil Std

April 11, 1997

John J. Callahan, Acting Commissioner
Social Security Administration
P.O. Box 1585
Baltimore, MD 21235

(Also sent 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:

These comments on the above referenced interim final rule are submitted on behalf of The Arc, a national organization on mental retardation. Formerly known as the Association for Retarded Citizens, The Arc is a voluntary membership organization made up of approximately 140,000 people with mental retardation, their families, friends, professionals, and other interested people forming more than 1,100 state and local chapters across the country.

The Arc is vitally interested in this interim final rule as well as any other regulations implementing The Personal Responsibility and Work Opportunity Reconciliation Act of 1996. Over 937,000 children and adults with mental retardation under age 65 depend upon the income supports of the Supplemental Security Income program; they constitute 38 percent of children and 24 percent of adults receiving SSI. We are concerned about the potential impact of the rules on the over 100,000 children with mental retardation whose cases are being reviewed under these new rules. We are also concerned about children with mental retardation who will apply for SSI in the future.

In fact, The Arc is deeply disappointed in the February 11 regulations for childhood disability determinations in the Supplemental Security Income (SSI) program. The eligibility standard established by the Social Security Administration (SSA) to implement the law is far more severe than required by the Personal Responsibility and Work Opportunity Reconciliation Act of 1996 (P.L. 104-193). We believe that it is clear from a strong legislative history that the new statutory definition of childhood disability gives SSA the flexibility to tighten the eligibility criteria, yet protect more children than will be protected by SSA's current overhaul approach. In addition, within the regulatory standard itself, there are a number of serious flaws which will harm children with severe disabilities.

These comments incorporate by reference the comments which we made as part of the CCD Task Force on Social Security, letter dated April 10, 1997, with attachments. A copy of the CCD comments and attachments are appended to this letter. An explanation of our recommendations are included in the CCD letter. Specifically, those recommendations are as follows:

1. 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.

2. 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)

3. 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)

4. 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.

5. 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)

6. 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)

7. 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.

8. 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.

9. If changes are made, fairness demands that SSA set aside or "flag" the potentially affected cases and hold any denial decisions.

10. SSA should instruct the state disability agencies to postpone completion of cases during the summer if school records are not available.

11. 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.

While this regulation was published as an interim final rule, The Arc urges SSA to seriously consider the comments made above. Without amendment of the regulation as recommended, this rule will only serve to unnecessarily hurt children with mental retardation and their families. The Arc urges you to take immediate action to remedy the issues above. If you have any questions on these comments, please contact Marty Ford in The Arc Governmental Affairs Office, (202/785-3388).

Sincerely,

Alan Abeson

Alan Abeson, Ed. D.
Executive Director

Mrs. Shriver, Soc Sec – Ch's Disabil Standard

RE: SSI - Meeting with Sylvia Matthews - Enter White House at gate across from Lafayette Park

You are meeting with Ms. Matthews and Ken Apfel from OMB at 11:00 A.M. Thursday, May 29th. Accompanying you will be Dr. Guy McKhann from Hopkins, Jonathan Stein from Community Legal Services and Marty Ford from The Arc. We will meet at the Foundation at 10:30.

From the conversation this A.M., following are the points we wish to make:

265,000 children are being reevaluated under the new regulations

135,000 are going to lose SSI benefits, though they will still get medicaid

90,000 of these 135,000 are children with mental retardation

If the current approach taken by SSA continues, hundreds of thousands of children not yet born and/or not currently on SSI will be denied both SSI and Medicaid in the next 6 years due to the regulations

We request that, immediately, SSA Issue **advisories** which state:

1. Each standardized test has a range - for example I.Q. 70 has a range of +/-5

2. Cognition and communication - can represent different areas of functioning

3. Mild MR - I.Q. 70 is actually **marked** cognitive disability. Moderate MR, I.Q. 50 is actually extreme cognitive disability.

4. Age group 1-3. Personal and Pace should be considered. The 3 domains listed in the regulations are too narrow and do not accurately reflect knowledge of child development steps.

Please note. Ken Apfel is currently the Deputy Director of OMB. He has been nominated by President Clinton to be the Commissioner of Social Security. He will need to be confirmed by the Senate, beginning with the Finance Committee.

We should meet with more Finance Committee members. You have already met with Senators Grassley and Conrad (staff). You have a meeting scheduled on June 4th with Senator Hatch who is also on the Committee.

Other Senators on Finance with whom you could meet are: Chafee; Lott; Moynihan; Rockefeller and Conrad.