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Social Security - Children's Disability Standard [4]

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DOCUMENT NO. AND TYPE	SUBJECT/TITLE	DATE	RESTRICTION
001. form	Children's Seashore House evaluation document (5 pages)	04/14/1995	P6/b(6)
002. form	Transitions Today evaluation document (4 pages)	09/22/1995	P6/b(6)
003. form	Philadelphia School District Individualized Education Program (6 pages)	03/1996	P6/b(6)
004. letter	From F. Koller re: disability (1 page)	04/22/1997	P6/b(6)
005. letter	From Larry Massanari re: SSI [partial] (4 pages)	05/07/1997	P6/b(6)

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Social Security - Children's Disability Standard [4]

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RESTRICTION CODES

Presidential Records Act - [44 U.S.C. 2204(a)]

- P1 National Security Classified Information [(a)(1) of the PRA]
- P2 Relating to the appointment to Federal office [(a)(2) of the PRA]
- P3 Release would violate a Federal statute [(a)(3) of the PRA]
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- b(7) Release would disclose information compiled for law enforcement purposes [(b)(7) of the FOIA]
- b(8) Release would disclose information concerning the regulation of financial institutions [(b)(8) of the FOIA]
- b(9) Release would disclose geological or geophysical information concerning wells [(b)(9) of the FOIA]

Social Security –
Children's Disability
Standard

The Joseph P. Kennedy, Jr. Foundation
1325 G STREET, N.W., SUITE 500
WASHINGTON, D.C. 20005-4709
(202) 393-1250

May 27, 1997

Sylvia Matthews, Deputy Chief of Staff
The White House
1600 Pennsylvania Avenue, N.W.
Washington, D. C. 20500

Dear Ms. Matthews:

I look forward to our meeting on Thursday, May 29, 1997. Jonathan Stein, a Kennedy Foundation Grantee from Community Legal Services in Philadelphia will accompany me. I am awaiting confirmation from another expert, and will contact you should that person be able to attend as well.

We have sent a great deal of material on the SSI for Children regulations to others, and thought you might like to have the complete package, which is enclosed for your reference.

Thank you.

Sincerely,

Eunice K Shriver
Eunice Kennedy Shriver

Attachments
May 27, 1997
Letter from Eunice Kennedy Shriver to Sylvia Matthews

1) Community Legal Services official comments on Interim Final Regulations;

2) Kennedy Foundation Expert Panel comments on Interim Final Regulations;

3) Consortium of Citizens with Disabilities (CCD) comments on Interim Final Regulations;

4) Eunice Kennedy Shriver's comments on Interim Final Regulations;

5) Letter to President Clinton from 10 Senators stating that the regulations do not comport with the intent of the Congress;

6) Memorandum to Kenneth Apfel, dated May 20, 1997 from Jonathan Stein of Stein from Community Legal Services;

7) Example of a child terminated (inappropriately) due to regulations.

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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]

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[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.

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[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

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[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

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[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.

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[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).

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[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 <u>failed</u> 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 <u>all</u> these IFA children were presumably reviewed previously under virtually the <u>same</u> functional equals test, and <u>all</u> 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 <u>Zebley</u> 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, <u>i.e.</u> 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 <u>all</u> 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." <u>Id.</u>

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 <u>how</u> 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, as evidenced by all relevant evidence in your case record, 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, and by all other relevant evidence concerning your impairment(s) in your case record, with the

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[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).[6]

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:

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[6] 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 <u>all</u> 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, <u>both</u> seriously impacting <u>but</u> 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 <u>same</u> 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 plus or minus 2 SEM's.

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

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[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 <u>all</u> 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]

<u>Quality Review</u>

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. (<u>See</u> 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?"

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[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.

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* 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
SJF

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

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;

Page 2
Letter to Comissioner Daniels
March 20, 1997

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 Or.

cc: Jonathan Stein

2

The Joseph P. Kennedy, Jr. Foundation
1325 G STREET, N.W., SUITE 500
WASHINGTON, D.C. 20005-4709
(202) 393-1250

April 8, 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:

The undersigned believe that the SSA has taken an inconsistent position in its proposed regulation as determined by a word by word analysis of both the proposed regulations and the existing (1992) manual on evaluation.

Specifically:

1) It is our 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 limitations.

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 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, and to be fair to all parties concerned. The concept of measurement error is recognized in other listings, such as measurement of physiological functions and is accepted universally by medical and psychological experts.

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

The same strategy applies to motor and communicative scores, but in these measures, one uses standard scores, not IQ. Standard scores less than 70 +/- 2 SEM are likewise reflective of marked and severe motor and communicative functional limitations. SEM's can be provided in tabular form for most accepted psychological tests.

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 pertain to self-care adaptive instruments. The four best measures 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 externalized 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.

2) 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.

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.

3) Experts 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.

A) 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;

B) 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 diagnosis and assessment;

C) 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 and 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 or other modalities that would be helpful in the presence of normal cognition;

4) The limitation of assessment for ages 1 to 3, to three domains as presently described, with the requirement that impairments in 2 domains are needed for eligibility is tantamount to requiring "pervasive" limitation in functioning - a standard in excess of that required by Congress;

5) Of great concern is the level of expertise to be employed for adjudication and for consultative exams. "Children are not just small adults". Expertise is available in every state through the Network of University Affiliated Programs

(UAP'S). These UAP's should be used for training by DDS's at the state and local level and for consultative and clinical expertise. State licensure regulations for physicians and psychologists do not differentiate between those with expertise with young children and those with expertise in older children and adults. Standards must be more specific than merely appropriate state licensure, in order to assure that assessors have the training and competencies necessary to make what are often fine distinctions in functioning;

6) Finally, any expert dealing with children will recognize that overall functioning is not the sum of the parts. A child's functioning must be viewed wholisitcally. How the whole child functions in relation to his/her peers is critical.

Sincerely,

Pasquale Accardo, M.D., Director of Pediatrics, Westchester Institute of Human Development, Professor, New York Medical College

Robert E. Cooke, M.D., Chairman, Scientific Advisory Comittee, The Joseph P. Kennedy, Jr. Foundation, Professor Emeritus of Pediatrics, State University of New York Buffalo

Gary Goldstein, M.D., President, Kennedy Kreiger Institute, Professor, Pediatrics and Neurology, Johns Hopkins University School of Medicine

Michael Hardman, Ph.D., Professor of Special Education and Associate Dean, University of Utah, School of Education, Salt Lake City, Utah

R. Rodney Howell, M.D.
Professor and Chairman, Department of Pediatrics
University of Miami School of Medicine

Guy McKhann, M.D., Director, Krieger Institute on the Brain, and Professor Emeritus of Neurology, Johns Hopkins University School of Medicine

Michael Msall, M.D., Director, Child Development Center and Professor of Pediatrics, Brown University Medical School

Mary Tierney, M.D., Medical Director
Health Services for Children with Special Needs, Inc.
Washington, D. C.

c Chief Counsel Arthur Fried
Associate Comissioner Susan Daniels
Janet Bendann, Office of Disability

nsortium for
Citizens with
Disabilities

③

April 10, 1997

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

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

Dear Acting Commissioner Callahan:

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

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

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

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

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

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

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

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

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

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

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

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

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

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

RECOMMENDATION:

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

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

II. SUBSTANTIVE ISSUES WITHIN THE STANDARD

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

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

1. Cognition and Communication Should Be Assessed Separately

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

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

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

RECOMMENDATION:

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

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

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

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

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

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

RECOMMENDATION:

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

3. Measurement of IQ Must Include Room for Measurement Error

The American Association on Mental Retardation describes the measurement and use of IQ scores in *Mental Retardation: Definition, Classification, and Systems of Supports* (9th Edition, 1992), the definitive authority on diagnosis and measurement of mental retardation. AAMR cautions against strict adherence to IQ scores and urges consideration of the concept of standard error of measurement, which is estimated to be about three to five IQ points (±3 to 5). An individual whose IQ score measures 70 should actually be considered to have an IQ in the range of at least 66 to 74 or 62 to 78 (depending on the probability of accuracy sought). Therefore it is critical that SSA not allow its disability examiners to use IQ scores to eliminate children from eligibility, rather they should look at the total child and his/her functional limitations. Children whose IQ scores are 75 or below should be considered as possibly having an impairment "two standard deviations below the norm" (SSA's definition of "marked" in areas where standard testing is available). For children with such an IQ score and the presence of a marked limitation in another area of childhood functioning, this could deny access to critical SSI cash support and medical and other supports through Medicaid. Strict adherence to numerical scores is inappropriate and could have a harsh impact on children who have severe functional limitations.

RECOMMENDATION:

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

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

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

RECOMMENDATION

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

"Other factors" Need Better Link to Functional Assessment

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

RECOMMENDATION

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

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

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

RECOMMENDATION

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

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

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

RECOMMENDATION

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

III. IMPLEMENTATION ISSUES

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

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

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

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

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.

no longer be protected by mmunity for reporting. Only ch reports will be protected.

lly, we have clarified the definiof child abuse or neglect to pro- additional guidance and assistance States as they endeavor to protect children from abuse and neglect.

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

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

STUDENT AID

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

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

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

CHILDREN'S SSI

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

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

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

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

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

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

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

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

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

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

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

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

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

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

may be some dif- bout the purpose of e SSI program was ed to provide a small to individuals who cannot se of age or disability. But n's SSI program had a some- ferent purpose—to help poor es with the extra costs of having ild with a disability. It seems the gram 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 co-manager of this bill.

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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September 17, 1996

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

Dear Mr. President:

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

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

The debate over this issue was heated at times, but, ultimately, we reached a compromise on the definition of childhood disability in September, 1995. That definition became part of the overall Congressional compromise on SSI, and was included in the first two versions of welfare reform approved by Congress and then finally in the bill enacted in August. The compromise is notable in two ways. First, it preserves a broad functional approach, <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

COMMITTEES
AGRICULTURE, NUTRITION, AND FORESTRY
FINANCE
BUDGET
[illegible]

United States Senate
WASHINGTON, DC 20510-2403

September 4, 1996

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

Dear Mr. President:

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

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

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

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

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

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

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

Sincerely,

KENT CONRAD
United States Senate

KC:wmah

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

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

October 4, 1996

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

Dear Mr. President:

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

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

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

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

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

With best wishes, I am

Sincerely,

Tom Daschle
United States Senator

cc: The Honorable Carol Rasco
The Honorable Shirley Chater

LEY-BRAUN
NOIS

COMMITTEES:
BANKING, HOUSING, A
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 welfa law could result in anywhere from a ten percent to a twenty-eight percent reduction in SSI caseloads. This demonstrates the considerable discretio 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 Coalitio 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 "on marked/one moderate" functional disability test. This standard is an acceptable and reasonable approach which fulfills the statutory demand fo 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

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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 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,

Cohen

William S. Cohen
Chairman

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

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

December 9, 1996

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

Dear Mr. President:

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

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

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

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

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

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

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

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

Sincerely,

Tom Harkin

Tom Harkin
United States Senator

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

United States Senate
WASHINGTON, DC 20510-2303

November 12, 1996

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

Dear Secretary Shalala:

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

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

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

addition, I would hope that in issuing its new bility standards, the Department of Health and Human vices would recognize that the medical and education ommunities 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 Joseph P. Kennedy, Jr. Foundation
1325 G STREET, N.W., SUITE 500
WASHINGTON, D.C. 20005-4709
(202) 393-1250

4

April 11, 1997

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

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

Dear Commissioner Callahan:

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

Sincerely, and with thanks

Eunice Kennedy Shriver

Eunice Kennedy Shriver

United States Senate
WASHINGTON, DC 20510

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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

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May 20, 1997

TO: KENNETH APFEL, OMB ASSOCIATE DIRECTOR

FROM: JONATHAN STEIN, GENERAL COUNSEL
RICHARD WEISHAUPT, HHS PROJECT HEAD

DATE: MAY 19, 1997

RE: SUMMARY RECOMMENDATIONS FOR CHANGES IN SSI CHILD DISABILITY REGULATIONS PUBLISHED AS "INTERIM FINAL" RULES, 62 FED. REG. 6408 (FEB. 11, 1997)

The new SSI rules for determining disability eligibility of children eschewed a middle course and opted for the extreme test of tying eligibility to the Listings of Impairments. The Listings were never designed to provide a final step and fair evaluation of disability but rather were designed as a screening device for obvious cases like an IQ under 59 or the requirement of leg braces or a wheelchair for a child with cerebral palsy.

The new test is so extreme that the great majority of the 260,000 children being reviewed are likely to be terminated. It is for this reason that a bipartisan group of ten Senators, including the prime drafters of the final "marked and severe functional limitations" language, urged the President to reconsider these rules to strike a mean between the old IFA test and the Listings. (See letter of April 14, 1997 of Sens. Conrad, Chafee, Kennedy, Harkin, Rockefeller, Baucus, Jeffords, Leahy, Dodd and Daschle.)

The Administration should adopt the following changes to avoid a disaster paralleling the Reagan purge of the disabled of the early 80's:

1. Effect of Combined Impairments: Since 1984, SSA has been required by statute to weigh the effect of combined impairments to meet the ultimate disability test. Thus a failure to thrive infant with many developmental delays in many areas of functioning, each one of which is not at a "marked" level (i.e. less than 3/4 of chronological age), is denied SSI under the new rules because there is no way to consider less than marked impairments. Also, an IQ over 70, e.g. 71 or 73, is similarly not counted at all, prejudicing children with mental retardation.

Recommendation: Make explicit provision for weighing combined effects of separate impairments so that even if they are less than "marked" they can all together meet the "marked and severe functional limitations" test.

2. Considering Multiple Impairments Impacting One "Broad Area": The child with two very separate medical problems, like severe asthma and mental depression, which impact the same "area" of functioning, e.g. concentration, persistence or pace, is treated unfairly as this registers just one "marked." The actual impact will be greater when two medical problems co-exist.

Recommendation: The rules must recognize that two impairments leading to two different functional limitations in the same functional "broad area" should be counted as separate marked limitations.

3. Inclusion of Standard Error of Measurement for Tests: When standardized tests are used, SSA defines "marked" as more than two standard deviations from the norm. However, SSA fails to apply the accepted scientific methodology of a plus or minus two Standard Errors of Measurement. (See comments of Mrs. Shriver and experts at the Jos. P. Kennedy, Jr. Foundation.) Children with mental retardation scoring just above a 70 IQ, but within the Standard Error of Measurement are thus prejudiced.

Recommendation: SSA must revise the definition of "marked" for standardized tests to include the universal concept of 2 SEM's to embrace children, e.g. with IQ's in the low 70's who are within the error range of the test.

4. Separating the Cognitive/Communication "Areas": Despite having previously evaluated cognitive and communication functioning separately, SSA, without any congressional directive, made them one "area" so that a child with mental retardation (a cognitive deficit) who also has a separate, major speech or hearing problem (a communication deficit) is considered to have only one "area" impacted. (Kennedy Foundation and other experts state that this is not good science or clinical practice.)

Recommendation: The rules should recognize that communication and cognition are two major and separate spheres of activity and should not be combined.

5. Expanding Areas of Functioning for Children Aged 1 to 3: The rules, again without congressional directive, have confined the youngest children, aged 1 to 3, to just three areas, eliminating the areas of personal development (e.g. problems in toileting or incontinence) and concentration, persistence or pace. Where other children must show two "marked" out of 5 areas, these children must show 2 of 3. Effectively they are required to show an almost total or "pervasive" disability (the latter extreme criterion, was rejected by the Senate.)

Recommendation: Restore the practice of evaluating children aged 1 to 3 in these two additional areas.

6. Fairly Evaluating Physically Disabled Children: The broad areas SSA has used in its new approach are borrowed from the mental disorder criteria, supplemented only with an assessment of motor skills. Physically impaired children often cannot be fairly assessed with largely mental disorder criteria, as the National Academy of Social Insurance Report to the House Ways & Means Committee concluded last year.

Recommendation: The rules must include an additional area of functioning to capture non-motor "marked and severe functional limitations" of physically disabled children. The area as has been suggested by many should be: "Other non-motor functions considered as 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."

7. Clarify and Expand "Other Factors" to Insure Realistic Evaluations: SSA continues an "other factors" policy to supplement the evaluation by taking into account, for example, how highly structured settings may mask or minimize the actual extent of a child's problems. But it is unclear how this is to be factored in with the two marked requirement. (The best explanations for making this a usable policy, that existed in prior Program Operation Manual Systems instructions, have been dropped.)

Recommendation: SSA must give more specific guidance in the regulations as to how the "other factors" are to be used in functional equals decisions, and how conditions may become "marked" and how the test of "marked and severe functional limitations" may be met through their application. Examples should be incorporated into the rules, as well as using prior POMS language.

* * * *

Only through adoption of these above changes can a disaster be avoided among these children now on SSI.

Process notes:

(a) We are aware of no timetable nor sense of urgency at SSA to quickly consider comments and make appropriate changes in the rules before large numbers of children are cut off. No timeline has been set.
This must change.

(b) Also, SSA has no plans to apply corrected rules to application or termination cases decided under the "interim" rules. This is grossly unfair, and would establish two sets of rules for children. Where rules changes are outcome determinative, SSA should apply corrected rules.

Because the new "interim final" SSI eligibility rules combine the functioning areas of cognition and communication into one, i.e. "cognition/communication", contrary to the views of all the medical organizations serving children with mental disorders who have commented on the these rules, it is very likely that the state disability agency was forced to evaluate the separate cognitive and communication disorders, (mental retardation and selective mutism), as one problem, thereby depriving the child of a rating of two functional areas at a "marked" level.

For more information please call Jonathan Stein (215) 981-3742, Mary Noland, 981-3788, or Richard Weishaupt at 981-3773 at CLS.

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5/20/97

Terminated from SSI, Y.D. is an 11 year with mental retardation, selective mutism, and major emotional/behavioral problems

On May 7, 1997 Y.D.'s mother received a termination letter from the Social Security Administration tell her that her 11 year old son, receiving SSI disability benefits in Pennsylvania since 1994, was ending.

The boy suffers from multiple problems: After testing by a pediatric psychologist in April, 1995 his mental retardation and "borderline intellectual functioning" was confirmed with IQ scores of 58 in Performance, 63 in Verbal, and 56 Full Scale using the WISC-III test.

The boy also suffers from a separate communication disorder, selective mutism. At age 4 he was taken out of day care when he did not talk there. His silence continued through kindergarten, first and second grades, and he was finally placed in a class with children with disabilities. At age 8 his serious behavior problems also began in school, manifested by aggressive, disrespectful and destructive behavior, along with frequent school suspensions.

Testing of adaptive behavior using the Vineland Adaptive Behavior Scales showed the boy with low adaptive behavior skills consistent with mental retardation. Although placed in a Special Education learning support class for children classified as Learning Disabled it was recommended that he instead be classified as a student with Mental Retardation.

The Pa. Bureau of Disability Determinations had scheduled a consultative examination with a psychologist but then it was inexplicably cancelled and a termination decision made.

The family was fortunate to have been referred by a social agency to Community Legal Services, as the mother had no understanding of her appeal rights even though she had received SSA's 4 page termination letter. With the aid of CLS the mother promptly appealed.

With such low IQ scores the child would appear to have met the mental retardation, Listing sec. 112.05(C), or "equaled" it because performance and full scale IQ scores were 59 or less, and when the case was reviewed in March and April 1997 the test score was not yet more than 2 years old. (If an updated test was needed, why was the CE cancelled? to save money? to rush the decision through without full development because of arbitrary time pressures to complete these reviews?)

(c) SSA has refused to include in termination letters the phone numbers and names of local, non-profit agencies who can assist families. This unnecessarily hurts low income families, almost all of whom have no ongoing legal representation and who are often of limited education.

Withdrawal/Redaction Marker
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DOCUMENT NO. AND TYPE	SUBJECT/TITLE	DATE	RESTRICTION
001. form	Children's Seashore House evaluation document (5 pages)	04/14/1995	P6/b(6)

COLLECTION:

Clinton Presidential Records
Domestic Policy Council
Elena Kagan
OA/Box Number: 14370

FOLDER TITLE:

Social Security - Children's Disability Standard [4]

2009-1006-F
ke680

RESTRICTION CODES

Presidential Records Act - [44 U.S.C. 2204(a)]

P1 National Security Classified Information [(a)(1) of the PRA]
P2 Relating to the appointment to Federal office [(a)(2) of the PRA]
P3 Release would violate a Federal statute [(a)(3) of the PRA]
P4 Release would disclose trade secrets or confidential commercial or financial information [(a)(4) of the PRA]
P5 Release would disclose confidential advice between the President and his advisors, or between such advisors [a)(5) of the PRA]
P6 Release would constitute a clearly unwarranted invasion of personal privacy [(a)(6) of the PRA]

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b(1) National security classified information [(b)(1) of the FOIA]
b(2) Release would disclose internal personnel rules and practices of an agency [(b)(2) of the FOIA]
b(3) Release would violate a Federal statute [(b)(3) of the FOIA]
b(4) Release would disclose trade secrets or confidential or financial information [(b)(4) of the FOIA]
b(6) Release would constitute a clearly unwarranted invasion of personal privacy [(b)(6) of the FOIA]
b(7) Release would disclose information compiled for law enforcement purposes [(b)(7) of the FOIA]
b(8) Release would disclose information concerning the regulation of financial institutions [(b)(8) of the FOIA]
b(9) Release would disclose geological or geophysical information concerning wells [(b)(9) of the FOIA]

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DOCUMENT NO. AND TYPE	SUBJECT/TITLE	DATE	RESTRICTION
002. form	Transitions Today evaluation document (4 pages)	09/22/1995	P6/b(6)

COLLECTION:
Clinton Presidential Records
Domestic Policy Council
Elena Kagan
OA/Box Number: 14370

FOLDER TITLE:
Social Security - Children's Disability Standard [4]

2009-1006-F
ke680

RESTRICTION CODES

Presidential Records Act - [44 U.S.C. 2204(a)]

- P1 National Security Classified Information [(a)(1) of the PRA]
- P2 Relating to the appointment to Federal office [(a)(2) of the PRA]
- P3 Release would violate a Federal statute [(a)(3) of the PRA]
- P4 Release would disclose trade secrets or confidential commercial or financial information [(a)(4) of the PRA]
- P5 Release would disclose confidential advice between the President and his advisors, or between such advisors [a)(5) of the PRA]
- P6 Release would constitute a clearly unwarranted invasion of personal privacy [(a)(6) of the PRA]

- C. Closed in accordance with restrictions contained in donor's deed of gift.
- PRM. Personal record misfile defined in accordance with 44 U.S.C. 2201(3).
- RR. Document will be reviewed upon request.

Freedom of Information Act - [5 U.S.C. 552(b)]

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- b(9) Release would disclose geological or geophysical information concerning wells [(b)(9) of the FOIA]

Withdrawal/Redaction Marker
Clinton Library

DOCUMENT NO. AND TYPE	SUBJECT/TITLE	DATE	RESTRICTION
003. form	Philadelphia School District Individualized Education Program (6 pages)	03/1996	P6/b(6)

COLLECTION:

Clinton Presidential Records
Domestic Policy Council
Elena Kagan
OA/Box Number: 14370

FOLDER TITLE:

Social Security - Children's Disability Standard [4]

2009-1006-F
ke680

RESTRICTION CODES

Presidential Records Act - [44 U.S.C. 2204(a)]

- P1 National Security Classified Information [(a)(1) of the PRA]
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112.05

OR

B. Mental incapacity evidenced by dependence upon others for personal needs (grossly in excess of age-appropriate dependence) and inability to follow directions such that the use of standardized measures of intellectual functioning is precluded;

OR

C. A valid verbal, performance, or full scale IQ of 59 or less;

OR

D. A valid verbal, performance, or full scale IQ of 60 through 70 and a physical or other mental impairment imposing additional and significant limitation of function;

OR

E. A valid verbal, performance, or full scale IQ of 60 through 70 and:

1. For older infants and toddlers (age 1 to attainment of age 3), resulting in attainment of development or function generally acquired by children no more than two-thirds of the child's chronological age in either paragraphs B1a or B1c of 112.02; or

2. For children (age 3 to attainment of age 18), resulting in at least one of paragraphs B2b or B2c or B2d of 112.02;

OR

F. Select the appropriate age group:

1. For older infants and toddlers (age 1 to attainment of age 3), resulting in attainment of development or function generally acquired by children no more than two-thirds of the child's chronological age in paragraph B1b of 112.02, and a physical or other mental impairment imposing additional and significant limitations of function;

OR

2. For children (age 3 to attainment of age 18), resulting in the satisfaction of 112.02B2a, and a physical or other mental impairment imposing additional and significant limitations of function.

12.06 *Anxiety Disorders:* In these disorders, anxiety is either the predominant disturbance or is experienced if the individual attempts to master symptoms, e.g., confronting the dreaded object or situation in a phobic disorder, attempting to go to school in a separation anxiety disorder, resisting the obsessions or compulsions in an obsessive compulsive disorder, or confronting strangers or peers in avoidant disorders.

performance, and full scale IQ's are provided, as on the Wechsler series, the lowest of these is used in conjunction with listing 112.05.

IQ test results must also be sufficiently current for accurate assessment under 112.05. Generally, the results of IQ tests tend to stabilize by the age of 16. Therefore, IQ test results obtained at age 16 or older should be viewed as a valid indication of the child's current status, provided they are compatible with the child's current behavior. IQ test results obtained between ages 7 and 16 should be considered current for 4 years when the tested IQ is less than 40, and for 2 years when the IQ is 40 and above. IQ test results obtained before age 7 are current for 2 years if the tested IQ is less than 40 and 1 year if at 40 or above.

Standardized intelligence test results are essential to the adjudication of all cases of mental retardation that are not covered under the provisions of listings 112.05A, 112.05B, and 112.05F. Listings 112.05A, 112.05B, and 112.05F may be the bases for adjudicating cases where the results of standardized intelligence tests are unavailable, e.g., where the child's young age or condition precludes formal standardized testing.

In conjunction with clinical examinations, sources may report the results of screening tests; i.e., tests used for gross determination of level of functioning. These tests do not have high validity and reliability and generally are not considered appropriate primary evidence for disability determinations. These screening instruments may be useful in uncovering potentially serious impairments, but generally must be supplemented by the use of formal, standardized psychological testing for the purposes of a disability determination, unless the determination is to be made on the basis of findings other than psychological test data; however, there will be cases in which the results of screening tests show such obvious abnormalities that further testing will clearly be unnecessary.

Where reference is made to developmental milestones, this is defined as the attainment of particular mental or motor skills at an age-appropriate level; i.e., the skills achieved by an infant or toddler sequentially and within a given time period in the motor and manipulative areas, in general understanding and social behavior, in self-feeding, dressing, and toilet training, and in language. This is sometimes expressed as a developmental quotient (DQ), the relation between developmental age and chronological age as determined by specific standardized measurements and observations. Such tests include, but are not limited to the Cattell Infant Intelligence Scale, the Bayley Scales of Infant Development, and the Revised Stanford-Binet. Formal tests of the attainment of developmental milestones are generally used in the clinical setting for determination of the developmental status of infants and toddlers.

Formal psychological tests of cognitive functioning are generally in use for preschool children, for primary school children, and for adolescents except for those instances noted below.

Exceptions to formal standardized psychological testing may be considered when a psychologist, psychiatrist, pediatrician, or other physician specialist who is qualified by training and experience to perform such an evaluation is not readily available. In such instances, appropriate medical, historical, social, and other information must be reviewed in arriving at a determination.

Exceptions may also be considered in the case of ethnic/cultural minorities where the native language or culture is not principally English-speaking. In such instances, psychological tests that are culture-free, such as the Leiter International Performance Scale or the Scale of Multi-Culture Pluralistic Assessment (SOMPA) may be substituted for the standardized tests described above. Any required tests must be administered in the child's principal language. When this is not possible, appropriate medical, historical, social, and other information must be reviewed in arriving at a determination. Furthermore, in evaluating culture, the best indicator of severity is often the level of adaptive functioning and how the child performs activities of daily living and social functioning.

"Neuropsychological testing" refers to the administration of standardized tests that are reliable and valid with respect to assessing impairment in brain functioning. It is intended that the psychologist or psychiatrist using these tests will be able to evaluate the following functions: Attention/concentration, problem-solving, language, memory, motor, visual-motor and visual-perceptual, laterality, and general intelligence (if not previously obtained).

E. *Effect of Hospitalization or Residential Placement:* As with adults, children with mental disorders may be placed in a variety of structured settings outside the home as part of their treatment. Such settings include, but are not limited to, psychiatric hospitals, developmental disabilities facilities, residential treatment centers and schools, community-based group homes, and workshop facilities. The reduced mental demands of such structured settings may attenuate overt symptomatology and superficially make the child's level of adaptive functioning appear better than it is. Therefore, the capacity of the child to function outside highly structured settings must be considered in evaluating impairment severity. This is done by determining the degree to which the child can function (based upon age-appropriate expectations) independently, appropriately, effectively, and on a sustained basis outside the highly structured setting.

On the other hand, there may be a variety of causes for placement of a child in a structured setting which may or may not be directly related to impairment severity and functional ability. Placement in a structured setting in and of itself does not equate with a finding of disability. The severity of the impairment must be compared with the requirements of the appropriate listing.

F. *Effects of Medication:* Attention must be given to the effect of medication on the child's signs, symptoms, and ability to function. While psychoactive medications may control certain primary manifestations of mental disorder, e.g., hallucinations, impaired attention, restlessness, or hyperactivity, such treatment may or may not affect the functional limitations imposed by the mental disorder. In cases where overt symptomatology is attenuated by the psychoactive medications, particular attention must be focused on the functional limitations which may persist. These functional limitations must be considered in assessing impairment severity.

Psychotropic medicines used in the treatment of some mental illnesses may cause drowsiness, blunted affect, or other side effects involving other body systems. Such side effects must be considered in evaluating overall impairment severity

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Clinton Library

DOCUMENT NO. AND TYPE	SUBJECT/TITLE	DATE	RESTRICTION
004. letter	From F. Koller re: disability (1 page)	04/22/1997	P6/b(6)

COLLECTION:

Clinton Presidential Records
Domestic Policy Council
Elena Kagan
OA/Box Number: 14370

FOLDER TITLE:

Social Security - Children's Disability Standard [4]

2009-1006-F
ke680

RESTRICTION CODES

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Withdrawal/Redaction Marker
Clinton Library

DOCUMENT NO. AND TYPE	SUBJECT/TITLE	DATE	RESTRICTION
005. letter	From Larry Massanari re: SSI [partial] (4 pages)	05/07/1997	P6/b(6)

COLLECTION:

Clinton Presidential Records
Domestic Policy Council
Elena Kagan
OA/Box Number: 14370

FOLDER TITLE:

Social Security - Children's Disability Standard [4]

2009-1006-F
ke680

RESTRICTION CODES

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SOCIAL SECURITY ADMINISTRATION
SUPPLEMENTAL SECURITY INCOME
Disability Redetermination Decision

MAY 07 1997

Date:

Social Security Number:
[redacted]

A[redacted] A[redacted] FOR
Y[redacted] D[redacted]
[redacted] AVENUE
PHILADELPHIA PA 19142

Important Notice--Y[redacted] SSI Will Stop

Earlier we told you that we were reviewing this child's case to see if he is disabled under the new definition of disability for children. After reviewing all the information carefully, we have decided that this child no longer qualifies for Supplemental Security Income (SSI).

WE URGE YOU TO READ THIS ENTIRE LETTER. IT INCLUDES IMPORTANT INFORMATION ABOUT APPEAL RIGHTS AND MEDICAID ELIGIBILITY. IT ALSO EXPLAINS HOW YOU CAN CONTINUE TO RECEIVE BENEFITS IF YOU APPEAL.

THE DECISION ON THIS CHILD'S CASE

The following reports were used to decide your child's claim.

Others who knew of Y[redacted] Health, report of 4/22/97.
School report of 4/24/97.

You said that your child is disabled due to learning disability and mental retardation.

Records shows that P6/(b)(6) is not severely learning disabled and can comprehend and follow instructions. His behavior is reported as having a negative impact on his learning. His grades in school and average.

WHEN PAYMENTS WILL STOP

P6/(b)(6)

[005]

INFORMATION ABOUT MEDICAID

If this child is getting medical assistance from the Medicaid program, even though he will not be eligible for SSI, he may still be eligible for medical assistance which provides help with

P6/(b)(6) P6/(b)(6)

health care bills. That is because many children may still be eligible for medical assistance if they live in households with little or no income or resources.

The State Medicaid agency may contact you for information they need to make a decision about Medicaid eligibility. If the agency decides that this child is eligible to remain on Medicaid, his medical assistance benefits will continue.

If the State Medicaid agency decides that this child is not eligible to continue on Medicaid, it must send you a separate letter and information about how to appeal that decision. If you appeal that decision on time, the child will continue to receive Medicaid benefits until the appeal is decided. If you have not heard from them in 60 days from the date of this letter, you may want to contact your local medical assistance office of the Department of Public Welfare. (Contact your county assistance office or call the Welfare Helpline at 1-800-692-7462.) If you call or visit that office, please have this letter with you.

YOU HAVE IMPORTANT APPEAL RIGHTS

If you disagree with the decision, you have the right to appeal. We will review the case and consider any new facts you have. A person who did not make the first decision will decide the case.

- You can ask for an appeal anytime within 60 days. But if you want to keep getting payments while we decide the case, you must ask for an appeal within the first 10 days.
- The 60 days start the day after you get this letter. We assume you got this letter 5 days after the date on it unless you show us that you did not get it within the 5-day period.
- You must have a good reason for waiting more than 60 days to ask for an appeal.
- You have to ask for an appeal in writing. We will ask you to sign a form SSA-789-U4, called "Request for Reconsideration--Disability Cessation." To get this form, contact one of our offices. Address and phone number are shown on the last page of this letter. We can help you fill out the form.

Please read the enclosed pamphlet, "Your Right to Question the Decision Made on Your SSI Claim." It contains more information about the appeal.

APPEAL IN 10 DAYS TO KEEP GETTING YOUR PAYMENT

- The 10 days also start the day after you get this letter. We assume you got this letter 5 days after the date on it unless you show us that you did not get it within the 5-day period.

- If you lose the appeal, you might have to pay back some or all of this money. However, we may decide that you do not have to pay the money back.

HOW AN APPEAL WORKS

A Disability Hearing Officer will decide this child's SSI appeal. We will call this person a DHO in the rest of our letter. The DHO will meet with you before making the decision on the appeal. The meeting works like this.

- The DHO will mail you a letter at least 20 days before the meeting to tell you it's date, time, and place.
- You can look at the child's file before the meeting.
- You can tell the DHO the reasons you feel this child is still disabled. You should give the DHO any information you think is missing from the child's file. You can bring someone to represent you at the meeting. And you can bring people to explain the reasons the child is disabled.
- You can have the DHO ask people to come to the meeting to speak about this child's disability and bring important papers. You can question these people at the meeting.
- You do not have to go to the meeting in person. If you do not want to go, you can still give the DHO more facts you may have. The DHO will decide the case using these facts, and what is now in the file. But if you go to the meeting, it may help the DHO decide the case.

IF YOU WANT HELP WITH YOUR APPEAL

You can have a lawyer, friend, or someone else help you. There are groups that can help you find a lawyer or give you free legal services if you qualify. There are also lawyers who do not charge unless you win your appeal. The local Social Security office has a list of groups that can help you with your appeal.

If you get someone to help you, you should let us know. If you hire someone, we must approve the fee before he or she can collect it.

IF THIS CHILD'S HEALTH GETS WORSE

If this child's health gets worse, please get in touch with us. The child may be able to get SSI again. We can help you file a new application for SSI.

You have the right to file a new application at any time, but filing a new application is not the same as appealing this decision. So, if you disagree with this decision, you should ask for an appeal within 60 days.

P6/(b)(6)

P6/(b)(6)

IF YOU HAVE ANY QUESTIONS

If you have any questions you may call us toll free at 1-800-772-1213, or call your local Social Security office at 215-729-4991. We can answer most questions over the phone. You can also write or visit any Social Security office. The office that serves your area is located at:

Social Security Administration
6120 Woodland Avenue
Second Floor
Philadelphia, PA 19142-3223

If you do call or visit an office, please have this letter with you. It will help us answer your questions. Also, if you plan to visit an office, you may call ahead to make an appointment. This will help us serve you more quickly.

Larry Massanari
Regional Commissioner

Enclosure:
SSA Pub. No. 05-11008
247
mh

Diana Fortuna 02/07/97 10:27:20 AM

Record Type: Record

To: Kathleen M. McKiernan/WHO/EOP

cc: Elena Kagan/OPD/EOP, Kenneth S. Apfel/OMB/EOP, Richard E. Green/OMB/EOP
Subject: Children's SSI stories

FYI, there is one number in most of the stories today on children's SSI that is wrong, due I believe to a misunderstanding between reporters and SSA.

It is the number that, over the next five years, another 45,000 children who would have qualified under the old rules will not get benefits. I think that number should have been 90,000, but we are checking. (There is no problem with SSA's main statement that 135,000 now on the rolls will lose eligibility.)

SSA has to straighten this out and figure out how to handle it. I am told they didn't put out the wrong number, but that reporters did an oversimplified calculation in their heads. The advocates were suspicious that the number was low, so they will certainly highlight it once they figure it out.

File: SSI

Diana Fortuna 02/14/97 03:41:54 PM

Record Type: Record

To: Cathy R. Mays/OPD/EOP

cc: Elena Kagan/OPD/EOP, Kenneth S. Apfel/OMB/EOP, Richard E. Green/OMB/EOP
Subject: Call from Wall St. Journal

FYI, Chris Georges of the Wall St Journal is working on a story on the "inside story" of how the administration made the decision on the childhood SSI disability regs. He just called me, and I understand he has called Ken. I don't know his angle, but he did a very detailed story on this a few months ago that talked about OMB's view vs. DPC's vs. SSA's.

Kathy McKiernan says that Larry Haas of OMB press will handle the calls, but I wanted you to know it's possible he'll call Bruce. Apparently he is writing the story for next week.

Diana Fortuna

01/29/97 07:03:52 PM

Record Type: Record

To: REED_B @ A1 @ CD @ LNGTWY

cc: Kenneth S. Apfel/OMB/EOP, MAYS_C @ A1 @ CD @ LNGTWY, Elena Kagan/OPD/EOP
Subject: Children's SSI

I know this is getting tiresome, but:

Chater apparently is still hoping/expecting to talk to you -- I think really as a courtesy on wrapping up the date to announce their decision. (FYI, if you talk to her, she may argue that Wednesday of next week is better than Thursday....)

Whatever the decision, it makes sense for the 7:45 senior staff meeting to hear what the planned date is, just to make sure everyone is on board.

File

File
SSI disability

FORTUNA_D @ A1
01/13/97 04:45:00 PM

Record Type: Record

To: REED_B @ A1@CD@LNGTWY

cc: Elena Kagan, RASCO_C @ A1@CD@LNGTWY, MAYS_C @ A1@CD@LNGTWY
Subject: Timing of announcement of children's SSI

There is a glitch in our plan to announce the children's SSI decision on Thursday: the disability advocacy community's major inaugural event is a brunch on Friday morning. It seems a mistake to announce what the community will perceive as perhaps the worst decision we have made on disability issues on the eve of this event, which will include the advocates who feel most strongly about this issue. Carol's recommendation, as well as my own, is that we have to wait until after Monday.

Considerations include:

- SSA is trying to limit the number of people who know about this, but waiting does increase the chance that it will leak (which is already a considerable risk).

- We need to make our decision on timing 2 days in advance of the announcement, because of the logistics of SSA sending the reg to OMB to clear. So, if it's Thursday, we have to decide by tomorrow.

- If for some reason the day or two after the inaugural are also perceived as bad days to announce this, then we will be sitting on this an awfully long time.

Ken A. thinks this must be decided at tomorrow's 7:30 meeting. However, if it is obvious to all of us that Thursday is dumb, then it's not clear to me this has to be decided there, although it would probably make sense to report to people on it.

Let me know if you disagree with a delay.

REED_B @ A1
01/13/97 05:16:00 PM

Record Type: Record

To: FORTUNA_D @ A1@CD@LNGTWY

cc: Elena Kagan, RASCO_C @ A1@CD@LNGTWY, MAYS_C @ A1@CD@LNGTWY
Subject: RE: Timing of announcement of children's SSI

Let's just put it off. But don't do it next week, do it the week after or later. We could get beat up from all sides for making this the very first thing we do in the new term.

FORTUNA_D @ A1
01/13/97 05:21:00 PM

Record Type: Record

To: REED_B @ A1@CD@LNGTWY

cc: Elena Kagan, Kenneth S. Apfel, RASCO_C @ A1@CD@LNGTWY, MAYS_C @ A1@CD@LNGTWY
Subject: RE: Timing of announcement of children's SSI

I hear what you're saying, and don't disagree.

I do want to make sure you're aware of the downsides of waiting that long -- the increased risk of a leak (people suspect strongly a decision has been made because they hear the budget is done); the continuing growth in the backlog of cases that SSA has been sitting on pending a decision; and the risk someone will do a story on the backlog itself (probably 100,000 new applications waiting since August, with many of these children eligible for benefits).

Diana Fortuna 02/06/97 04:39:06 PM

Record Type: Record

To: Elena Kagan/OPD/EOP, William H. White Jr./WHO/EOP

cc:
Subject: FYI reaction of major advocacy group to SSI children

--------------------- Forwarded by Diana Fortuna/OPD/EOP on 02/06/97 04:25 PM ---------------------------

HASKINS_M @ A1
02/06/97 03:26:00 PM

Record Type: Record

To: See the distribution list at the bottom of this message

cc:
Subject: THE ARC CONDEMNS LOSS OF SSI ASSISTANCE FOR DISABLED ...

Date: 02/06/97 Time: 14:47
bThe Arc Condemns Loss of SSI Assistance for Disabled Children

To: National Desk
Contact: Marty Ford, 202-785-3388, or Stacey Ellis,
202-223-4933,
both for the The Arc of the United States

WASHINGTON, Feb. 6 /U.S. Newswire/ -- The Arc of the United States, a national organization on mental retardation, is deeply disappointed in today's announcement by the Social Security Administration (SSA) of its new, overly harsh standards for a child's eligibility for benefits under the Supplement Security Income (SSI) program. While we acknowledge the attempt by the SSA to recognize the importance of functional abilities in assessing SSI eligibility, we reject as excessive the severity thresholds the new requirements establish. The SSA had considerable leeway in setting the new eligibility standards, yet chose to push for changes that go beyond what was necessary under last year's welfare law. The Arc is also very disappointed that this decision appears to have been driven by budget targets, rather than by what is in the best interest of the children involved. The proposal is expected to save $4.8 billion over the next six years.

To achieve the Clinton Administration's budgetary goals, 135,000 children with disabilities who are currently on the SSI program must lose essential benefits that serve as a lifeline for keeping the family together. It is estimated that an equal number will have to be denied access to this lifeline program over the next six years. This equals a total of almost 250,000 children with severe disabilities who will lose or be denied critical benefits.

Today's decision will have a staggering impact in a number of ways:

-- Families across America will lose basic support and, in many cases, medical benefits. Already families are reporting to The Arc that they will be forced to give up their child to foster care or institutionalization. Removing a child from loving parents and a home atmosphere increases the likelihood that a child will never achieve her or his highest level of functional ability and violates all of our values regarding family life.

-- The potential influx of these children into state and local service systems will place a severe strain on local communities, if the children receive any assistance at all.

-- While these changes may help cut federal spending, the impact that they will have on the families who are already living at or near poverty will be devastating. The children who are dropped from the SSI program remain severely disabled and in need of assistance. If state and local governments cannot or will not make up the difference in lost support to these children, their families will simply find themselves abandoned in their efforts to provide proper care.

The Arc demands that the administration:

-- Take responsibility for thoroughly assessing each child before dropping him or her from the rolls;

-- Evaluate the impact of these new eligibility requirements on families of children with disabilities by tracking what happens to the families that lose these critical supports;

-- Ensure that all families being reviewed have information about available assistance in the review process;

-- Continue providing SSI assistance to families of children with sever disabilities who are already on the program until a final decision is made by a Social Security judge.

The Arc calls upon the public to express its disapproval of these new eligibility standards through the planned public comment period. It is only through the activism of the public that this damaging decision can be amended.

As a result of today's announcement, The Arc expresses its grave concern for children with disabilities and their families as they are dropped from federal assistance rolls.

Founded in 1950, The Arc is the nation's largest volunteer organization dedicated solely to issues of mental retardation. There are 140,000 members working through 1,100 local and state chapters. The National Headquarters is in Arlington, Texas, with the Governmental Affairs office in Washington, D.C.

-0-

/U.S. Newswire 202-347-2770/
APNP-02-06-97 1453EST

Message Sent To:____

Diana Fortuna 02/06/97 10:37:30 AM

Record Type: Record

To: Bruce N. Reed/OPD/EOP, Elena Kagan/OPD/EOP

cc: Cathy R. Mays/OPD/EOP
Subject: OMB strategy on kids ssi

Ken tells me that Frank plans to emphasize how we are saving 55,000 kids in press conference in response to questions on childrens' SSI. This is getting a lot of press interest (Pear, Havemann will come to SSA press conference today to cover this).

I wanted to flag this to you because it increases the risk that people figure out we spent $2 billion and they add it to the fix package total. That $2b is nowhere in our documents. We can say this is an administrative interpretation, not a policy change, so it shouldn't be added to $17.9, but it is a risk.

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 far 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.

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ADDITIONAL TALKING POINTS ON CHILDREN'S SSI

- The Administration's position on this issue reflects the best understanding of Congressional intent.

- It is a middle ground position. It is not the position that disability advocates have urged on the Administration. But it is less harsh than a prior understanding of the law, under which 55,000 additional children would have been cut off.

- This interpretation ensures that severely disabled children and their families are protected under the new law, while tightening standards for the program in accord with congressional intent.

- In addition, the President is proposing legislation as part of his budget to allow all children who lose benefits as a result of this change to retain Medicaid. For many families on SSI, the most valuable part of their benefit is not the monthly cash payment, but Medicaid coverage.

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01/17/97 05:55:00 PM

Record Type: Record

To: Bruce N. Reed, Elena Kagan

cc:
Subject: timing of ssi children announcement

As you think about this timing issue and events next week, you should know that Chater's last day is Friday, Jan. 31. It certainly would not be appropriate to do this after she leaves, or even in her last few days so that it appears she is running out the door as she announces it. My recommendation would be to do it Thursday or Friday of next week; or else Monday or at the latest Tuesday of the following week.

Bruce —
Agree?
Elena

Diana Fortuna 02/13/97 07:40:35 PM

Record Type: Record

To: Bruce N. Reed/OPD/EOP, Elena Kagan/OPD/EOP, Kenneth S. Apfel/OMB/EOP

cc:

Subject: Clay Shaw and childhood disability regs

FYI from Clay Shaw. So far, I haven't seen anything suggesting that we've provoked the Republican leadership on the children's SSI regulation we did.

(By the way, I also hear that the Wall St. Journal may be doing a story on the inside debate on this issue.)

---------------------- Forwarded by Diana Fortuna/OPD/EOP on 02/13/97 07:10 PM ---------------------------

Laura Oliven Silberfarb
02/13/97 05:26:24 PM

Record Type: Record

To: Diana Fortuna/OPD/EOP

cc: Richard E. Green/OMB/EOP

Subject: House Ways and Means Hearing

I was at the Human Resource Subcommittee hearing today because Carolyn Colvin and Olivia Golden were testifying on the President's Budget proposals - and Chairman Clay Shaw publicly praised the SSA Childhood Disability rules.

From his written remarks:
"I want to congratulate the Administration on publishing these regulations. They will serve the goal of ensuring that only truly disabled children receive SSI benefits...I think SSA did a good job of implementing the intent of the law we passed last year."