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The Joseph P. Kennedy, Jr. Foundation

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(2)

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

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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

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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 remains the same – We consider whether the impairment(s) meets, or medically or functionally equals, a listing.... The policy of functional equivalence has not changed, 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"). See 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]See also 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 bi-partisan 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 does not 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 failed to qualify at the step three "meets or equals" step, SSA's estimate that only half of those children whose claims will be reviewed will be terminated is not credible. Thus SSA's representation to the White House and public in the policy Assessment of charting a middle course is disingenuous.

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

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

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

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

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

B. Specific Remediable Problems with the Interim Final Regulations

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

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

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

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

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

--separate the cognitive/communicative "area";

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

4. Section 416.924b--Functioning in children.

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

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

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

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

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

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

To avoid "other factors" continuing to be a largely ignored policy in adjudications, SSA should give more specific guidance in the regulation as to <u>how</u> it should be used in the very concrete contexts of the critical "marked" and "moderate" adjudicative terms. Thus SSA should prescribe in accordance with the clear intent of, for example, the structured setting "factor," § 416.924c(d), 62 Fed. Reg. at 6423, that a "moderate" level of

functioning in a supportive setting may in fact be a "marked" level outside of the setting. SSA should bring into the rules the more helpful discussion of the "other factors" from the POMS § DI 25214.001.A.2 (Draft, Mar. 5, 1997), but this cannot substitute for guidance on how they affect "marked"/"moderate" and the ultimate finding.

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

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

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

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

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

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

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

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

> (A) How medical equivalence is determined. We will decide that your impairment(s) is medically equivalent to a listed impairment in appendix 1 of subpart P of part 404 of this chapter if the medical findings, 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

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

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

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

7. Section 416.926a--Functional Equivalence

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

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

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

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

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

broad areas should contain an explanation and examples of how deficits in development in one area can delay development or functioning in other areas.

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

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

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

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

This is also a problem in Form SSA-538.

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

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

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

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

This is also a problem in Form SSA-538.

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

(5) In considering the methods under which you may have an impairment(s) that is functionally equivalent to a listed impairment, we will consider the following factors, which are discussed elsewhere in these regulations:

- corrected chronological age (20 C.F.R. § 416.926a(b));
- your ability to adapt to an impairment(s) (20 C.F.R. § 416.926a(c)(1));
- the interactive and interdependent impact of severe impairments on you if you are a younger child (20 C.F.R. § 416.926a(c)(3));
- the impact of degenerative disorders on you if you are an older child (20 C.F.R. § 416.926a(c)(4));
- the importance of developmental milestones for you from birth to attainment of age 3 (20 C.F.R. § 416.926b(b)(2));
- the importance of activities of daily living for you from age 3 to attainment of age 16 (20 C.F.R. § 416.926b(b)(3));

- the importance of work-related activities for you from age 16 to the attainment of age 18 (20 C.F.R. § 416.926b(b)(4));

- the importance of the factors of chronic illness, effects of medication, effects of highly structured settings, adaptations, time spent in therapy, and school attendance (20 C.F.R. § 416.926c); and

- consideration of your pain and other symptoms (20 C.F.R. § 416.929).[8]

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

properly considered as causing a separate "marked" problem in fine motor skills. Similar problems can, of course, arise in any of the broad areas of function, be they motor, cognition/communication, personal, social or concentration, persistence or pace.

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

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

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

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

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

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

Thus, as Mrs. Shriver wrote with regard to the IQ test, the WISC3, "A Full Scale Score of less than 76, a Performance Score less than 79, and a Verbal Score less than 78 all meet this requirement." Mrs. Shriver goes on to other objective measurements of childhood functioning where the same principle should be applied, e.g. for motor and communicative scores, "standard scores less than 70 +/- 2 SEM are likewise reflective of marked and severe motor and communicative functional limitations;" similarly where social functioning/behavioral rating scales are used (consisting of T scores with a Mean of 50 and a standard deviation of 10), "scores of greater that 70 +/- two SEM's reflect marked and severe functional social-behavioral limitations…."

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

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

Mrs. Shriver's letter dated March 14, 1997 to Associate Commissioner Daniels also makes reference to a number of key standardized tests beyond IQ tests for areas of social functioning, personal functioning and other areas. These are all amenable to the two standard deviations +/- two SEM scoring. SSA has never had a set policy on the use of these tests, and they are often not used or purchased through Consultative Examinations. The

current laissez-faire practice that leaves it up to state agencies is not conducive to obtaining the best and most objective evaluations of children, and worse, almost guarantee non-uniform and subjective assessments of what functional equivalence is.

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

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

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

vi. Clarify the Meaning of "Extreme" Limitations

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

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

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

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

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

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

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

The addition of a motor skills area to the mental disorder functional areas of the Listings incorporated into the functional equivalence test does nothing to cure the existing deficiencies of the IFA test, which inadequately evaluated children with physical problems using the same set of domains, as areas were

then called. SSA must honestly admit that the mental disorder "B" functional criteria were never intended to evaluate the physical disabilities of children. And it simply is not fair to these children to assume as the rules do that all manifestations of physical impairments will be fairly assessed in the personal or concentration, persistence or pace (or motor skills) areas.

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

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

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

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

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

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

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

"1. Scientific Considerations.

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

2. Communication warrants a separate domain.

Communication is the foundation for acquiring skills in many other domains and, therefore, warrants a separate area. Individuals who lack basic communication skills find it difficult to form friendships, be integrated into educational settings, acquire vocational skills, live independently and meet daily life requirements. In fact, perhaps no other facet of human behavior so directly impacts daily life and efforts by persons with disabilities to be productive and independent members of society. It is a category that should stand alone in both diagnostics and assessments.

3. Clinical Implications of Combined Effects.

A combination of Mental Retardation (i.e. I.Q. 2 S.D. below the mean +/-2 SEM's) and a moderate to severe functional limitation in communication (2 S.D's below the mean +/-2 S.E.M.'s) is extremely disabling since there is minimal ability to compensate for functional limitations by the use of assistive technology that would be helpful in the presence of cognition in the normal range."

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

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

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

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

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

This regulation should incorporate language from 20 C.F.R. §§ 416.924d(j) and 416.924e(d), concerning how SSA will evaluate young adults who generally have no work experience, under

the adult disability standard. That language, deleted by SSA as a result of the welfare act, provides an excellent discussion of how persons age 18 and older satisfy the adult standard, and thus provides vital guidance to deciding young adult cases. This is extremely important if the transition from child to adult is a smooth one in terms of SSI eligibility.

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

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

C. Implementation Issues to Address and Remedy

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

Interim Rule Changes

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

Appeal Procedures

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

Outreach To Other Agencies

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

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

Casefile Development

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

BDD Procedures

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

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

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

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

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

Quality Review

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

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

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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	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.
for a child age 3 up to 18 years, she or he has "two" marked impairments. *	
The paragraph "B" criteria were:	The areas of development or functioning to be considered are:
for children from birth to age 1: a) cognitive/communication development; b) motor development; c) social development; and d) responsiveness to stimuli.	for children from birth to age 1: a) cognitive/communication development; b) motor development; c) social development; and d) responsiveness to stimuli;
for children aged 1 to age 3: a) gross or fine motor development; b) cognitive/communicative function; c) social function; and	for children aged 1 to age 3: a) gross or fine motor development; b) cognitive/communicative function; c) social function; and
for children age 3 to age 18: a) cognitive/communicative function; b) social functioning; c) personal/behavioral functioning; and d) concentration, persistence, or pace.	for children age 3 to age 18: a) cognitive/communicative function; b) social functioning; c) personal/behavioral functioning; and d) concentration, persistence, or pace.

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

The Joseph P. Kennedy, Jr. Foundation

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SUBJECT FILE
SF

March 14, 1997

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

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

Dear Dr. Daniels:

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

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

In order to be fair to both children and the government, it must be recognized that, in every test, there is a range of precision(s) expressed as Standard Error of Measurement, SEM. Two SEM's in each standardized test will provide 95% confidence limits. The use of such limits, seems to us essential, in order to avoid challenges on every score in the two standard deviations range.

As an example, a preschool child (age 3-6) has marked and severe functional limitations in cognition if his/her performance scores are two or more standard deviations below the Mean. For example, using the

EXHIBIT C

WISC3 in a six year old, a score of 70 meets this requirement. However, this is not an exact measurement, so it is necessary to include two SEM's to obtain the 95% confidence limits. A Full Scale Score of less than 76, a Performance Score less than 79, and a Verbal Score less than 78 all meet this requirement. I have enclosed the WISC 3 cutpoints as an example. All standardized instruments have manuals with similar tables.

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

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

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

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

a severe feeding problem.

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

Unless specifically warned and trained to deal with these differences, a child who is mildly retarded will not be labeled with a marked and severe impairment, a child who is moderately retarded will not be labeled as having an extreme impairment.

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

Please advise, and thank you.

Sincerely,

Eunice K Shriver

Eunice Kennedy Shriver

& [illegible] 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;

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, I wish warm good wishes

Eunice Kennedy Shriver

Eunice Kennedy Shriver

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

cc: Jonathan Stein

United States Senate

WASHINGTON, DC 20510

(5)

April 14, 1997

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

Dear Mr. President:

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

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

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

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

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

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

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

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

Sincerely,

Senator Kent Conrad

Senator John Chafee

Senator Edward Kennedy

Senator Tom Harkin

Senator John D. Rockefeller IV

Senator James Jeffords

Senator Max Baucus

Senator Patrick Leahy

Senator Christopher Dodd

Senator Tom Daschle

COMMUNITY LEGAL SERVICES, INC.

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(6)

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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(7)

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.

Children's
Seashore House
A Regional Pediatric Specialized Rehabilitation

Name: Y[redacted] D[redacted]
Date of Birth: 1/22/86
Date of Evaluation: 4/14/95
Age: 9 years, 3 months
Lateral Dominance: right handed

REASON FOR REFERRAL: Y[redacted] and his parents have been treated through the Children's Seashore House Section of Pediatric Psychology, for remediation of Y[redacted]' elective mutism and noncompliance. The parents and current therapist (Gretchen Lovett, Ph.D., supervised by John Parrish, Ph.D.) agreed that cognitive and educational assessment at this time were necessary in order to evaluate the appropriateness of Y[redacted]' school placement and to further understand his behavioral difficulties.

BACKGROUND INFORMATION:
Medical History: Y[redacted] was born at full-term and went home with his mother after a 3-day hospital stay. He is currently on no medications and has no known drug allergies. He has never been hospitalized and does not suffer any frequent or recurrent illnesses.

Social History: Y[redacted] lives with his mother, Ms. A[redacted], his father, Mr. D[redacted], and two older brothers. His parents immigrated from Ethiopia approximately 11 years ago. Y[redacted]' parents speak English with some difficulty and do not read any English. Mr. D[redacted] is employed as a custodian and Ms. A[redacted] is not employed outside the home. The family has been seen through Pediatric Psychology at Children's Seashore House intermittently since 8/2/93, initially for treatment of elective mutism and more recently due to concerns regarding aggressivity and noncompliance at school.

School History: Y[redacted] has a history of refusal to speak in school which began in Kindergarten. More recently, he does not refuse to speak but offers only limited responses to questions. He is currently in a non-graded Special Education learning support class for all academic subjects and is "mainstreamed" for art, gym, and music (he receives these with Regular Education teachers, but not with Regular Education students). His current classification is Learning Disabled. Results of previous testing, conducted in 4/92, document Borderline intellectual functioning. His school teacher, counselor and principal report extreme difficulty managing his behavior. Yohannes is aggressive in school; he hits other children and destroys their property. Discipline at the school has consisted of taking him to the Principal's office, even preventively as in not allowing him to go outside for recess each day and instead having him go directly to the Principal's office

even before he has committed an offense that day. Parents are very dissatisfied with the school's treatment of Y[redacted] and believe that his current educational placement is not meeting his needs. Because they do not read English, they have had much difficulty understanding the documentation regarding his placement and in functioning as an advocate for him in the school system.

PROCEDURES:
Parent Interview, Student Interview; Review of School Records; Wechsler Intelligence Scale for Children, Third Edition (WISC-III); Wechsler Individual Achievement Test (WIAT); Vineland Adaptive Behavior Scales-Survey Form, Interview Edition.

BEHAVIORAL OBSERVATIONS: Y[redacted] approached the testing environment in a compliant manner but, as is his typical response style, exhibited a low level of verbalization. He offered no spontaneous conversation. He responded, minimally, to verbal questions. During nonverbal tasks, he appeared to exert considerable effort in trying to solve problems and sometimes became frustrated when the solution was not apparent to him.

Y[redacted] exhibited age-appropriate levels of attention and concentration during testing procedures. He was not noted to be overly active, distractible, or impulsive.

TEST RESULTS:

General Intellectual:

Wechsler Intelligence Scale for Children - Third Edition (WISC-III)	
Verbal IQ (VIQ)	Mildly Intellectually Deficient (63)
Performance IQ (PIQ)	Mildly Intellectually Deficient (58)
Full Scale IQ (FSIQ)	Mildly Intellectually Deficient (56)

On the WISC-III, Yohannes demonstrated cognitive skills in the Mildly Intellectually Deficient range. There was not a significant discrepancy between his verbal and nonverbal intellectual abilities. Individual subtest scores are as follows.

WISC-III (Average 10, with a standard deviation of 3)

VIQ Subtests	Scaled Score	PIQ Subtests	Scaled Score
Information	5	Picture Completion	3
Similarities	4	Coding	1
Arithmetic	6	Picture Arrangement	6
Vocabulary	1	Block Design	4
Comprehension	1	Object Assembly	1
(Digit Span)	10		

Among the subtests on the Verbal Scale, Y[redacted] exhibited a relative strength on the Digit Span subtest indicating Average short-term auditory memory. He demonstrated weaknesses on the Vocabulary and Comprehension subtests, both of which require longer, more complex verbal responses than Yohannes was capable of making.

Y[redacted]' scores on the Performance Scale, which is designed to measure nonverbal perceptual problem solving abilities, reveal broad difficulty with a variety of nonverbal tasks. His performance on the Picture Arrangement subtest was a relative strength (Borderline range). This subtest assesses a child's understanding of cause and effect relationships in social situations.

Academic:	Standard Score	Grade Equivalent
Basic Reading	71	K:8
Reading Comprehension	63	1:0
Spelling to Dictation	67	K:7
Numerical Operations	85	2:5
Mathematics Reasoning	73	1:3
Composites		
Reading	64	1:2
Mathematics	74	2:3

Because Y[redacted] is having difficulty in school, his scores on tests of academic achievement were compared to norms for his age group (rather than his grade) to obtain standard scores.

On tests of core reading skills, Y[redacted] is functioning in the Kindergarten to 1st grade level. On the Basic Reading subtest (i.e. word recognition) he was clearly using phonetic strategies to try to decode the words. For example, he read 'said' as 'sit' and 'slow' as 'sow.' On the Reading Comprehension subtest, Y[redacted] was not able to read the required passages, thus his low score reflects his poor basic reading skills as opposed to a lack of comprehension of what he reads. Y[redacted]' spelling skills are similarly developed, at the K:7 grade level. He could usually produce some of the required letters in the word, but did not know how to spell many words in their entirety.

On tests of math skills, Y[redacted] demonstrated great difficulty solving word problems, identifying shapes, or interpreting simple tables, graphs, or charts. He was more successful on a rote written computation subtest (Numerical Operations) where he demonstrated some command of simple addition and subtraction facts. It is noteworthy that he successfully executed an elaborate strategy for calculating the multiplication problem (4x8=_) by

adding eight four times and keeping a running count of the total. Thus, while he has not memorized that multiplication fact, he demonstrated a solid understanding of the underlying principle. Y[redacted] could not carry out multi-digit subtraction or multiplication problems; he did not appear to know any strategies for going about these problems and did not attempt to solve them.

Adaptive Behavior: By parental response to the Vineland Adaptive Behavior Scales - Survey Form, Y[redacted] appears to be functioning in the Low range overall (Standard Score=44, Moderately Deficient range)). His scores in the three areas assessed were all very similar (Communication=49, Daily Living Skills=50, and Socialization Skills=44). Thus, by his parents' report of what Y[redacted] does in the home environment, it is clear that Yohannes is not functioning at an age appropriate level.

Summary and Recommendations: The current assessment reveals intellectual deficiency and low adaptive behavior skills consistent with a diagnosis of mental retardation, which can be characterized as falling in the mild range. Y[redacted]' academic achievement is at least as advanced as one would predict with such overall cognitive impairments.

Based on the obtained results the following are recommended:

1) Y[redacted] should be referred to his school district for reclassification as a student with Mental Retardation as opposed to his current classification as Learning Disabled.

2) Y[redacted]' inability to complete school work both in class and at home should not be attributed to "laziness" or lack of "motivation." He is truly unable to do much of what may be placed before him and in fact has demonstrated a greater than expected command of academic skills given his level of overall cognitive impairment (suggestive of great effort and achievement on his part). Y[redacted]' reluctant verbal style also should be seen in the context of overall impaired cognitive functioning and the extent to which he is misbehaving when he does not respond to questions should be considered in this light.

3) Y[redacted]' educational programming should continue to focus on academic skill development. To date he has shown adequate absorption of academic skills given his cognitive ability and this educational programming should continue.

4) Y[redacted]' aggressive and noncompliant behaviors require greater one-on-one, systematic behavior management techniques in the classroom/school setting. To this aim, Y[redacted] requires a full-time, individual behavior management aid (Psych-Tech) if he is to function in and benefit from the educational environment.

5) Continuation of parent consultation in behavior management for the home environment is recommended and the current evaluator is participating in ongoing efforts with Yohannes' parents in this regard.

Please do not hesitate to call Dr. Lovett, at (215) 895-3732, or Dr. Moss, at (215) 895-3728, with any questions you may have regarding this evaluation.

Gretchen Lovett

Gretchen D. Lovett, Ph.D.
Post-Doctoral Fellow
Pediatric Psychology

Edward M. Moss, Ph.D.
Clinical Neuropsychologist
PA Licensed Psychologist

TRANSITIONS TODAY

KATHRYN WOODS, Ph.D.
Licensed Clinical Psychologist
Certified School Psychologist

ELIZABETH EDGERTON, MSW
Licensed Social Worker
Academy of Certified Social Workers

~~CONFIDENTIAL~~ EVALUATION

DETERMINED TO BE AN ADMINISTRATIVE MARKING
INITIALS: RY DATE: 4/12/2018
2018-0525-S

IDENTIFYING INFORMATION

Name: J[redacted] D[redacted]
Date of Birth: January 22, 1986
Age: 9
Date of Evaluation: September 22, 1995
Address: [redacted]
Philadelphia, PA 19142
(215) [redacted]
School: Patterson School (LS class)
MA Recipient Number: [redacted]
Social Security Number: [redacted]

COMMUNITY AGENCIES

The Consortium: Tracy Halliday (case manager) 596-8300
Children's Outreach: Harvey Rempel 844-5400
Greg James (TSS)
Children's Seashore House

REASON FOR EVALUATION

J[redacted] was referred for an evaluation by his case manager, Tracy Halliday, for an assessment of his current emotional and functional needs. He has been diagnosed with elective mutism and mild mental retardation and has a history of behavior problems at home and at school.

RELEVANT INFORMATION

J[redacted] is the third of his parents' four children. He has two older brothers (12 and 10) and a two-month-old baby sister. His parents are from Ethiopia and have been in this country for about eleven years. J[redacted] speaks English but understands his parents' native language. He

was the result of a normal, full term pregnancy and uncomplicated delivery, and his developmental milestones were not significantly delayed.

J[redacted] has a history of selective mutism since he began school. His parents placed him in day care when he was four, but they took him out because he did not talk. In kindergarten, he had no behavior problems, but he did not talk to the teacher or his peers. His silence continued through first and second grades. He was identified as having special needs and was placed in a class for children with learning disabilities.

Last year, he was enrolled at Patterson School in a learning support (LS) class, and he began to have significant behavior problems as well as his limited verbal communication. He was aggressive toward peers and destroyed property. He cursed, was disrespectful toward other students, and got into fights. His mother said that they received phone calls from school every day, and he was given suspensions. He has been suspended once this year.

His parents reported that he is quite vocal at home. Although he is affectionate toward his baby sister, he fights with his older brothers and seems very jealous of his parents' attention toward them. He is noncompliant, has had fights with neighborhood children, and kicked the car. He is impulsive and has run into the street without looking.

They have taken him to Pediatric Psychology at Seashore House intermittently for the last two years because of the mutism and, more recently, because of his aggression in school. In April, 1995, a psychological evaluation was completed, which indicated that he was functioning in the mild range of mental retardation. It was recommended that he be reclassified as a student with mental retardation and that a classroom behavioral program be developed with a one-on-one therapeutic support staff to implement it in the classroom. Continued consultation with the parents regarding behavior management was also recommended.

INTERVIEW

J[redacted] came to the session with his parents and infant sister. His parents were interviewed when he was not present, and Johannes was seen with his family. I also met with his case manager.

He was an attractive, casually dressed boy, who smiled but had very limited eye contact. He appeared shy and answered questions with gestures or brief spoken replies after looking toward his parents first. At times, they reacted by encouraging him to speak and reinforcing his verbalizations; at other times, they answered for him or became irritated by his lack of response (e.g., "What's the matter with you?...answer!").

He was clearly tense and uncomfortable in a situation in which he was expected to speak for himself, and he became agitated when his parents brought up problems he has at home and at school. Noticeable changes in expression crossed his face, transforming from shy smiles to

anxious glances and angry glares. He kicked his feet and wrung his hands, as he glanced fiercely at his mother. When she commented that he "gets angry fast," he began to cry, furiously brushing aside the tears as he glared at her. In response, she pulled him closer to her and reassured him, which defused his rage.

DISCUSSION

J[redacted] is a nine-year-old boy with a history of selective mutism, a short attention span, and aggressive behavior at home and in school. He was an anxious, irritable child, who gave the impression that he was on the verge of flaring up. His parents seemed distrustful about how their son is being treated at school. They were ambivalent about wraparound services but eager for him to do better in school. A team meeting is scheduled at school on October 12 to discuss how he is doing there.

DIAGNOSIS

Axis I	313.23 Selective Mutism
	R/O Dysthymia
Axis II	317.0 Mild Mental Retardation
Axis III	General good health
Axis IV	Moderate: problems in school
Axis V	GAF = 53

RECOMMENDATIONS

1. Behavioral consultation up to three hours a week to develop and supervise the implementation of a program to improve his social, communication, and daily living skills.

2. Therapeutic support staff up to forty hours a week to help to implement the behavioral program.

3. Services should be coordinated with his school and Children's Seashore House to coordinate the plan and to prevent duplication of services.

Kathryn M. Woods, Ph.D.
Licensed Psychologist
Certified School Psychologist

ADDENDUM

J[redacted] D[redacted]

October 10, 1995

His TSS, Greg James, has been working with him for about two weeks. The program includes basic rules (e.g., he must answer verbally, not shrug or nod) and individualized attention to keep him on task. J[redacted] is easily distracted and needs a great deal of structure. Mr. James said that once he gets his attention, J[redacted] can concentrate for ten or fifteen minutes. His teacher has seen progress. Although he does not socialize with peers, J[redacted] participates in class and volunteers to answer questions. A point system will be implemented that gives him responsibility while rewarding positive behaviors. He had one episode recently in which he tried to run out of the classroom but Mr. James stopped him. He is generally doing better.

J[redacted] said that he wants to be in school by himself, but he admitted that he has done better with Mr. James there. After some prompting from his parents, he admitted that he was upset when his TSS spent a few minutes with another child.

A team meeting is schedule for October 12 at his school.

Kathryn M. Woods, Ph.D.
Licensed Psychologist
Certified School Psychologist

SCHOOL DISTRICT OF PHILADELPHIA
DIVISION OF SPECIAL EDUCATION

INDIVIDUALIZED EDUCATION PROGRAM (IEP)

SCHOOL YEAR 95-96

1. STUDENT'S NAME (LAST, FIRST) [redacted]
2. ADDRESS [redacted] Ave
3A. PHONE
3B. ZIP CODE 19142

4A. MEETING DATE	4B. IEP REVIEW DATE	4C. REGION	4D. DATE OF BIRTH	4E. AGE	4F. PUPIL I.D.#
3/96	3/97	Southwest	12/7/86	9yrs 2mos	[redacted]

SIGNATURES OF PERSONS PARTICIPATING IN THE INDIVIDUALIZED EDUCATION PROGRAM DEVELOPMENT

5. SCHOOL DISTRICT REPRESENTATIVE (NAME AND TITLE) Mrs. Mildred Miller - Counselor
6. TEACHER(S) Mrs. Wanda Royer — SIGNATURE(S)
7. TEACHER(S) — SIGNATURE(S)
8. OTHERS (INDICATE POSITION)
9. OTHERS (INDICATE POSITION)
10. STUDENT
11. PARENT Mekonen Difar

ASSIGNMENT IN SPECIAL EDUCATION

INSTRUCTIONAL GROUPING	LEVEL OF INTERVENTION	LOCATION OF INTERVENTION	WHEN SERVICE WILL BEGIN	ANTICIPATED DURATION OF SERVICE
Learning Support	Full time	Elem Sch Spec Public School	3/96 4/96	1 yr.
INCLUSION IN REGULAR EDUCATION				
Learning Support			3/96	1 yr
RELATED/ADDITIONAL SERVICES: TYPE, AMOUNT & FREQUENCY				
Speech				

EXIT CRITERIA Student will no longer be eligible for special education when she is able to accomplish the goals and objectives listed in the IEP without support

IEP TEAM HAS ALSO CONSIDERED THE NEED FOR:

	ADAPTIVE PHYSICAL EDUCATION		GRADUATION PLANNING
/	ASSISTING DEVICES		TRANSITION SERVICES
	BEHAVIOR MANAGEMENT PROGRAMS pp 6		STUDENT HEALTH PLAN
	EXTENDED SCHOOL YEAR REVIEW NEEDED		ENRICHMENT/ADVANCEMENT
	VOCATIONAL ASSESSMENT		INFORMATION FROM INSTRUCTIONAL SUPPORT TEAM
	OTHER (SPECIFY)		

16. TRANSITION SERVICES REVIEW: Transition planning is required at age 16. The School District encourages transition team planning when students reach age 14.

☐ IEP TRANSITION COMPONENT IS COMPLETED.

17A. NAME OF SCHOOL ASSIGNMENT Dolly M Patterson
17B. SCHOOL ADDRESS 70th & Buist Ave
18A. NAME OF PRINCIPAL RESPONSIBLE FOR PROGRAM J. P. Salandra
18B. PHONE (215) 492-6473

SCHOOL DISTRICT OF PHILADELPHIA – IEP CONTENT Page 2 of ____

STUDENT NAME Y[redacted] D[redacted] DATE 3/96

INSTRUCTIONAL AREA Reading/Language Arts Woodcock Reading [illegible]

PRESENT EDUCATIONAL LEVELS (Strengths/Needs/Strategies proven effective or ineffective)

Strengths: [illegible] tested at the 2.7 overall grade level or age equivalent of 8 yrs. 0 months. His strengths were in word attack and passage comprehension (2.8).

Needs: His weakness were in the areas of word identification (2.5) and word comprehension (2.6)

ANNUAL GOAL

To improve his skills in reading and language arts

SPECIFICALLY DESIGNED INSTRUCTION (Strategies and Equipment) Encourage verbal communication instead of shaking of head. Use concrete materials when possible. Lessons should be given in small, precise steps. To build self esteem, much praise and positive reinforcement are needed. When giving instructions and directions, make sure child understands. Offer many opportunities for practice and drill.

SHORT-TERM INSTRUCTIONAL OBJECTIVES (Include expected level of achievement, evaluation schedule, and procedures for evaluation)	Evaluation Procedure and Schedule	Mastery Criteria and Date
Recognize and express vowels and single consonant		80% accuracy
sounds with blends and digraphs	teacher made tests	Significant
Use consonant and vowel skills to blend consonant	Classwork	mastery of
vowels and consonant symbols into a meaningful word		specific topic
Recognize & express prefixes, suffixes, syllables	homework	when material
and word combinations	commercial tests	is evaluated
Recognize & express wh- words question words & sentences	tests	
Write complete sentences & paragraphs with proper		
capitalization and punctuation		

TRANSITION SERVICES REVIEW: ☐ Transition planning is <u>required</u> at age 16. The School District encourages transition team planning when students reach age 14.

Instructional Areas	
Post Secondary Training/Education	
Community Experiences	
Community Employment	
Functional Vocation Evaluation	
Daily Living Skills	

Planned courses in all curricular areas are available upon request

HOOL DISTRICT OF PHILADELPHIA – IEP CONTENT Page 3 of ____

STUDENT NAME [redacted] DATE 3/96

INSTRUCTIONAL AREA Math & Key Math

PRESENT EDUCATIONAL LEVELS (Strengths/Needs/Strategies proven effective or ineffective)

Strengths: Johanna tested at the 3.1 overall grade level. His strengths were in Basic Concepts (3.5) numeration, geometry and some natural numbers and in applications (3.6) measurement, time and money

Needs: Some estimation, interpreting data, problem solving. His area of weakness was in operations (2.6) multiplication, division and mental computation

ANNUAL GOAL

To improve his skills in math.

SPECIFICALLY DESIGNED INSTRUCTION (Strategies and Equipment) Use both concrete and visual material. Allow much opportunity for drill and practice. New material should be taught in small segments. Question student often to ensure understanding of concept and that student stays on task.

SHORT-TERM INSTRUCTIONAL OBJECTIVES (Include expected level of achievement, evaluation schedule, and procedures for evaluation)	Evaluation Procedure and Schedule	Mastery Criteria and Date
(1) Add and subtract as many as 3 numbers in vertical and horizontal alignment with/without regrouping	Teacher made test	80% accuracy
(2) multiply as many as 3 digits in vertical or horizontal alignment with/without regrouping	Classwork	mastery of specific objectives within a given unit with indicated materials
(3) divide with a 3 digit divisor, with/without remainder, regardless of format	Homework	
(use 1/2, 1/4 and 1/3 as unit fractional numbers)		
(4) tell time to the hour, half hour, quarter hour		

TRANSITION SERVICES REVIEW: ☐ Transition planning is required at age 16. The School District encourages transition team planning when students reach age 14.

Instructional Areas	
Post Secondary Training/Education	
Community Experiences	
Community Employment	
Functional Vocation Evaluation	
Daily Living Skills	

Planned courses in all curricular areas are available upon request

SCHOOL DISTRICT OF PHILADELPHIA – IEP CONTENT Page 4 of ____

STUDENT NAME [redacted] DATE 3/96

INSTRUCTIONAL AREA Science

PRESENT EDUCATIONAL LEVELS (Strengths/Needs/Strategies proven effective or ineffective)

Strengths: [redacted] is age appropriate for the 5th grade science curriculum.

Needs: Reading may be difficult due to Reading level. Material may need to be broken down for understand.

ANNUAL GOAL

To improve Science skills

SPECIFICALLY DESIGNED INSTRUCTION (Strategies and Equipment) Remake material, keeping content, but lowering reading level. Question student often to insure student understands material and is on task. New vocabulary should be taught prior to lesson. Group student with other students to work on projects where students are accountable for each other.

SHORT-TERM INSTRUCTIONAL OBJECTIVES (Include expected level of achievement, evaluation schedule, and procedures for evaluation)	Evaluation Procedure and Schedule	Mastery Criteria and Date
1) Communities of organisms have producers (and consumers) and	Teacher made tests; Anecdotal	80% accuracy
2) We get energy from various sources	Classwork	Quarterly
3) Changes in energy can be measured by temperature and erupts	Homework	Monthly
4) Formation of stars are called constellations	Group projects	Specific
5) Make observations		objectives
		when presented with, written material

TRANSITION SERVICES REVIEW: ☐ Transition planning is required at age 16. The School District encourages transition team planning when students reach age 14

Instructional Areas	
Post Secondary Training/Education	
Community Experiences	
Community Employment	
Functional Vocation Evaluation	
Daily Living Skills	

Planned courses in all curricular areas are available upon request

SCHOOL DISTRICT OF PHILADELPHIA – IEP CONTENT

Page 5 of ____

STUDENT NAME [redacted] DATE 3/96

INSTRUCTIONAL AREA Social Studies

PRESENT EDUCATIONAL LEVELS (Strengths/Needs/Strategies proven effective or ineffective)

Strengths: Yohannes is age appropriate for the 5th grade curriculum for Social Studies

Needs: Reading material may be difficult since child reads at a lower level.

ANNUAL GOAL

To improve skills in Social Studies

SPECIFICALLY DESIGNED INSTRUCTION (Strategies and Equipment) Many opportunities for review should be offered. Question child often to make sure child understands and stays on task. Material should be presented in small segments. Monitor child. Material may need to be rewritten, lowering reading level, but keeping content.

SHORT-TERM INSTRUCTIONAL OBJECTIVES (Include expected level of achievement, evaluation schedule, and procedures for evaluation)	Evaluation Procedure and Schedule	Mastery Criteria and Date
1. function as a wise consumer (decision maker.	Teacher made test. Observation	80% accuracy signifies
2. understand functions of a strong central government and the 3 branches	classwork homework	mastery of specific
3. understand our nation's birth and our documents of freedom	class projects map projects	objectives in lieu assessment
4. identify limited resources as a world citizen		with teacher
5. understand how interdependence among states were developed		material.

TRANSITION SERVICES REVIEW ☐ Transition planning is required at age 16. The School District encourages transition team planning when students reach age 14.

Instructional Areas	
Post Secondary Training/Education	
Community Experiences	
Community Employment	
Functional Vocation Evaluation	
Daily Living Skills	

Planned courses in all curricular areas are available upon request

SCHOOL DISTRICT OF PHILADELPHIA – IEP CONTENT Page 6 of ____

STUDENT NAME [redacted] DATE ____

INSTRUCTIONAL AREA Social / Emotional Development

PRESENT EDUCATIONAL LEVELS (Strengths/Needs/Strategies proven effective or ineffective)

Strengths: Yohannes responds more readily to adults. He is beginning to react more positively to praise and positive reinforcement.

Needs: Can display impulsive behavior. Becomes aggressive with students if antagonized or thinks he's being intimidated

ANNUAL GOAL

To be able to control his own behavior and to demonstrate he is responsible for his own actions.

SPECIFICALLY DESIGNED INSTRUCTION (Strategies and Equipment) Be consistent with rules and consequences and make sure they are clearly defined. Develop positive self image. Develop standards regarding attitudes behaviors and expectations. To accept others as individuals to respect each person's rights, values, aspirations, possessions and privacy.

SHORT-TERM INSTRUCTIONAL OBJECTIVES (Include expected level of achievement, evaluation schedule, and procedures for evaluation)	Evaluation Procedure and Schedule	Mastery Criteria and Date
1) Demonstrate appropriate behavior and self-control in daily interaction with peers, staff	Teacher observation, daily progress reports, behavior contracts, token economy, positive reinforcement techniques, rewards	80% accuracy specified mastery date
2) Show respect for himself and others		
3) Practice self-control and adhere to a system of rules and consequences		
4) Learn to work well with others		
5)		

TRANSITION SERVICES REVIEW: ☐ Transition planning is required at age 16. The School District encourages transition team planning when students reach age 14.

Instructional Areas	
Post Secondary Training/Education	
Community Experiences	
Community Employment	
Functional Vocation Evaluation	
Daily Living Skills	

Planned courses in all curricular areas are available upon request

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 paced 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.

BUREAU OF DISABILITY DETERMINATION
COMMONWEALTH OF PENNSYLVANIA
DEPARTMENT OF LABOR AND INDUSTRY
POST OFFICE BOX 8229
HARRISBURG, PENNSYLVANIA 17105

DIAL TOLL FREE
LOCAL TELEPHONE NUMBER: 783-36
FROM PHILADELPHIA CALL: 561-29
FROM OTHER AREAS CALL: 800-932-07
TT #: 717-772-17-

EXT. 245

Y[redacted] D[redacted]
[redacted]
PHILA PA 19142-2726

DATE: 04/22/97

SSN: [redacted]

DEAR Y[redacted] D[redacted]:

We are writing to you about your Social Security disability benefits. The Social Security Administration asked us to review your disability claim to determine whether you are still disabled. We have tried to obtain medical evidence to document your condition.

The evidence we have obtained is not complete enough for us to make a decision. Therefore, we have arranged for you to be examined by the psychologist listed below. This examination is designed to provide the specific medical information we still need. It may not include evaluation of all your complaints. During the examination, it may be determined that other tests are needed or that a scheduled test is not needed or should not be done. We will pay all authorized medical costs for this examination.

Psychologist Name: CRAIG S HARRIS MS

Address: HALL MERCER COMMUNITY MH/MR
8TH & LOCUST STS
PHILA PA 19107

Telephone: (610) 664-1272 ext. 0000

TYPE OF EXAMINATION: Mental Examination
TESTS(S):
Mental Ability Test
Achievement Test
Appointment Date: 05/10/97 Time: 01:00 PM

SPECIAL INSTRUCTIONS:

The psychologist will contact you about the appointment if a date and time is not shown above.

Cancelled as well as another C.E. with Ph.D. Psychologist

Consultative Exam

Sincerely,

F. Koller/BJC
Disability Claims Adjudicator

730049

ENCLOSURE: 122, 1001 Release Request

SOCIAL SECURITY ADMINISTRATION
SUPPLEMENTAL SECURITY INCOME
Disability Redetermination Decision

MAY 07 19[redacted]

Date:

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

Social Security Number:
[redacted]

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 Yohannes 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

Under the new definition of disability for children this child is no longer disabled as of May 1997. The child will get SSI for that month and the next 2 months. This child's last SSI payment will be for July 1997, as long as he continues to meet all other eligibility requirements until then.

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

Withdrawal/Redaction Marker
Clinton Library

DOCUMENT NO. AND TYPE	SUBJECT/TITLE	DATE	RESTRICTION
001. report	[Personally Identifiable Information] [partial] (3 pages)	05/07/1997	b(6)

COLLECTION:
Clinton Presidential Records
Domestic Policy Council
Diana Fortuna
OA/Box Number: 12022

FOLDER TITLE:
SSI [Supplemental Security Income] Children 5/97 [2]

2018-0525-S
ds474

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)]

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]

Yohannes Difar -2- (b)(6) [001]

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. <u>There are groups that can help you find a lawyer or give you free legal services if you qualify.</u> 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.

Yohannes Difar -4- (b)(6) C001

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. 05-11005
247
mh

PROFILE OF CHILDREN

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

Even Advocates Agree to cut:

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

Advocates want to preserve benefits for:

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

Middle Ground Option would preserve benefits for:

- many children with physical disabilities
- children with episodic illness

Strictest Option would be unfair to:

- children with physical disabilities
- children with chronic physical problems

How SSA Determines If a Child is Disabled

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

- o Children are eligible for SSI if:

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

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

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

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

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

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

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

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

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

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

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

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

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

Elena --

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

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

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

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

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

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

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

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

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

CHILDREN'S SSI CUTS

Background

- o Program geared to families with income under 190% of poverty; maximum monthly payment of $460 a month declines as income increases

- o SSI also makes you eligible for Medicaid

- o Tremendous growth in program due to Supreme Court decision, outreach, better recognition of mental impairments -- now 1 million children, up from 300,000 children in 1989, at a cost of almost $5 billion a year

- o Supreme Court decision led SSA to lower its standard -- "IFA" test -- and emphasize child's functioning, not just disease

- o Media stories of coaching children to "act crazy" never documented beyond a tiny number; more likely resentment sprang from marginal cases -- learning disabilities, behavioral problems, ADHD -- many of which SSA probably rejected

Legislative Change

- o House initially wanted to block grant, or cut grants to <u>all</u> children; Senate resisted and crafted this compromise, which we ultimately endorsed

- o New definition: child must have "marked and severe functional limitations"; IFA repealed

- o We and Congressional leadership assumed strict interpretation at the time, including cost estimates (savings of $8 billion over 5 years)

- o Advocates worked quietly with Daschle, Conrad, and Chafee to add some legislative history to support their current contention that SSA could add back a new version of the IFA test (most Dems were silent, however)

- o Conference report supports strict interpretation; Republican leadership would have charged us with bad faith if we endorsed advocates' plan

- o We chose middle ground interpretation that will cut off 135,000 children.

Implementation

- o Law required SSA to issue new definition by Nov. '96, but reg issued Feb. '97.

- o By next August, SSA must redetermine eligibility of the approximately 300,000 children who got on current rolls through IFA test; families received notices

- o Now that decisions are starting to be made, there are likely to be inaccurate stories about children who will lose their benefits, but decisions about individual children will not be made until summer.

WORK INCENTIVES FOR DISABLED

Talking Points

- Movement toward encouraging people with disabilities to work, especially those on SSI/SSDI because of exploding cost to government, increasingly young average age

- Barriers are many -- lack of good rehab, access to health insurance, technology, personal assistance services, etc.

- Interest running high on this in disability community; interest on Hill (Bunning) both from return to work and cost saving perspectives

Working on 2 fronts to get into budget. Concerned about the second front, since budget process on Medicare/Medicaid has not allowed time for deliberations on more minor items like this.

Ticket demo -- already agreed to as part of the budget

- Today, those on SSI/SSDI not well served by federal vocational rehabilitation program

- This plan would offer recipients a "ticket" they could take to private rehab providers

- Providers who successfully get clients off the SSI/SSDI rolls would get 50 percent of the benefits for up to 5 years

- Begin in 5 states; potential to expand to 25–35 if successful and costs do not increase

Extend health insurance to those who return to work -- under discussion with OMB, HHS, SSA

- Entry level jobs unlikely to offer adequate coverage, particularly for disabled

- SSDI: Allow free Medicare Part A as long as person is disabled (now 3 year trial period)

- SSI: Allow states to offer Medicaid buy–in for those earning more than current threshold

- OMB has legitimate questions about whether proposals would attract disabled to apply for benefits (woodwork effect)

- OMB and HCFA also have legitimate concern about impact on Medicare trust fund solvency and want SSA to reimburse HCFA for its costs; SSA resisting

- We must work to resolve this in next day or two

- Might make sense to do as a demonstration

- If we can resolve roadblocks, do we have your support for the concept?

- the hard to categorize

OPTIONS

How SSA Determines If a Child is Disabled

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selected

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Implementation Tasks

- o Law required SSA to issue new definition by Nov. 22

- o Since August, new applications in the "grey area" have been on hold (60,000–100,000)

- o By next August, SSA must redetermine eligibility of the approximately 300,000 children who got on current rolls through IFA test; families received notices

- o Once decision is made, we will work with SSA to respond to media reports. There are likely to be inaccurate stories about children who will lose their benefits, but decisions about individual children will not be made until summer.

THE WHITE HOUSE

WASHINGTON

Facsimile from Diane Ikemiyashiro
Office of Presidential Letters and Messages

Voice: (202) 456-5519 FAX: (202) 456-5426

Number of Pages (including cover): (4) 3

Date: 5.13.97 6.16.97

Time: ~~3:45 pm~~ 3:00 pm

To: Lisa Fortuna

Voice: 6.5570

FAX: 6.7431

[ ] incoming letter(s) from: Robert E. Hannegan, MD - AAP

re: Children's SSI

[ ] for your review

[ ] per my e-mail or voice-mail message to you

[ ] per your request

Additional comments:

American Academy of Pediatrics

Department of Government Liaison
American Academy of Pediatrics
The Homer Building
601 Thirteenth Street, NW
Suite 400 North
Washington, DC 20005
202/347-8600
800/336-5475
Fax: 202/393-6137
Internet: kids1st@aap.org

217048

April 28, 1997

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

Dear President Clinton:

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

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

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

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

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

Sincerely,

Robert E Hannemann MD

Robert E. Hannemann, MD
President