Children's SSI Terminations -- Sample of 151 Cases

Diagnosis at Termination	Number of Children	Percent of Total
Learning Disabilities	31	21%
Attention Deficit Disorder	30	20%
Various Mental Disorders (e.g., Conduct Disorder, Adjustment Disorder, Affective Disorder, Developmental Delays, Developmental Disorders, Personality Disorders, Oppositional Defiant Dis., Relational Disorder)	21	14%
Borderline Intellectual Functioning	12	8%
Mental Retardation	10	7%
Physical Disabilities (other than asthma)	9	6%
Asthma	7	5%
Speech Delay	4	3%
None	3	2%
Subtotal	127	84%
Failure to Cooperate	24	16%
TOTAL	151	100%

FOREWORD

Over the past quarter century, the Supplemental Security Income (SSI) program has helped families of children with disabilities meet their special needs. The SSI program has come to represent an important safety net to some of our most vulnerable families. That is why, during my confirmation hearing before the Senate Finance Committee, I made a commitment to conduct a "top-to-bottom" review of the implementation of the changes to the SSI childhood disability program brought about by The Personal Responsibility and Work Opportunity Reconciliation Act of 1996. I believed that this review was needed because of public concern with the implementation of the new law. I believed that the Congress, the President, and the American people deserved to know whether the law and the regulations were being applied fairly.

The following report shows that, overall, the Social Security Administration (SSA), and the State Disability Determination Services that make determinations for the Agency, have done a good job of implementing the provisions of the welfare reform law. Of the approximately one million children receiving SSI benefits based on disability, about 288,000 were subject to redetermination under the new law, and most of those cases were handled properly. However, the report also found some inconsistencies in the application of the rules and in compliance with SSA instructions. Where specific problems have been identified, SSA is taking corrective action. And because of my concern for the welfare of children, shared by the Congress, the President, and the American people, we are taking steps above and beyond normal actions to assure that every child receives a fair assessment to receive the benefits for which he or she may be eligible.

I am pleased with the overall performance of SSA and the States in completing most of the required reviews accurately and in such a short period of time. And while there have been relatively few problems identified in the process, I am deeply concerned that *any* child could be disadvantaged as a result of deficiencies in the manner in which decisions are made. One of my top priorities as Commissioner of Social Security is to guarantee the equity of SSA's programs for all beneficiaries and claimants. I am committed to ensuring that all children who meet the eligibility requirements for SSI receive the benefits for which they are eligible.

All Americans must know that the provisions of the SSI program are applied with fairness, compassion, and consistency across the nation.

Kenneth S. Apfel
Commissioner of Social Security

All #s ??
Regression - still in?
Accuracy #s stable yes

Why only 48,000 ~
thought much higher

EXECUTIVE SUMMARY

The Supplemental Security Income (SSI) program provides cash benefits to financially needy individuals who are aged, blind or disabled. SSI has paid benefits to disabled children since the program's inception in 1974. Until 1996, the Social Security Act (the Act) did not contain a separate definition of disability for children; a child was considered disabled if he or she had a medically determinable impairment (or a combination of impairments) that was of *comparable severity* to an impairment that would disable an adult. Beginning in 1991, following the 1990 Supreme Court decision in the case of *Sullivan v. Zebley*, SSA introduced a new policy of "functional equivalence" to its medical listings and an "Individualized Functional Assessment" (IFA) for evaluating disability in children.

On August 22, 1996, the Personal Responsibility and Work Opportunity Reconciliation Act of 1996, Public Law 104-193 (the PRWORA) established a new and stricter definition of disability specifically for children. The definition is no longer based on comparability to the adult standard, but instead provides that a child is disabled if he or she "has a medically determinable physical or mental impairment which results in marked and severe functional limitations." The PRWORA also eliminated the IFA and certain other provisions of SSA's regulations, and required that SSA redetermine the cases of children whose eligibility might terminate because of the provisions of the law.

SSA estimated that, of approximately one million children receiving benefits, about 288,000 would need to have their eligibility redetermined under the new law, and that about 135,000 would eventually be determined ineligible for SSI benefits. Now that most of the initial redeterminations have been completed, and in view of the actions directed by Commissioner Apfel in this report, the estimate must be revised downward to about 100,000 children when all actions are completed. (President Clinton proposed continuing Medicaid eligibility for most children who lose eligibility for SSI as a result of the new definition of disability, and that provision was included in the Balanced Budget Act of 1997, enacted in August 1997.)

Implementing the legislation was a major undertaking for SSA. The Agency had to first identify and then notify those families potentially impacted by the PRWORA, publish regulations implementing the legislation, train staff and, working with the State Disability Determination Services (DDSs), the State agencies that make determinations for the Agency, conduct the redeterminations of eligibility. All of this had to be accomplished within the very short time frames mandated by the legislation.

As of November 1, 1997, SSA had completed 263,000 reviews and notified the families of 135,800 children (52 percent) of an unfavorable redetermination. The families of 127,400 children (48 percent) were notified that their eligibility would continue. During this review process, concerns were raised about the Agency's adjudication of these SSI childhood disability cases, and also about the efficacy of Agency administrative procedures.

During his confirmation hearing, Commissioner Kenneth Apfel pledged that SSA would conduct a top-to-bottom review of the implementation of provisions of the PRWORA that

affected the SSI childhood disability program. After taking the oath of office, he directed the Agency to look at the implementation of the SSI childhood disability provisions to determine if they were being applied fairly and correctly.

This report concludes that, of the cases that have been completed thus far, most have been processed properly. Some problems, however, were identified. In the interest of assuring that every child receives a fair assessment to receive the benefits for which he or she may be eligible, corrective actions are being taken. The three specific areas of concern that were reviewed, and the corrective actions being taken, follow:

1. CESSATIONS OF CHILDREN CLASSIFIED IN SSA RECORDS AS HAVING MENTAL RETARDATION

Mental retardation (MR) is characterized by significantly subaverage general intellectual functioning, accompanied by significant limitations in adaptive functioning. Children who do not exhibit both of these characteristics cannot be classified as having MR.

Of the approximately one million children on the rolls in December, 1996, about 407,000 children (almost 41 percent of all children on the rolls) were coded in SSA's data with the primary diagnosis of MR. Eighty percent of these children (over 325,000 children) had impairments that met one of SSA's listings for MR and were not subject to redetermination under the PRWORA. SSA sent redetermination notices to the remaining 20 percent (about 79,500) of these children. As of November 1, 1997, SSA had redetermined 73,950 of these cases and determined that 42,425 (57 percent) did not meet the new disability standards.

Concerns were raised about the precision of SSA's coding data and decisional accuracy, especially whether the eligibility of children with IQs in the range of 60 to 70 was being ceased erroneously because of misapplication of the listings. Another concern was whether the eligibility of children with MR who have IQ scores *above* 70 was being ceased because of adjudicator failure to consider the range of error inherent in all test scores, called the Standard Error of Measurement (SEM).

SSA found that in a large number of the cases with the computer code for MR, the children did not actually have MR, and were never thought to have MR, but were only shown in SSA's data with this diagnosis code. In most cases, these children were found to have learning disabilities or borderline intellectual functioning, and these claims were more likely to be ceased than claims of children who had MR.

A diagnosis code must be entered into the computer system, but codes do not exist for all possible impairments. In such cases, SSA instructs DDS adjudicators to choose a code for a "closely analogous" impairment. As a result, DDSs have used the MR code for other impairments since it was first established years ago. (In 1994, SSA established additional codes for certain impairments, including learning disabilities, which were often coded as MR. And in connection with this top-to-bottom review, another new code was established in October, 1997, for "borderline intellectual functioning," another impairment that was often coded as MR.)

In addition, some children who were accurately diagnosed as having MR properly lost eligibility. This can happen for two reasons supported in the MR literature. First, some children who were correctly diagnosed with mild MR do not have functional limitations severe enough to meet or equal (including functionally equal) a listing. SSA does not believe that there are many children who fall into this category; however, the Agency plans to track this group. Second, the diagnosis of MR is not necessarily lifelong in every case. With supports and interventions, some children who were once classified as having MR may no longer have the level of impairment required for a diagnosis of MR.

However, SSA's quality assurance data also show that some cessations of cases with the code for MR have documentational or decisional deficiencies. This means that, regardless of the correct diagnosis, some children with the code for MR may have had their eligibility ceased incorrectly. SSA was especially concerned that the claims of children with the code for MR, who had IQ scores of 75 or below, and whose eligibility was ceased (or denied) should be carefully reviewed, since some of these children may have mild MR. Although the diagnosis of mild MR in and of itself does not indicate that benefits should be continued, these claims should be reviewed to ensure accurate determinations.

Similar questions exist for denials of new applications after enactment of the PRWORA showing the code for MR.

Actions To Be Taken

To address these findings, Commissioner Apfel has directed that the following steps, above and beyond normal action, be taken to ensure that every child receives a fair assessment and is given every chance to receive the benefits for which he or she may be eligible:

- In addition to reviewing all redetermination cessation cases, SSA will, through the DDSs, review all denials of initial applications adjudicated on or after August 22, 1996, that show the code for MR.

- For *all* cases of children with the code for MR with valid IQs of 75 or below whose eligibility for benefits was ceased or whose applications were denied on or after August 22, 1996, SSA will reopen, develop as needed, and provide a revised redetermination, if appropriate, for each, individual case. The review will determine whether all necessary documentation is present, that the determination was correct, and that the proper diagnosis code was used. If it is determined that a different code should have been used (or if the new code for borderline intellectual functioning should now be used) the code will be revised.

- For cases of children with the code for MR and whose IQ scores are above 75, the review will be a two-stage process: (1) A review of the case file to determine whether all necessary documentation is present, that the determination was correct, and that the proper diagnosis code was used. If it is determined that a different code should have been used (or if the new code for borderline intellectual functioning should now be used) the code will be revised and no further action will be taken. (2)

If deficiencies are found in a determination (either documentational or decisional), the case will be reopened, developed as necessary, and the determination revised if appropriate.

- Before beginning the reviews, SSA will provide additional training to its adjudicators on the MR evaluation issues raised in this report.

2. QUALITY OF CASE PROCESSING

SSA's primary concern is whether its determinations are correct; there was no ideal rate of continuance or cessation which all the States were expected to achieve. However, when wide variations in rates appeared, the Agency investigated reasons for the variations. SSA examined differences in case characteristics among State workloads, the quality of development, and the overall accuracy of determinations to see how these factors helped explain the differences in results.

Case Development Practices

Although the Agency's quality assurance data did not show widespread deficiencies in the processing of the childhood redeterminations, SSA examined the possibility that differences in case development practices (i.e., how evidence from medical and other sources was obtained) contributed to differences in the rates of continuance and cessation among the States. This evaluation also addressed concerns that had been raised that some cases had not been adequately developed.

The Act and SSA's regulations require claimants to provide current medical evidence showing the existence and severity of their impairments. Although claimants are technically responsible for providing the evidence SSA needs to make a disability determination, in practice SSA often assists in this process by obtaining this evidence for children—existing medical evidence from treatment sources, consultative medical examinations, and information from other sources, including school records and parents, where appropriate.

Concerns were raised that DDSs rushed redeterminations to meet the original August 22, 1997, deadline of the PRWORA, and thus did not always obtain the evidence needed to support their determinations. In particular, the allegations focused on the quality and quantity of consultative medical examinations and the perception that the DDSs failed to obtain school records. The Agency looked at whether sufficient effort was made to secure evidence from these sources and whether the evidence in the case files was sufficient to adjudicate the cases correctly.

Following a careful review of these concerns, SSA determined that the contention of inadequate development in these cases was not supported.

Failure To Cooperate

The Agency did find problems in certain States in cases that had been ceased based on a

"failure to cooperate." A child's eligibility for SSI may be ceased on the basis of a "failure to cooperate" when the child's parent or legal guardian does not respond to a notice initiating the disability redetermination, does not take the child to a consultative examination, or otherwise does not cooperate in processing the claim without good cause. SSA policy is to make repeated attempts to contact the child's parent or legal guardian by mail and by telephone, and when necessary to make special efforts to identify and contact another adult or agency responsible for the child's care.

Nationally, cessations based on a failure to cooperate make up less than five percent of all cases. However, there were wide variances among the States in cessations on this basis, ranging from less than one percent in the lowest States to 9.5 percent in the highest States. In a study of cessations based on "failure to cooperate," SSA found that in 68 percent of the cases either all of the contacts required had not been attempted or the contact efforts were not documented in the case file.

Actions To Be Taken

- Failure to cooperate cessations will be included in SSA's review of all redetermination cessations. (Many redetermination cases that were ceased on the basis of a failure to cooperate have already been reworked using the correct procedures.) The case reviews will ensure that all contacts and followups required in the special instructions for children's cases have been made and documented in case files. When reviews of "failure to cooperate" cases show deficiencies in such procedures, claimants who wish to pursue their claims will be given the opportunity for a new initial determination and an opportunity to have their benefits reinstated during the new redetermination process including any benefits that would have been paid since the month in which payments ceased.

Accuracy of Cases

Nationally, the accuracy of both continuance and cessation determinations is above 90.6 percent (the regulatory threshold for accuracy). Almost two-thirds of the deficiencies were "documentational," meaning that there was some deficiency in the evidence that formed the basis for the determinations, not necessarily that the determinations were incorrect.

While these rates are satisfactory based on SSA's regulatory quality assurance standards, the Agency is aware that the cessation errors still represent a number of children whose eligibility was potentially wrongly ceased from receiving benefits. While SSA's quality assurance data show some States with lower accuracy than others, every State has some likelihood of improper cessations. Similarly, there is concern that, particularly in some States, there was an unacceptably high rate of error in the continuances of some children.

The quality assurance data show low cessation accuracy resulting mainly from cases involving mental disorders. There is some indication that adjudicators would benefit from additional

instruction on the evaluation of these types of cases.

There was also concern that the single area of functioning for cognition and communication in the implementing regulations for determining functional equivalence to listed impairments disadvantaged some children with separate cognitive and speech impairments. Although the data do not show any negative effects caused by the retention of the cognitive/communicative area of functioning, there is some indication that adjudicators would benefit from additional instruction on the evaluation of a combination of cognitive and speech disorders that separates speech disorders from cognitive disorders.

Finally, through its quality assurance reviews, SSA will be able to monitor childhood case processing to determine if any specific areas of concern arise that may require further actions in the redeterminations and in determinations made on initial applications.

Actions To Be Taken

Commissioner Apfel directed that the following steps, above and beyond normal actions, be taken:

- In addition to the reviews of cases with the code for MR that all States will do under Section 1, above, DDSs will screen a portion of their remaining initial redetermination cessations. DDSs with higher QA accuracy will review proportionately fewer cases than those DDSs with lower QA accuracy. These screenings will cover cases in the categories of cessations having the most likelihood of containing errors based on SSA's QA results. If deficiencies, such as the absence of necessary documentation, are found during the screening, the cases will be reopened, developed as necessary, and the determinations revised if appropriate.

- SSA will conduct QA reviews of the accuracy of these screenings as part of its quality assurance process. In addition, the DDSs will conduct their own quality assurance reviews of the cases as they are screened.

- For those DDSs in which cessation accuracy on redeterminations is below 90.6 percent, SSA will do a quality assurance review on a larger sample of cases than for DDSs that are above the threshold.

- For those DDSs in which continuance accuracy is below 90.6 percent, SSA will give childhood disability cases priority for continuing disability reviews.

- Before beginning the reviews, SSA will provide additional training to all of its adjudicators addressing the issues regarding the evaluation of mental retardation, maladaptive behaviors, and the evaluation of speech disorders in combination with cognitive limitations as well as, any other specific case processing concerns about which adjudicators should be aware.

- In addition to the training, SSA will issue a Social Security Ruling on the evaluation of speech disorders in combination with cognitive limitations. SSA will also encourage the DDSs to include experts in the evaluation of speech and language disorders on their staffs and to continue to purchase consultative examinations from speech/language pathologists whenever necessary.

- Through its quality assurance reviews, SSA will continue to monitor any specific areas of concern that may require further actions in the redeterminations and in determinations made on initial applications.

3. APPEALS AND REQUESTS FOR BENEFIT CONTINUATION DURING APPEAL

When SSA sends notices telling families (or other payees) that a redetermination has found a child is no longer eligible for benefits, the notice also advises them of their legal rights. They are told how to ask for a reconsideration, and that they can request continuation of their benefit payments during this appeal process. They are also told, as required by law, how to obtain information concerning attorney representation.

However, concerns have been raised that (1) the cessation notice was hard to understand; (2) some beneficiaries were discouraged from filing appeals or requesting benefit continuation; (3) some beneficiaries were not told about the availability of free legal services; and (4) procedures in effect when the redeterminations began did not require a full explanation of the overpayment waiver process.

Throughout the notification and redetermination process, SSA responded with revised instructions and retraining when concerns were raised about the clarity of information. Of course, those actions would have had only prospective effect. These changes were made over time as case processing proceeded; therefore, children who were found ineligible earlier in the process did not receive the same explanations as those who were found ineligible later in the process.

SSA therefore conducted two polls to test the validity of the concerns. In the first poll, SSA telephoned social services organizations, public agencies, major umbrella advocacy organizations, and legal aid organizations. In the second poll, SSA surveyed more than 400 beneficiaries who filed appeals but did not request benefit continuation. SSA found little evidence to indicate that Agency employees were actively discouraging beneficiaries from exercising their rights to appeal or to continue to receive their SSI payments during appeals that are ultimately unsuccessful. However, the poll suggested that some individuals who did not appeal—and some individuals who appealed but did not request benefit continuation—did not understand their rights.

Actions To Be Taken

Commissioner Apfel has directed that the following actions above and beyond several steps already taken be instituted to clarify SSA policies:

- SSA will send special supplementary notices in simpler language to families (or other payees) of all children whose eligibility for SSI was ceased under the PRWORA, and who have not appealed. The families will be given a new period of 60 days in which to request a reconsideration. The supplementary notice will also provide a new 10-day period in which to request benefit continuation during the appeal and include information on the claimants' right to request waiver of any overpayment that might result from the request.

- SSA will also send special supplementary notices in simpler language to families (or other payees) of all children whose eligibility for SSI has ceased under the PRWORA, who have requested a reconsideration, but who have not requested benefit continuation, providing a new 10-day period in which to request benefit continuation during appeal. The notice will also include information on the claimants' right to request waiver of any overpayment that might result from the request.

- If claimants whose eligiblity was ceased based on a redetermination elect continued benefits in accordance with SSA's regulations, the payments will include any benefits that would have been paid since the month in which payments ceased.

- SSA will provide a "script" that the Field Offices and Teleservice Centers will follow in informing claimants of their appeal and benefit continuation rights. The script will ensure that all claimants receive the same information and will assist individuals who may have difficulty understanding the circumstances under which good cause may be found. It will also include an explanation of good cause for waiver of overpayments that may result from requests for continued benefits during appeal.

- SSA is making a concerted effort to ensure that claimants are aware of legal representation available through the American Bar Association's (ABA's) Children's SSI Project by making toll-free numbers available through Field Offices, teleservice centers, and the Agency's Internet site. The Agency is also working with the ABA to include toll-free 800 numbers with future redetermination notices in those States where they are available.

CONCLUSION

When the regulations were issued, SSA estimated that 135,000 children would lose eligibility after all appeals. Now that most of the initial redeterminations have been completed, and in view of the actions directed by Commissioner Apfel in this report, the estimate must be revised downward. It is now estimated that 100,000 children will be found ineligible after all

appeals as a result of the changes in the PRWORA. The reasons for this are as follows:

- First, there were fewer cessations at the initial level than SSA originally estimated. This may be due in part to actions the Agency had already taken to address quality issues raised during the implementation of the PRWORA and the regulations.

- Second, the additional actions directed by Commissioner Apfel in this report will ensure that children who are eligible for SSI disability benefits receive them. The actions to review ceased cases will result in the screening of about 48,000 cases, and it is estimated that about 18,000 of these cases will be reopened. In addition, SSA estimates that about 20,000 additional children will choose to appeal as a result of the renotification. It is likely that the training and clarifying instructions that Commissioner Apfel has also directed in this report will have an effect on the outcomes of some of the reconsideration determinations.

This report affirms that SSA, and the State Disability Determination Services that make determinations for the Agency, have done an overall good job in implementing the new SSI childhood disability provisions of the PRWORA. It also demonstrates the Agency's commitment to make whatever adjustments are necessary to ensure the fair and equitable administration of the SSI disability program for all children now and in the future.

In addition to the actions outlined in this review, the Agency will continue to conduct quality reviews and will continue to take corrective action whenever it is required. Commissioner Apfel has also directed an expansive study of the children who were impacted and not impacted by the PRWORA that will improve knowledge about children with disabilities and the effects of the PRWORA on children with disabilities and their families

News

SOCIAL SECURITY
Kenneth S. Apfel, Commissioner
WEDNESDAY, OCTOBER 1, 1997

Split Decisions

A Youngster Has HIV, Poor Attention Span; Is He Really Disabled?

That's Up to Sandy Smith And Others Now Cutting Social Security Benefits

The Clues in the Case File

By Christopher Georges
Staff Reporter of The Wall Street Journal

BINGHAMTON, N.Y. — Sandy Smith sifts through the case folder, making mental notes as she goes: seven years old . . . likes to color . . . in school, average grades . . . after school, plays with friends . . . IQ above 90.

"I am not getting the picture of a sickly child," says Mrs. Smith, a state welfare official, as she tries to decide whether to cut off the boy's $450-a-month disability benefits under the new federal welfare law. But she lingers over the case. The child is HIV-positive. He has bouts of fatigue, a meager appetite and occasional infections, though none severe.

Sandy Smith

On another day she picks through the file on an 11-year-old boy who, his parents say, is "verbally abusive" and "gets phone messages wrong." He plays sports. He is strong enough to beat up classmates. His IQ is 83, above the 69 score that generally is considered a cutoff for being severely disabled. But she pulls out other clues: He tests at first-grade level, can't write, has a short attention span, suffered brain damage at birth and sometimes climbs ledges, threatening to jump.

In the end, Mrs. Smith will decide that one of these two youngsters will join the 125,000 children nationwide who this year are being cut off from disability benefits, also known as Supplemental Security Income or SSI. Congress concluded last year that many of the nearly one million children getting benefits — which are based on the family's income and the child's disability — suffered from mild ailments, if any. As part of the broader welfare overhaul, legislators cut $8 billion over six years from the $10 billion-a-year program.

'Marked and Severe'

Congress ordered caseworkers to continue aid only to children with "marked and severe" disabilities. But it left it to the Social Security Administration to decide what that meant. Three dozen top administration officials wrestled for months with the issue last fall. "What is 'marked' limitation anyway?" asks Susan Daniels, who heads Social Security's disability program. "We can't look at a child and say, 'We have a marked one here.' "

The agency eventually wrote a complex web of standards aimed at calibrating how children behave and feel. Officials pinpointed 265,000 recipients as the least disabled, and about half of these are likely to be cut off by February. But the real-life decisions on which children will keep their aid, or lose it, are up to the Sandy Smiths in state agencies across the country.

Mrs. Smith, 46, was working as a pediatric nurse when she heard last winter that the state was looking for people — particularly nurses — to make SSI decisions. She was intrigued by the challenges of the job and welcomed the regular hours. She works in a cubicle, surrounded by pictures of her own three grown children — one of whom has attention-deficit disorder.

'I Have a Heart'

Her decisions underscore the tensions in carrying out welfare reform and provide an early clue to the impact of the new law. Are officials such as Mrs. Smith stranding the disabled, as advocates for the poor claim, or are they cleaning up a program pockmarked by abuse?

Some calls are easy. Children with severe mental retardation or cerebral palsy won't be cut off. Kids whose only trouble is an eagerness to pummel classmates probably will lose benefits. But not all cases are so simple — to decide or to live with. "I have a heart. I sympathize. But the bottom line is the law," says Mark Gordon, a New York caseworker who has judged hundreds of the state's 26,000 disability review cases over the past few months. "I can feel sorry, but that is not my job."

Those who enforce the new guidelines acknowledge the difficulties in applying textbook rules — found in a 160-page SSI handbook — to children such as Mrs. Smith's HIV-positive case. These cases are presented within thick binders of parents' pleas, lab results, doctors' reports and teachers' opinions. Some of the data are conflicting, others irrelevant.

Mrs. Smith's introduction to the HIV-positive child is a simple request, penned in an unsteady hand by the boy's mother: "My child is disabled." Mrs. Smith searches thoroughly to dig out proof of a severe case of AIDS. But other factors can help win approval, such as evidence

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that the boy is thinking, speaking or hearing far below his age level.

The search begins: The youngster has "speech delays" and trouble in school, his mother says. But as Mrs. Smith digs deeper, the evidence is contradictory. A recent language test shows him just below age level, and his IQ is 25 points above the usual cutoff. A teacher's report notes a poor attention span, but Mrs. Smith puts that aside: "If it were severe, he wouldn't be able to sit still at all," she says.

Soon, her options have dwindled to one: How severe is his disease? A doctor's report notes aching knuckles and a regimen of AZT. A teacher reports the boy tires easily. But Mrs. Smith searches in vain for evidence that he must leave school early or even be excused to nap.

Suddenly, her interest is piqued by medical records showing he is small for his age. "Could be 'failure to thrive,'" she says, reaching for a binder of growth charts. She must prove not only that he is small, but that he is growing at a slower-than-normal rate.

Family History

What Mrs. Smith does not - in fact, may not — factor into the decision are the child's financial situation and family history. That point is the topic of conversation as Mrs. Smith joins a dozen colleagues over pizza and soft drinks in the office common area. Most agree that not using such data can make a tough decision tougher, but doesn't lead to a "wrong" evaluation. "If something is going on with the family, it will be dealt with elsewhere," says Mark Diefendorf, who runs the Binghamton office. "It's a big system. We are just one part."

In this case, though, Mrs. Smith ventures into the back of the file where income data and family history are found. The boy's mother, HIV-positive herself, lost her son to foster care when he was two, the record reports. But two years later she won a battle to get back custody. She has been through rehabilitation of some sort, and on and off public assistance.

"She's finally pulling it together. I think she's doing a good job," Mrs. Smith says. Still, "none of this will make a difference," she says, flipping back to front of the folder.

During the past few weeks, Mrs. Smith has cut off dozens of children. She tempers the strain by reconciling her professional task with her personal values. "This is good for them," she says, describing those who are cut. "We are helping these children become self-supporting human beings. We hamstring them when we tell them they have a severe disability." She explains further: "I would never say to my child, 'You are disabled.'"

And she hasn't. Her teenage son was diagnosed with attention-deficit disorder in grade school, attended special-education classes but received little other special treatment. "He adjusted," she says, and he is now training to be a chef.

For Mrs. Smith and her colleagues, emotional distance is made easier by a physical one. She reviews each case from her Binghamton office, hundreds of miles from where many of the children live. She never sees or talks to the children or their families.

But Mrs. Smith is also helped by her skeptical view of the old standards. Delving into the back files of a boy with attention-deficit disorder, she plucks evidence used three years ago to allow the child to get benefits. A teacher wrote that the child "longs for praise and attention. . . . He asks to sit on my lap."

"Come on," Mrs. Smith says, "some of these kids needs just a little handholding."

To date, most cutoffs, in New York and nationwide, have affected children claiming learning disorders, especially attention-deficit disorder. The decisions have touched off protests from advocates who say that the new guidelines are too strict and that determiners, pressured by tight deadlines, are conducting cursory reviews. "The SSI killing fields are upon us," says Jonathan Stein, of Philadelphia's Community Legal Services, an advocacy group for the disabled.

Mr. Stein and others have collected a handful of questionable denials, such as a 13-year-old girl diagnosed as having severe psychotic disorders. But it isn't clear whether such decisions are widespread or isolated. Still, Social Security officials concede some mistakes and have promised to review the regulations. Cutoffs can be appealed to other officials, or a judge. Of the nearly 2,700 cases nationwide that have been reassessed at any level so far, 1,750 children have been allowed back on the rolls.

The $507 Check

Officials recently cut benefits for a boy who lives just a few miles from Mrs. Smith's HIV case. Samuel is also in elementary school, has roughly the same family income and an almost identical medical condition. After his first day of school, Samuel tangles playfully with classmates. The boy, mixing into the sea of children, is dressed smartly in a new denim outfit and Nikes. He is taking protease inhibitors, courtesy of Medicaid and a local hospital, and his HIV-positive condition remains a secret to his teachers, classmates, even some relatives. Samuel himself is unaware.

Later he will ride his bike and then take on the miniature basketball hoop in his basement. Medical records show he tests near his age level in such skills as coordination, speech and hearing. The boy has "no limitations," his doctor reports in the case file.

But his grandmother fiercely defends the $507 monthly disability check, citing circumstances absent from Samuel's medical file. His mother, a cocaine addict now in prison, and his father, a recovering alcoholic, essentially abandoned the child at birth to her. Samuel appears healthy, she insists, only because she quit her clerical job to become a full-time mother again. She is a slave to her grandson's on-demand eating habits. Morning and evening medications require her to coax Samuel from hiding in his room.

When officials cut off Samuel's SSI a few weeks ago (Mrs. Smith wasn't involved in the case), his grandmother appealed. A judge reversed the decision.

Emotional Troubles

In another case, Maria Lugo recently received a letter saying that her teenage son had been cut off after 11 years of aid. Ms. Lugo, who says she receives adult SSI for depression, makes no effort to hide her anger: The boy "is emotionally in trouble. He can hurt someone," she explains.

Her son isn't home to hear the news, but will soon return from a vacation in England, paid for by his mother. Though he holds a part-time job in a sporting-goods store, scuba dives and attends regular school classes, his mother defends the aid, citing her son's violent temper. "We need to buy him things to keep him calm," she explains, listing some of the placating devices: a computer, CB radio and "laser-beam toys to play with his friends."

But a few weeks later, Ms. Lugo has calmed. "I guess he's OK," she says, adding she won't appeal the decision.

Mrs. Smith also wasn't involved in that case, but she uses similar standards. She examines a new file of a 12-year-old boy whose parents say he suffers from attention-deficit disorder and "mental problems." He takes Ritalin and gets weekly psychiatric counseling. "He cannot finish a task without supervision," they explain.

"This one looks serious," Mrs. Smith says, then reads further. "He is argumentative . . . aggressive . . . rude and disrespectful," the government-hired psychiatrist reports after a visit from the child. That still isn't enough to merit "severe," Mrs. Smith says.

Finally, the school report provides the telling evidence: In the past year, he has jumped three grade levels in his test scores; his IQ is 78, well above the cutoff for disability. She looks up from the paperwork and reads the teacher's notes aloud, running her finger along the line: "He gets things done on time. . . . He thinks creatively."

A new picture has emerged. The teacher reports that the child's medication controls his violent impulses. He "is beginning to connect — he's compensating," Mrs. Smith says. "He may not be a rocket scientist, but he'll be fine." She decides to end his SSI.

Terrorizing the Teachers

Each case is a challenge. The 11-year-old who "gets phone messages wrong" and is "verbally abusive" appears headed for cessation. His father cites fetal-alcohol

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syndrome but provides no clue that it is severe. The boy takes no medications, and although he picks fights, the new guidelines no longer regard that as a criterion for aid.

But despite his IQ of 83, the boy tests in most areas at first-grade level. He still can't read or write. "This is more than just slow," Mrs. Smith says. "It's a marked disorder," giving him credit for one disability. But the new rules require another area of severe disability. Although reluctant at first to judge his temper a disorder, Mrs. Smith is moved by, among other evidence, a school report that he "terrorizes his teachers."

"This child is going backward," she concludes. She allows his disability checks to continue.

The dilemma remains over her HIV case. The growth charts she turned to show that this boy, though small for his age, is growing at a normal rate. Yes, he carries the virus, but, she says, pausing between each word for emphasis, "he is totally asymptomatic." She cuts off the benefits, effective today.

The case is through, but Mrs. Smith isn't. "There are all kinds of programs, free ones, that can help," she says. The boy will continue to get Medicaid and probably other social services. "If he gets sicker, they can reapply," she says.

"Maybe," she says pausing, "if his IQ were lower . . . I could have . . ." her voice trailing off. "He definitely has disability," she says, "but I couldn't say he is disabled."

Putting Social Security On Minorities' Agendas

IF SOCIAL Security really runs dry early next century, blacks and Hispanics may be the hardest hit, but it's been a nonissue for their leadership groups.

Enter Third Millennium. The group, which made its name as a Generation X spokesman, is reaching out to black and Hispanic groups to add savings, investment and a potential Social Security crisis to minority groups' agendas. Executive director Richard Thau got the idea after attending one too many seminars on the subject with no blacks or Hispanics involved. He says younger workers may face ever higher payroll taxes to fund baby boomer benefits, even as their own future benefits are imperiled.

"If blacks and Hispanics will be the largest segment of working population in 30 years, and mostly white boomers are the retirees, aren't we sewing the seeds for not only a generational, but a racial battle?" asks Mr. Thau.

A recent Rand Corp. study says blacks and Hispanics are more likely to rely on Social Security benefits than whites. Such benefits were 40% and 44% respectively of the wealth of the average fiftysomething black and Hispanic household, versus 25% for similar white households. White households put more away for retirement, the report says, because they have higher average incomes.

"We're just not planning for the future," says Bob McAlpine of the National Urban League in Washington. It teamed with Third Millennium for a seminar there in June that featured Sen. Carol Moseley-Braun, but only about 50 black movers and shakers showed. "We were trying to see whether this issue was on civil rights radar screens; we found out that it isn't," says Mr. McAlpine.

This month Third Millennium will try to reach Hispanics by co-sponsoring a Washington event with the Mexican American Legal Defense Fund. Hispanics "sacrifice and invest in their kids' educations, not their own retirements," says Syddia Lee-Chee, who coordinates marketing savings bonds to Hispanics for the Treasury Department. "There's a lack of awareness because there's a lack of information," she says.

Please send your comments to me at BizRace@aol.com.

EVENT: HOUSE COMMITTEE ON THE BUDGET meets

=======> SUBJECT: Canceled. Hearing on the impending bankruptcy of the Social Security Trust Fund.

LOCATION: 210 Cannon House Office Bldg.
-- October 1

CONTACT: 202-226-7200

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cc Cynthia

For Immediate Release:
Wednesday, December 17, 1997

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THE ARC RESPONDS TO RESULTS OF SSI 30-DAY PROGRAM REVIEW

Washington, DC -- The Arc of the United States, a national organization on mental retardation, commends Social Security Administration Commissioner Kenneth Apfel for the bold and necessary corrective action he is taking to review cases where benefits were denied under the new Supplemental Security Income (SSI) regulations. His decision to reopen the appeals process for some families who have lost benefits and to automatically review other cases reflects an understanding that many families have unfairly been denied these lifeline benefits. More importantly, his decision provides families an opportunity to redress the situation.

The Arc urges families who receive notification of the reopening of the appeals process to take that opportunity to appeal restoration of benefits. In addition, families may request that their child's cash benefits continue during the appeal, which can take some time. This request should be made within 10 days of receiving the notice. Further, The Arc urges families to get assistance in filing appeals and commends Commissioner Apfel for including a toll-free number for legal services in the notice which families will receive.

While we appreciate Commissioner Apfel's announced actions, we believe that the recent implementation problems have revealed systemic flaws which must be addressed in coming months. We look forward to working with Commissioner Apfel on these issues.

The Arc remains disappointed in the administration's action earlier this year in the establishment of overly harsh, fundamentally flawed criteria for determining childhood disability. The new standard goes far beyond what was required by the 1996 welfare law; more than 142,000 low-income children with disabilities have lost essential benefits that serve to keep their family together. Still more have been denied eligibility upon initial application.

-more-

The children who are dropped from the SSI program, and many of those who are denied assistance when they first apply, remain severely disabled and in need of assistance. While commending Commissioner Apfel's demonstrated commitment to a fair process for children, The Arc strongly urges Commissioner Apfel to revise the current standard so that it better reflects knowledge of childhood disability and so that far fewer children are harmed. The Arc looks forward to working with him in this endeavor.

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

-30-

For Immediate Release

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cc Cynthia

News Release

SOCIAL SECURITY

Statement by Kenneth S. Apfel
Commissioner of Social Security
on SSI Childhood Disability Reviews

Good afternoon. Upon assuming office, I directed the Social Security Administration to conduct a "top-to-bottom" review of the implementation of the childhood disability provisions of the welfare reform law. I believed that this review was needed because the Congress, the President and the American public deserved to know whether the law and the regulations were being applied fairly.

Today, I am releasing a report of the Social Security Administration's review of cases of children who were affected by changes in the law.

For the past two months, SSA has been examining quality assurance data, developing case profiles, reviewing adjudicators' instructions and conducting other oversight activities with this goal: to ensure that our implementation process permitted every child who is eligible for disability benefits to receive them.

Before discussing the results of the report, I think it is important to note that there are approximately one million children receiving SSI disability benefits. Of those one million children, only about 288,000 were subject to redetermination under the new law.

Our review found that overall SSA and the States did a good job in the implementation of the childhood disability provisions of the law; but we did find problems with the manner in which certain redeterminations were made.

Most importantly, I want to emphasize that our review has not been just about numbers--it has been about children. And because of that, SSA is taking steps above and beyond normal action to assure that every child receives a fair assessment of his or her benefit eligibility. **Today, I am directing the Agency and the State Disability Determination Services to review approximately 45,000 of the SSI childhood disability cases which were ceased during this process.**

In addition, families of all children whose eligibility for SSI has been ceased under the new law and who have not appealed will receive another opportunity to do so.

Let me now outline the specific actions to be taken, and the reasons for each.

The problems we identified generally fall into three areas: (1) the status of children classified as having mental retardation; (2) the actual case processing in some areas; and (3) confusion regarding appeal rights.

Eighty percent of the children with mental retardation on the SSI disability rolls were not subject to this review. Of the 80,000 children who were, over half were ceased. The question that needs to be answered is why.

Part of the answer can be attributed to the fact that historically some children who do not have mental retardation were actually coded as having mental retardation. But we also found that some redetermination decisions in mental retardation cases were wrong. In particular, we were concerned that some children with mental retardation may have been inaccurately ceased.

Therefore, I have directed that all benefit cessation cases showing the mental retardation code be reviewed, as well as all denials of initial applications filed on or after August 22, 1996. In addition, for those children with the code for mental retardation and an IQ score of 75 or below, we will reopen their case, develop it as needed, and provide a new redetermination if their benefits were ceased or their applications were denied. For those children with the code for mental retardation and an IQ score above 75, we will review their case and, if deficiencies exist, we will reopen it, develop as needed, and provide a new redetermination.

Before these reviews begin, SSA will provide additional training to its adjudicators on the mental retardation evaluation issues raised in the report.

A second area of concern relates to the quality of our case processing in some areas. Our quality reviews found that in most cases, the case development practices were adequate and the decisions to either continue or deny benefit payments were correct. However, there were variations in accuracy rates. The review found that in some instances, SSA did not follow or fully document all required contacts with beneficiary families to enlist cooperation in processing the claim.

Also, while the accuracy of decisions has been above the regulatory threshold for accuracy nationally, the Agency's quality assurance data show that accuracy varies by state and by impairment.

Therefore, to ensure that each child's case was handled correctly, I have directed the following action. In addition to the review of all cases with the code for mental retardation, we will review a portion of the cessation cases in those areas which have been found to have the greatest likelihood of errors.

SSA will continue to monitor for quality assurance throughout the review of these cessation cases.

The third area of concern focuses on confusion regarding our appeals process and requests for benefit continuation. Concerns were also voiced that beneficiaries did not receive information about the availability of free legal services.

We found evidence which suggests that some beneficiaries and their families who were ceased did not receive full information and did not fully understand their rights. Because of that, I believe these families deserve a second chance.

Therefore, I have directed the Agency to send special notices to those families who were notified that a child had lost SSI eligibility but who did not file an appeal. These families will be given another opportunity to do so. And, if they should choose to appeal, they will be given a new 10-day period to request benefit payments to continue during the appeals process.

Families who did file an appeal but did not request continuation of their benefit payments will also be given a new 10-day period in which to request that benefit payments continue.

Also, SSA is making a concerted effort to ensure that families are aware of available legal assistance by providing toll-free numbers in our field offices, teleservice centers, our Internet site and on the notices we send. We will include the numbers in our notices in those States in which they are available.

Given the results to date of our initial redeterminations and the actions outlined here today, I believe that the Agency's initial estimate of 135,000 children losing benefit eligibility must be modified. We now believe that about 100,000 children, approximately 10 percent of those who were receiving SSI benefits based on a disability, will be impacted by the new law.

As I said at the beginning of my remarks, this review has been about children. During the review we sampled 151 cessation cases to help us answer the question "who are these children?" We found that the children affected do have limitations in functioning, but by and large, their conditions are not as severe as those of the 900,000 children who will continue to receive benefits. The majority of cases in which children came off the rolls involved learning problems, such as attention deficit hyperactivity disorder and conduct disorders. A third of the children sampled had demonstrated medical improvement.

This was an exhaustive process that received input from many people--advocates, service providers, members of Congress and the public. We could not have conducted this review without their support and I want to personally thank them. I also want to take this opportunity to say that this agency is doing all that it can to protect the rights of disabled children.

Finally, let me say that I ordered this review because I wanted a higher level of assurance that children are given every chance to receive the benefits for which he or she is eligible under the new law, and that is why I have announced these actions today. I believe the actions will leave little doubt that the Social Security Administration is committed to providing fair, thorough and equitable reviews for all SSI childhood disability claimants and beneficiaries.

Thank you. I'll now take your questions.

TALKING POINTS
SUPPLEMENTAL SECURITY INCOME PROGRAM (SSI)
CHILDHOOD DISABILITY REVIEWS
December 17, 1997

"Our review has not been just about numbers – it has been about children. Because of that, SSA is taking steps above and beyond normal action to assure that every child receives a fair assessment of his or her benefit eligibility." *Commissioner Kenneth Apfel*

- Social Security Administration (SSA) Commissioner Kenneth Apfel today released a report directing the Agency and the State Disability Determination Services (DDSs) to review approximately 45,000 of the SSI childhood disability cases which were ceased under tighter eligibility provisions of the 1996 welfare reform law.

- Those new provisions tightened the definition of childhood disability, resulting in redeterminations for 288,000 of the one million children receiving SSI disability benefits.

- Commissioner Apfel directed the Agency to conduct a "top-to-bottom" review of the implementation of the childhood disability provisions of the 1996 welfare reform law. The resulting report notes that while overall the Agency and the states have done a good job in implementing complex, technical changes in disability criteria in a short time frame, the decision to review the 45,000 cessation cases was made to assure that children are not disadvantaged as a result of some deficiencies in how decisions were made.

- SSA identified three areas of concern: first, the status of children classified as having mental retardation; second, the actual case processing in some areas; and third, confusion among some parents and guardians regarding their appeal rights.

Mental Retardation:

- 407,000 of the one million children on the SSI disability rolls were identified as having mental retardation (MR). Eighty percent of those children had impairments that met current eligibility criteria and were not subject to redetermination. Of the 80,000 children who received redeterminations, over half were ceased.

- Part of this cessation rate is due to the fact that historically some children who do not have mental retardation were coded as having MR. New diagnosis codes have helped rectify this problem. In addition, some children were erroneously removed from eligibility.

- Therefore, the Commissioner has directed that all benefit cessation cases showing the mental retardation code be reviewed, as well as all denials of initial applications with the MR code filed on or after August, 22, 1996.

Actual Case Processing in Some Areas:

- While the accuracy of case decisions has generally exceeded the national standard, SSA was concerned about variations in accuracy rates and instances where children were found ineligible because of the failure of their parents to provide all the necessary documentation. In some cases, the Agency did not make every effort as required to enlist the cooperation of families in processing their claims.

- Therefore, the Commissioner has directed that all cases which were ceased because of a family's failure to cooperate will be reviewed. Also, each State will review a portion of its cessation cases in those areas, in addition to mental retardation, which show the greatest likelihood of errors.

Confusion Regarding Appeals Process:

- The report found some confusion regarding SSA's appeal process and the right of every family to request benefit continuation during appeal. Concerns were also raised that some beneficiaries did not receive information about the availability of free legal services.

- Therefore, the Commissioner has directed the Agency to give families of children who lost or were denied eligibility but did not file an appeal, another chance to do so. Those families who do appeal will be given a new 10-day period to request benefit continuation during the appeals process.

- The Agency is also taking additional measures to make sure families are aware of free legal services.

Consulting Partners

- The Commissioner made this decision in consultation with the White House, Members of Congress, advocates, State agencies and SSA staff.

Conclusion:

- **Given the results to date of initial redeterminations and the actions outlined in today's report, SSA now believes that its initial estimate of 135,000 children losing benefits should be modified. The Agency now believes that about 100,000 children will be impacted by the new law.**

Date: 12/17/97 Time: 19:16
DChildren cut from disability rolls get second chance

WASHINGTON (AP) Admitting some poor children were wrongly taken off disability rolls, the Social Security Administration will review at least 45,000 cases and give every child who was cut another chance to appeal.

Newly installed Commissioner Kenneth S. Apfel said Wednesday that a ``top-to-bottom'' review found a variety of problems as states determined whether 288,000 children met a new, stricter definition of disability.

Social Security now estimates that 100,000 children will ultimately be cut from the Supplemental Security Income program, which had grown to serve 1 million children. Officials had earlier estimated 135,000 children would ultimately be cut off.

Apfel, who promised during his Senate confirmation hearing to review the program, concluded many mentally retarded children were wrongly cut from the rolls, some states made too many mistakes in terminating cases and some families were confused about their right to appeal.

``I believe these families deserve a second chance,'' Apfel said. He called the effort ``above and beyond'' normal actions to assure every child receives a fair assessment of his or her eligibility.

``I am deeply concerned that children could be disadvantaged as a result of deficiencies in the manner in which decisions are made,'' he wrote in his report.

All families will be given another opportunity to appeal, and Social Security workers will get new training to be sure the rules are applied fairly. The new reviews should be completed by October 1998, Apfel said, but they will not begin until the training is complete.

Advocates welcomed the announcement Wednesday. The Arc of the United States, which represents people with mental retardation, commended Apfel for ``bold and necessary corrective action'' and urged families to take advantage of their second chance to appeal.

So far, about 135,000 children have been cut from the SSI program, and fewer than half have appealed. Of the 75,000 children who have not appealed, Social Security will automatically reconsider 45,000 cases including:

17,000 children whose files indicate they are mentally retarded, including some whose files were mislabeled. Children with IQs below 76 will automatically be returned to the rolls. Additionally, about 15,000 mentally retarded children who have applied for SSI since August 1996 and were denied will have their cases reviewed.

20,000 to 27,000 children with a variety of ailments, concentrated in 17 states with accuracy rates below 90.6 percent.

6,000 children who were cut from the rolls because their parents ``failed to cooperate'' with reviewers. In 68 percent of these cases, proper contacts to families were not made or not documented.

Last year's welfare reform bill tightened the standards poor children must meet to qualify for SSI, which provides an average of $436 a month to help parents meet their children's special needs. Alarmed by the rapid growth in the program, Congress wrote a tougher definition of disability, and the Clinton administration issued a strict interpretation of the new standards.

Apfel said Wednesday that given time constraints, the Social Security Administration and the states did a good job implementing the new rules. But his final report notes several problems,

including:

Some families did not get full information about their rights to appeal termination from the program. Printed materials were hard to understand.

In some isolated cases, inaccurate information was given to families in person or over the government's toll-free telephone line.

The report also looked at children who were properly taken off the rolls and found most had learning problems such as attention deficit hyperactivity disorder or behavior disorders. A third of the children taken off the program had improved medically since they joined it.

Changes in the program were originally projected to save $4.7 billion over five years. Officials said they did not know how the revision will affect the budget.

Advocates for the disabled, who opposed the changes in the first place, have complained that the administration interpreted the law too harshly, meaning more children will be cut off SSI than necessary.

But Apfel said this review did not address those concerns: ``That is an issue for another day,'' he said.

APNP-12-17-97 1922EST

Q&A's -- Children's SSI Report -- For Internal Use Only

Question: **Does SSA conclude in this report that it did a good job on these reviews?**

Answer: The report concludes that overall SSA did a good job evaluating over 200,000 children in a short time frame, but it identifies areas of concern that SSA will address. As a result of the report, SSA will review the cases of about 45,000 children whose benefits were terminated. SSA will examine a portion of the terminations in every state, choosing the kinds of cases most needing review in each state and focusing heavily on states with higher error rates. All children terminated from the program who were coded as having mental retardation will have their cases reviewed. Also, because of concerns that families didn't always understand their rights to appeal, SSA will offer the families of all children who didn't appeal their termination a new chance to do so.

Question: **How can SSA say it did a good job in these reviews when it's going back and reviewing the cases of tens of thousands of children it cut off?**

Answer: Overall, the performance by the state agencies that perform these reviews for SSA exceeded SSA's standard (a 90.6% rate of accuracy and completeness). However, Commissioner Apfel found certain shortcomings in the process and he plans to take action in those areas.

Question: **Is it true that SSA was prepared to go further and review more cases, but that the White House disagreed and made SSA revise its report?**

Answer: Commissioner Apfel and his staff kept White House and OMB staff apprised of their progress during their review, and informed us of their findings and planned actions, but the substance of the report was determined by SSA, not the White House.

Question: **Did the White House review this report before it was issued?**

Answer: Commissioner Apfel kept White House and OMB officials informed during his review, but we did not determine the report's content.

Question: **What does the White House think of this report?**

Answer: We have not yet had an opportunity to review it in detail (although Commissioner Apfel has advised us of its general contents). It appears to be a thorough examination of SSA's process, and its recommendations appear to give top priority to ensuring that children who must be reevaluated under the new standard get a fair and complete assessment.

Question: **What kinds of kids are being cut off?**

Answer: You should look at the case studies of 151 children that SSA is releasing with this report. My understanding is that most of them have mental disabilities, such as learning disabilities or attention deficit disorder.

Question: **Advocates for children with disabilities say that this report doesn't address the real issue, which is that the standard set by the Administration and SSA is too strict. Is that right?**

Answer: This report addresses SSA's process for implementing the new standard. Some advocates and members of Congress say that SSA could have established a standard that was far less strict and that still complied with Congress's intent in the welfare law. However, SSA's judgment was that it did not have the legal flexibility to do so.

Question: **Advocates point out that the rate of cutoffs vary tremendously from state to state -- from 32% in Nevada to 82% in Mississippi. Doesn't this demonstrate that the reviews were done incorrectly? And, if not, how do you explain these discrepancies from state to state?**

Answer: That's why Commissioner Apfel has ordered the reviews of 48,000 cases. But the report also found that you would expect significant variance among states in the rates of terminations, based upon the characteristics of the children in that state and the extent to which children in that state became eligible for SSI through criteria that the Congress eliminated in the welfare law.

Question: **Some Republicans charge SSA is using administrative means to soften the impact of the law and cut off fewer kids. The report revises downward the number of kids who will be cut off -- from 135,000 to 100,000. Is this true?**

Answer: No. The actions outlined in this report simply ensure that SSA adheres to the standard set out in the law.

Question: **Does the White House favor cutting these kids from the rolls?**

Answer: In 1995 and 1996, the Administration fought and defeated proposals by House Republicans that would have block granted children's SSI and slashed its funding. In the end, a compromise was reached as part of the welfare bill that ended eligibility for those children with less serious disabilities. SSA's interpretation of the statute has been fair and balanced, working within Congressional intent to ensure that those children who meet the new standard remain eligible. Also, the President fought for and won a provision in the Balanced Budget Act that grandfathered Medicaid for all children cut from the rolls who do not meet the new standard.

Children's SSI Report

Background: The Social Security Administration released a report today on its implementation of the new definition of childhood disability for SSI. This report follows Commissioner Ken Apfel's promise, at his confirmation hearing in September, of a "top to bottom" review of SSA's process for redetermining the eligibility of children.

The welfare law tightened the definition of childhood disability for SSI, and required the Social Security Administration to redetermine the eligibility of approximately 288,000 children, out of about one million children now on the rolls. These reevaluations have led to almost 140,000 terminations to date. (At the time the welfare law was enacted, CBO estimated that 180,000 children would lose SSI; when SSA announced its interpretation of the law, it projected that 135,000 children would become ineligible.) Advocates charge that SSA has done a poor job on these reevaluations, causing eligible children to be dropped from the rolls.

The report concludes that SSA did a generally good job of redetermining eligibility for these children. The report, however, identifies three areas of concern and announces actions to address them.

First, SSA will review the cases of all children "coded" as mentally retarded who were cut from the rolls and have not appealed. This action addresses SSA's finding that some of these children may have been terminated incorrectly. Second, SSA will review a portion of every state's unappealed terminations, choosing the kinds of cases most needing review in each state and focusing heavily on states that SSA has found to have a relatively high error rate. This review will allow SSA to give special attention to states with the highest error rates, without singling them out as "bad actors." Third, SSA will offer all 70,000 families who did not appeal its termination decisions a new opportunity to do so. These actions, and the problems they address, are further described in an appendix attached to this memo.

In all, SSA will review the cases of 45,000 children dropped from the program. (Another 70,000 have appealed.) As a result of these actions, SSA now projects that approximately 100,000 children ultimately will lose SSI benefits.

With the report, SSA also released case studies of a random sample of 151 children who have lost benefits. This document is intended to explain to the public what kinds of children are no longer eligible. Most of the children have mental disabilities other than mental retardation, including learning disabilities and attention deficit disorder. Over a third have improved since they were first found eligible. The majority are teenagers; only a handful are age six or younger.

Advocates will probably have a mixed reaction to the report -- generally pleased about the actions, but still arguing that SSA's regulation interpreting the statute is needlessly strict. The report does not address the latter issue. The Republican leadership in Congress has been extremely supportive of SSA's implementation of the law to date, but probably will criticize this report on the ground that it bends over backwards to restore benefits.

SSA Report on Childhood Disability Process
Summary for Internal Use Only

SSA's report examined three areas of concern raised by advocacy groups:

I. Mental Retardation

Advocates' Charge: Too many children with mental retardation were cut from the rolls.

SSA Finding: Of the 136,000 children terminated to date, 42,000 were "coded" as mentally retarded (MR). However, most of these children do not actually have MR, because until recently SSA's systems did not have all the necessary codes. Instead, most of these children have other mental disorders, such as learning disabilities or "borderline intellectual functioning" (which falls short of full-fledged MR). Some unknown subset of the 42,000 do have MR, but either their impairments are not severe enough to qualify them for SSI, or they were denied incorrectly.

Even with these terminations, approximately 350,000 children coded as MR will remain on the rolls, out of the total of one million children on SSI.

SSA Action: SSA will review all cases terminated that were coded as MR, to ensure that all those decisions were made properly.

II. State Variations in Cutoffs

Advocates' Charge: Errors in cutoffs appear likely, since termination rates varied widely by state, from 32% in Nevada to 82% in Mississippi. Also, SSA may not have acquired all documentation, such as school records, needed to judge a child's disability. Finally, some states were disqualifying too many families for failure to cooperate without making adequate efforts to reach them.

SSA Findings: SSA data show that on average 93% of termination decisions were both accurate and complete (i.e., they included all required documentation). This exceeds SSA's required level of overall state performance for SSI, which is 90.6%. However, 10 states had accuracy/completion rates below 90%. Another 9 states had accuracy/completion rates below the national average. (SSA's experience is that about one-third of the errors identified in these measures will ultimately prove to be accurate decisions that simply lacked documentation.) SSA found that many inaccurate decisions stem from an overly strict interpretation of the new rules for children who exhibit maladaptive behavior.

Claims that SSA did not acquire all needed documentation were determined to be largely unfounded. However, SSA found wide state variations in the percentage of children cut off because their families did not cooperate with the redetermination. In a study of such cessations, SSA found that 68% of the cases did not include documentation that all required efforts to contact the family had been made.

SSA also performed a regression analysis to determine whether wide state-to-state variations in overall termination rates should be expected because of legitimate factors, such as the child's age and impairment and whether the child was initially added to the rolls based on the less strict criteria eliminated by the welfare law. SSA found that these factors would lead you to expect the cutoff rate to vary from 40% in Idaho to 78% in Mississippi. While this regression analysis does not fully explain the actual state-by-state variance, it does convince SSA that most of the variance among states is due not to errors, but to characteristics of the children.

SSA Action: SSA will review a portion of the decisions in all states, focusing more on states with lower accuracy rates. All cases terminated as a result of failure to cooperate will be reviewed. SSA will also provide more training on maladaptive behavior.

III. Appeal Rights

Advocates' Charge: Too few families are appealing because SSA's notice to families was confusing, and workers discouraged appeals. Also, SSA discouraged families from requesting that benefits be continued during the appeal, and didn't do enough to publicize free legal services.

SSA Finding: SSA found that its workers did not discourage appeals, although this may have occurred in isolated instances. At the same time, a survey conducted by SSA confirms that many families did not understand their appeal rights.

SSA Action: All 70,000 families of children who were terminated and did not appeal will be given a new opportunity to do so. In addition, all families of children who appealed but did not request continuation of benefits during the appeal will also be given a new opportunity to make that request. SSA will also publicize the availability of free legal services for families.

Children's SSI Terminations -- Sample of 151 Cases

Diagnosis at Termination	Number of Children	Percent of Total
Learning Disabilities	31	21%
Attention Deficit Disorder	30	20%
Various Mental Disorders (e.g., Conduct Disorder, Adjustment Disorder, Affective Disorder, Developmental Delays, Developmental Disorders, Personality Disorders, Oppositional Defiant Dis., Relational Disorder)	21	14%
Borderline Intellectual Functioning	12	8%
Mental Retardation	10	7%
Physical Disabilities (other than asthma)	9	6%
Asthma	7	5%
Speech Delay	4	3%
None	3	2%
Subtotal	127	84%
Failure to Cooperate	24	16%
TOTAL	151	100%

7 errors

Laura Oliven Silberfarb
12/18/97 08:31:44 AM

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Subject: NYT

By ROBERT PEAR

ASHINGTON -- The Clinton administration said on Wednesday night that it would re-examine the cases of 60,000 poor children who were denied disability benefits in the last year because it had concluded that the government might have made mistakes.

In addition, the new commissioner of Social Security, Kenneth Apfel, said a separate group of 75,000 to 80,000 families would be given new opportunities to appeal the loss of children's disability benefits.

His actions are an unusual reversal by an agency that until recently had contended that its decisions to cut off benefits were proper.

The commissioner said many of the children might actually have been disabled enough to qualify for benefits under the tough new standards set by the 1996 welfare law. Many of the children are mentally retarded. Others suffer from diabetes, cerebral palsy and AIDS.

At a news conference on Wednesday night, Apfel said, "The Social Security Administration is taking steps above and beyond normal action to assure that every child receives a fair assessment of his or her benefit eligibility." He also said he was "deeply concerned that children" could be harmed by his agency's erroneous decisions.

The commissioner estimated that the new reviews and appeals would ultimately increase the number of children on the rolls by 35,000. The number losing benefits, after all appeals, will be 100,000, rather than the 135,000 initially estimated, he said. One million children receive disability benefits under the Supplemental Security Income program.

Apfel ordered new reviews of all mentally retardedchildren with mental retardation who have been removed from the rolls or have applied unsuccessfully for benefits since Aug. 22, 1996, when President Clinton signed the Republican-sponsored welfare law.

Lawyers and other advocates for disabled children applauded the commissioner's actions. Jerome Shestack, president of the American Bar Association, said, "This is the best possible Christmas present the Social

Security Administration could give to families with disabled children."

Martha Ford, a lobbyist for the Arc, formerly known as the Association for Retarded Citizens, praised Apfel, saying he had taken "bold and necessary corrective action."

Sen. John Chafee, R-R.I., said Apfel was taking "a timely, much-needed step in the right direction." The senator said the Social Security Administration had terminated benefits for "many more children than Congress ever intended."

Congress, alarmed at the rapid growth of the disability program, tightened the eligibility criteria when it passed the 1996 welfare law. Benefits paid under the Supplemental Security Income program average $436 a month, or $5,232 a year. They help families pay for food, clothing, shelter and the extra costs of caring for disabled children.

Of the 60,000 children whose cases will be automatically reviewed, 45,000 were previously on the rolls and lost their benefits after being evaluated under the new eligibility criteria. They have a variety of impairments. (Slightly more than one-third are mentally retarded.)

The other 15,000 children have not been on the disability rolls, but unsuccessfully applied for benefits in the last year. In their applications, parents said these children had mental retardation.

In some cases, Apfel said, the government did not make adequate efforts to obtain evidence of children's disabilities. In other cases, federal officials found that parents were misinformed of their legal rights or discouraged from appealing the termination of benefits.

The commissioner said he had not analyzed the cost of the actions announced on Wednesday. But he said the necessary money would be included in Clinton's budget request to Congress early next year.

The disability program has a troubled history. Federal judges repeatedly upheld the claims of adults and children who were removed from the disability rolls in the first years of the Reagan administration.

The number of children on the disability rolls has tripled since 1989, and costs have quadrupled, to more than $5 billion a year. Enrollment grew because of court decisions, an increase in the childhood poverty rate and a loosening of eligibility rules that provided benefits to children with mental impairments.

Apfel, who took office on Sept. 29, promised to do a "top-to-bottom review" of the program in his first 30 days on the job. The review took longer than he expected.

Since the president signed the welfare law last year, Social Security officials have terminated disability benefits for more than 135,000 children. About 80 percent of them have mental disorders.

Many of these families did not fully understand their appellate rights, Apfel

said.

"I believe these families deserve a second chance," he added. "I have directed the agency to send special notices to those families who were notified that a child had lost eligibility, but who did not file an appeal."

The 75,000 to 80,000 families that will be afforded new opportunities to appeal decisions denying benefits had not done so in the 60-day period they originally had to do so.

These families will have 60 more days to appeal, and can continue receiving benefits if they appeal in the first 10 days. They can also recover payments that they would have received since their benefits were halted.

Apfel predicted that 20,000 families, about one-fourth of those who receive the notices, would appeal.

Families who appeal have a good chance of success. Children have won restoration of benefits in more than half of the appeals decided to date, with especially high rates of success in Illinois, Louisiana, Michigan, New Jersey and New York.

Besides reviewing cases of mental retardation, Apfel said, Social Security officials will identify other types of cases "with the greatest likelihood of error" by the government, and children with these impairments will be re-evaluated.

Officials will also scrutinize more cases in states like Mississippi and Pennsylvania, where the initial decisions to stop benefits seem often to have been inaccurate.

In letters terminating benefits, Social Security officials have invited parents to call a toll-free telephone number with questions. Apfel said that he would give the phone operators a new script to make sure they did not mislead parents with incorrect answers.

Jonathan Stein, general counsel of Community Legal Services of Philadelphia, who has represented thousands of people seeking disability benefits in the last 20 years, said Apfel "has shown compassion and courage in trying to do the right thing."

But Stein added, "We are disappointed that Mr. Apfel has not addressed the inadequacy of the regulation" issued by the government in February to interpret the new eligibility criteria set by Congress last year.

Message Sent To:

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TO: Diana Fortuna

FIRM: Domestic Policy Council

FAX NO.: (202) 456-7028

FROM: JONATHAN STEIN, GENERAL COUNSEL

DIRECT DIAL: (215) 981-3742

MESSAGE: Our critique of SSA "report" on SSI children; please share w/ Elena Kagan, Sylvia Mathews & Frank Raines

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9/17/97

SSA CASE STUDIES REPORT FAILS TO SHOW ABUSE AMONG TERMINATED CHILDREN AND IGNORES WIDE-SPREAD REPORTS OF SEVERELY DISABLED CHILDREN BEING TERMINATED FROM SSI

House Republicans are releasing today a September 3, 1997, SSA compilation of sanitized, incomplete summaries of children continued and terminated from SSI in the face of wide-spread documentation that great numbers of severely disabled children have been terminated among the 124,000 children cut.

This report refutes the assertion that there has been abuse of the system. Nor do the data demonstrate that the application of the stricken Individualized Functional Assessmemt (IFA) test had been abused.

1. The cessation cases do not include a single child with Mental Retardation (MR) but SSA data show that 45% of SSI eligible children have MR and termination reports around the country show that children with IQ's in the 40's, 50s, and 60s have been terminated in recent months.

2. Fifty percent (20 of 40) of these cessation cases are for Attention Deficit Hyperactivity Disorder (ADHD). SSA's own data show that ADHD children constitute no more than 8% of the children receiving SSI benefits.

3. Contrary to the assertion that parents of disabled children are abusing the system, not a single child in this sample was terminated for failure to follow treatment. Fifteen of the 40 children (37%) were terminated because of apparent medical improvement," largely due to parental compliance with treatment plans and medication. This fact only proves that the use of Continuing Disability Reviews with a Medical Improvement test, rather than elimination of the IFA, was all that was needed. (See Majority Leader Bob Dole's statement that the program only needed "fine tuning." Senate floor statement of September 14, 1995).

4. In none of the 40 cessations reported here was there any suggestion of evidence of fraud, abuse, or "coaching" which was the main point of attack of House Republicans.

5. These bogus case summaries are all written solely to justify cessation. They obviously do not reveal all of the facts and documents and medical information in each child's case. The summaries on many of these children do not even address the problems which resulted in their initial allowances. Many change the diagnosis or ignore the previous concerns. Given the fact that SSA is now reporting that 65%-70% or all cessations are now being reversed at the first appeal level, reconsideration, it is highly likely that many of these purported

"correct" cessations will be reversed when a more thorough and objective evaluation of the evidence is afforded the child.

6. The report clearly does not refute the 65%-70% reversal rate nor justify the up to 300% variation in cessation rates among the states. These data therefore ignore the major problems already documented about the fairness of the process, the severity of the redetermination standards, and the variation among states of application of the new standards.

7. The manner in which this report is coming out raises serious questions about its good faith. This report, although dated September 3, 1997, was published on the same day that Acting Commissioner John Callahan met with child disability advocates, including the Arc of the U.S., at which time Callahan made no reference to the completed report or offered those present a copy. One can only conclude that this was an effort to avoid scrutiny and criticism of a report prepared, it appears, more for public relations purposes.

It is also interesting that the report was not cited nor offered to the Senate Finance Committee on September 10, 1997 at the confirmation hearing on SSA Commissioner designate Kenneth Apfel, where the issue of the wrongful termination of SSI disabled children was explored. At that hearing, Mr. Apfel acknowledged to Senator Kent Conrad that in the face of nationwide reports of unfair terminations of children, according to Apfel, it "sounds like the system is not working."

Social Sec: Children's Disability Standard

Diana —
Could you look into this? It seems absurd to require a reapplication for Medicaid.
Elena

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October 16, 1997

cc: Bruce

Harriet Rabb
Chief Counsel
U.S. Dept. of Health and Human Services
615F Humphrey Building
200 Independence Ave., SW
Washington, DC 20201

Re: SSI and Medical Assistance
and
Disabled Children

Dear Harriet,

Following our phone call last week we have not been able to receive from HCFA any assurance that the two problems we articulated to you, their acting chief counsel and then to HCFA program staff would be satisfactorily addressed at this time. As a result we are giving you notice that we will initiate class action litigation against Secretary Shalala and HCFA unless an immediate remedial response is forthcoming.

The two problems needing resolution, and set forth in more detail in the enclosed letter of October 10, 1997 to Judith Moore, Deputy Director of HCFA's Center for Medical and State Operations, are:

(1) the failure of HCFA to implement, via instructions to state Medicaid agencies, the grandfathering provision providing for continuous, uninterrupted Medicaid eligibility for any children terminated from SSI child disability benefits, Sec. 4913, Balanced Budget Act; and

(2) the planned implementation policy of allowing states to require an entirely new application for Medicaid for children already cut from SSI since July 1, 1997, most of whom were cut in violation of HCFA policy mandating automatic eligibility redeterminations to keep people on Medicaid even prior to the Balanced Budget Act amendment.

We and co-counsel have already filed a class action against the Georgia Medicaid agency which has now admitted to that at least 1,700 disabled children cut from SSI were also cut from Medicaid without any inquiry to determine whether they remained eligible under another provision of the Act. The failure of HCFA to issue implementing instructions and HCFA's plan to implement a re-application policy that will further impede Medicaid eligibility constitute violations of Section 4913 and other federal law.

You may reach us at (215) 981-3742 (or -3773) to remedy these issues without the need for litigation.

Sincerely yours,

JONATHAN M. STEIN
General Counsel

RICHARD P. WEISHAUPT
Senior Attorney

cc: Secretary Donna Shalala
Nancy Ann Min Deparle, HCFA
Judith D. Moore, HCFA
Bob Jay, HCFA Acting General Counsel
Chris Jennings, Domestic Policy Counsel, The White House
Senator Edward Kennedy
Mrs. Eunice Kennedy Shriver
Claudia Schlosberg, National Health Law Program
Marty Ford, The Arc
Herb Semmell, National Senior Citizens Law Center
Chris Koyanagi/Rhoda Schulzinger, Judge Bazelon Mental Health Law Center
Marilyn Holle, Calif. Protection and Advocacy

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nhelpdc@healthlaw.org ◻ http://www.healthlaw.org

October 10, 1997

Judith D. Moore
Deputy Director
Center for Medicaid and State Operations
Health Care Financing Administration
Department of Health and Human Services
7500 Security Boulevard
Baltimore, Maryland 21244-1850

Dear Judy:

Thank you for your response to our letter of July 31, 1997 regarding implementation of BBA's restoration of Medicaid benefits to children losing SSI under the welfare law. We are pleased that HCFA agrees that children who lose SSI under the new definition of disability will be deemed mandatory categorically needy for Medicaid eligibility purposes. However, your response in Paragraph 5 is deeply disturbing. Specifically, you state: "HCFA does not believe the States should be prohibited from requiring that terminated children reapply [in order to be reinstated to the Medicaid program]. "

In enacting the Balanced Budget Act, Section 4913, Congress restored Medicaid eligibility to an identifiable group of children: children who were receiving SSI cash assistance as of August 22, 1996 and who, but for the operation of the welfare law, would continue to be eligible for such cash assistance. Congress understood what the Social Security Administration has been reporting -- thousands of children who are being terminated from SSI have serious illnesses and disabilities and remain in dire need of medical assistance. Requiring these "grandfathered" children to reapply in order to be reinstated to the Medicaid roles undermines Congress' intent and conflicts with long-standing law and policy. It is also contrary to President Clinton's strong commitment to assuring that children receive adequate health coverage.

Under the Medicaid statute and HCFA policy, when an individual is about to lose Medicaid, the State is required to make an *ex parte* redetermination of the individual's Medicaid eligibility under all other eligibility categories. Indeed, last year, you personally drafted specific guidance clarifying that "[states] should inform the individual that reapplication is not necessary to retain Medicaid." The purpose of the *ex parte* redetermination is to assure that Medicaid continues until there is an affirmative finding of ineligibility. The law and HCFA policy squarely place the onus on the state agency, and not the beneficiary to initiate the review process.

In the instant situation, Congress has decreed that these children remain eligible for Medicaid under the old *Zebley* standard. Although some children have already been terminated from SSI and therefore Medicaid, those determinations were made under the new standard. There has been no

affirmative finding of ineligibility under the old *Zebley* standard. Furthermore, it is important to note that SSI terminations under the welfare law were effective beginning July 1, 1997, while the BBA restores eligibility effective July 1, 1997. Thus, Congress assured that there would be no period of ineligibility for these children. Moreover, except in rare cases, the 60 day SSI appeal period during which Medicaid must continue would not have expired prior to when the grandfather provision took effect. Therefore, these children ought to be continued automatically on Medicaid.

Absent automatic continuation and reinstatement for those terminated illegally, the burden of proving eligibility shifts to the children in the "grandfathered" group. We know from past experience, that requiring reapplication will result in loss of coverage. Furthermore, without Medicaid or other insurance, these children are likely to encounter significant obstacles in trying to develop the medical evidence necessary to complete their applications. Furthermore, there can be significant delays between the filing of the application and when it is acted upon. States have 90 days to make a determination when eligibility is based on disability, 42 C.F.R. Section 435.911, and we know from experience that the deadline is often missed. States now will have to make determinations based on a disability standard that no longer applies to SSI, complicating the issue. Some state Medicaid agencies have not had experience making disability determinations for SSA, so a new disability unit will have to be established and trained, while complex inter-agency relationships will need to be revamped. In the interim, these eligible children will have no access to on-going medical care for many months if a new application is required.

Finally, our monitoring of state activity reveals that at least one state, Georgia, is systematically terminating children from Medicaid despite pending SSA appeals and without conducting *ex parte* redeterminations. We have also encountered other reports of erroneous or illegal terminations. HCFA's policy of not prohibiting states from requiring grandfathered children from reapplying effectively condones these illegal and erroneous terminations.

We trust that you will give our concerns serious consideration, and ask that the policy regarding reapplications not be finalized or published. We also would like an opportunity to meet and to discuss this further. Please call me so that we can schedule a meeting immediately on this issue.

Sincerely,

Claudia Schlosberg
National Health Law Program

Jonathan Stein
Community Legal Services, Inc.

Richard P. Weishaupt
Community Legal Services, Inc.

Marty Ford
The Arc

Marilyn Holle
Protection and Advocacy

Herb Semmel
National Senior Citizens Law Center

Chris Koyanagi
Bazelon Center for Mental Health Law

cc: Nancy Ann Min Deparle, HCFA
Sally Richardson, HCFA
Deborah Chang, HCFA
Lloyd Bishop, HCFA
Michael McMullan, HCFA
Bill Hickman, HCFA
Dan Waldo, HCFA
Judy Chesser, SSA
Chris Jennings, DPC
Lee Partridge, APWA
Senator Edward Kennedy
Eunice Kennedy Shriver

Following statistics on SSI
for
Elena Kagan

Please call re: these data.

Jonathan
(212) 981-3742

SSI Childhood Disability Cessations, New Initial Allowances, and Reconsideration Appeal Reversals
Cumulative Through 10/04/97

State (DDS)	Initial Cease Rate (%)	Total Ceased	New Initial Allowance Rates (%)	Recon Reversal Rate (%)
National Totals	59.8	135,841	32.2*	57.6**
Mississippi	82.2	4,774	15.7	45.0
Texas	79.0	8,556	26.4	39.1
Montana	78.4	352	34.0	35.5
Iowa	77.0	1,233	31.1	48.0
Louisiana	76.8	8,475	18.0	100.0
Arkansas	76.4	4,027	20.2	48.5
Kansas	75.7	1,803	27.6	58.3
Oklahoma	75.5	1,062	28.1	22.1
Tennessee	73.6	3,722	28.1	39.2
Alabama	72.6	4,374	23.3	19.4
Missouri	72.5	4,226	22.6	94.9
Illinois	70.6	8,485	30.2	100.0
South Carolina	70.5	2,624	28.7	100.0
Rhode Island	69.6	521	29.7	65.4
Georgia	69.1	3,010	29.51	50.9
Nebraska	68.6	589	33.3	62.5
New Mexico	67.4	787	31.7	46.2
North Dakota	66.9	113	39.3	20.0
Wisconsin	65.3	3,430	32.5	94.4
Ohio	65.1	7,180	32.3	100.0
West Virginia	65.0	1,284	26.2	17.3
New York	62.8	14,787	28.9	80.8
Indiana	61.1	2,865	34.2	93.5
Utah	59.9	438	52.0	60.0
Florida	58.2	7,428	30.4	41.9

*The pre-Zebley, 1989 new initial allowance rate, when a similar Listings-level policy was in use, was 42%.
**Historical reversal rates at reconsideration ("recon"), the first step of appeal, are about 10%.

State (DDS)	Initial Cease Rate (%)	Total Ceased	New Initial Allowance Rates (%)	Recon Reversal Rate (%)
New Hampshire	57.8	160	42.9	83.3
Connecticut	56.3	647	36.1	78.0
Idaho	56.2	590	42.1	54.7
Maine	55.9	277	37.4	61.5
Colorado	55.4	945	46.5	94.9
Maryland	53.2	1,516	41.3	70.8
Vermont	52.4	193	41.9	85.7
Virginia	52.0	3,910	33.3	50.0
Wyoming	51.8	147	27.8	.0
Massachusetts	50.8	2,183	40.2	80.0
Delaware	47.7	217	41.0	100.0
Alaska	46.9	83	55.2	.0
Washington	46.7	871	51.9	84.2
Michigan	46.3	4,981	31.9	100.0
Arizona	44.7	1,014	44.5	67.3
Kentucky	44.1	3,068	37.4	100.0
New Jersey	44.1	2,206	38.8	100.0
North Carolina	43.6	4,760	15.7	46.0
South Dakota	43.5	229	36.4	57.7
Oregon	41.0	375	51.2	88.9
Minnesota	40.0	1,146	55.0	62.5
Pennsylvania	39.9	4,908	32.1	42.1
California	39.7	4,837	47.5	70.9
Nevada	38.3	194	48.0	100.0
Hawaii	36.8	28	58.4	.0
D.C.	36.4	211	41.1	.0

Source: Social Security Administration, Office of Disability, Social Security Childhood Status Report (1997)

ngeles Times

MONDAY, OCTOBER 13, 1997
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DAILY 25¢
DESIGNATED AREAS HIGHER

New Rules Cut Disability Aid for 135,000 Children

■ **Benefits:** Many cases wrongly closed, advocate groups say. Social Security officials insist evaluations are fair.

By JOCELYN Y. STEWART
TIMES STAFF WRITER

Richard started talking about killing himself when he was 5½ years old.

He was not joking. He was not being manipulative.

"I didn't see him try to attempt it," said Richard's mother. "It's just the fact that I was hearing it—that his mind was going there—that was alarming and suggested we should address it."

Now Richard is 11, on medication for attention deficit disorder, and in therapy with a psychiatrist and a psychologist for depression. He is also one of the more than 135,000 low-income children nationwide who have received notices saying they are being cut from the disability rolls.

The terminations are a consequence of a controversial section of the 1996 federal welfare overhaul calling for a redefinition of childhood disability. In February, the Social Security Administration began a review of more than 200,000 low-income children who had been receiving monthly supplemental security income and medical benefits. Children who are judged as not meeting the new criteria are being dropped from the assistance program.

"We're not talking about kids that suddenly got better," said Julie Justicz, who is heading an American Bar Assn. effort to assist families nationwide in appealing the terminations. "The kids have not changed; what's changed is the definition of disability."

The Social Security Administration says that children who have been cut from the program are not severely disabled and that evaluations conducted in recent months have been fair.

Please see CUTS, A23

CUTS: 135,000 Children Lose Disability Benefits

Continued from A1

Children's advocates, who have been scrambling to locate and provide assistance to affected families, counter that the process is rife with problems. They are calling, along with some in Congress, for the Social Security Administration to halt its remaining reviews until the issues can be resolved.

"The first round of terminations were so shoddy and rushed and hurried, it has resulted in tens of thousands of severely disabled children being wrongly terminated in the last months," said Philadelphia attorney Jonathan Stein, who serves as an advocate for disabled children. "I believe the evidence is in now to justify a halt and a review of these kids already cut."

Late last month, Kenneth S. Apfel, the nominee to be director of the Social Security Administration, promised a 30-day "top-to-bottom" assessment of the reviews.

"He's very concerned about that program and has pledged to the Senate and the nation that he will, very first thing, look at that program," said John Trollinger, spokesman for the administration.

For families who have been terminated, the impact is already being felt. The income loss has brought a sudden change in their lives—and an uncertain future.

"This past month has been very difficult," said Richard's mother, who received her last monthly check for $534 in August. "Next month, it will be impossible."

According to the Social Security Administration, of the 135,841 children who have been cut, 112,016 were classified as having a mental disorder. That category includes children with personality disorders, conduct disorders, maladaptive behavior, learning disabilities and attention deficit disorder. And 3,126 were diagnosed with a physiologically based neurological condition. In addition, 4,255 children with respiratory problems such as asthma have been dropped.

"Overall, nationally the data that we have is not surprising," said Susan Daniels, the administration's associate commissioner for disability. "It is right on target with the estimates that were expected."

The new law requires that eligible children have impairments that are marked and severe.

"Many of the children have ... said. "These children coming off the rolls are not fakers but children who [once] met a standard that is now stricter."

Facing a Future Under New Rules

Parents like Richard's (whose real name is being withheld by The Times) say the benefits have helped their children. Without them, they say, their children face the risk of severe reversals, and families as a whole will have little ability to support themselves.

SSI advocates say the cuts caused by the federal welfare overhaul could have the ironic effect of forcing some families who lose benefits onto welfare.

Richard's mother knows that her son's condition does not fit with the easy picture that comes to mind when people think of the word disability. He is not in a wheelchair or on crutches. He has no visible signs of limitations. Yet they are painfully evidenced in his life every day, and have been since kindergarten, she said.

A series of trips to medical centers led to the discovery that the boy suffers from learning disabilities and hyperactivity as well as depression.

Though the therapy and medicine have helped, Richard is still subject to bouts of depression and crying, a child for whom simple tasks are trials: learning to read, learning to control his impulses, learning to understand himself, his mother said.

Over the years, his mother has spun an intricate web of support around her son. She is a full-time homemaker and advocate, working with schools, therapists, psychologists and tutors to help him learn to navigate the world.

"The reason I've been able to maintain him at home is because I've been so aggressive" to get the support system, his mother said.

That task, coupled with the needs of her teenage daughter who is physically disabled, consumes her days. She has not worked outside the home for three years.

"I couldn't really hold my job down because of the kids," said the former home health care nurse. "Things became too much to handle—the doctor ...

The $534 Richard's mother received each month paid for his daily care, for his medication, tutoring, books and other learning aides, and extracurricular activities designed to help him adjust socially. SSI also covered Richard's appointments with physicians and psychiatrists.

Before the sixth-grader's benefits were terminated, officials ordered his mother to take him to a psychologist for an examination that lasted "no more than 15 minutes," she said.

"You cannot do a thorough evaluation in 15 minutes," she said. "It's a sham. It takes time to pick up what's going on."

Now she is appealing.

Since the national review began, the staff at agencies such as Protection & Advocacy on Wilshire Boulevard have been preparing to help with appeals for people like Richard's mother. By law, no child's benefits could be cut before July 1, but since then the advocacy group has fielded calls from scores of families who are appealing terminations, said attorney Melinda Bird. The group provides some assistance and refers many families to attorneys who offer free services or services on contingency.

Richard's mother, who also receives about $500 a month from SSI for her daughter, will have to pay the attorney assisting her.

The appeal process is the one hope many families have for retaining benefits. But it is what distresses Bird most.

So far, of the more than 4,800 families who have lost benefits in California, fewer than 400 have appealed. "The appeal rate is so low and the success rate, if you do appeal, is so great that any incentive we can give to appeal we should."

The number of families whose benefits are restored on appeal "show essentially how bad and in error the termination decisions have been," advocacy attorney Stein said.

But the administration's Daniels said the agency does not yet have enough data to reach any conclusions. "That could change dramatically," she said.

Advocates say that key information about the appeal process is buried in the ...

quickly. According to the administration, families have 60 days to appeal a termination. But families may continue to receive benefits during the first level of appeal if they request a continuance within 10 days. Some may not read the letter thoroughly and may miss this small window, Bird said.

When Gwendolyn Law of South Los Angeles read the termination letter, she mistakenly believed it was related to her son's placement in school. By the time the confusion was cleared, 10 days had passed.

"My son's problems to me are severe," said Law, who is appealing the termination. After Bird wrote a declaration to SSI explaining Law's confusion, the boy's benefits were restored, and will remain in place while she appeals.

In Richard's case, his mother said the 10-day window had passed before she was able to get forms filled out by the medical personnel who had treated her son.

In a letter to Apfel, U.S. Sen. Paul Wellstone (D-Minn.) has called for a short moratorium on terminations and "an effort undertaken promptly to educate families facing a loss of benefits about their rights to appeal."

Groups Fight to Help Parents

Along with other groups, the American Bar Assn. has requested that the Social Security Administration include with the termination letter a list of hotline numbers and legal services' phone numbers, calling the act a "simple, fair step" that would assist families in the review process.

The administration has refused.

"What we do is offer that information when the families come in to inquire about the loss of benefits," Trollinger said.

But parents and advocates argue that some SSI workers add to the confusion.

Advocates from across the country have collected affidavits from families who say they received inaccurate information—and often harsh treatment—from local SSI workers. The affidavits tell of workers who refused to give out the appeal form and others who told families that they would be forced to repay money received while appealing if they do not win the case, Stein said.

Rachel Shigekane of the Volunteer Legal Services Program, an arm of the ABA in San Francisco, is encouraging families to appeal. Even if a family loses the case, she points out, the administration has the option of waiving the repayment if the appeal was filed in good faith.

"When terminating a child from SSI, you're talking about destabilizing families," she said.

After Sally Magnuson's son was terminated, an SSI worker told the San Francisco resident that the office would not send her an appeal form because Magnuson had no new information on the boy's condition to support his appeal, Magnuson said.

Magnuson persisted and ultimately received the form. Her 14-year-old son has dyslexia and other learning problems.

"This whole thing has been like a shock," Magnuson said. "They're treating us like criminals now, and we were encouraged [in the years before the 1996 welfare law] to apply. . . . It's demeaning."

Children's advocates and advocates for the poor have questioned the huge disparity in the termination rates between different states, suggesting that the law is being applied unequally.

In Mississippi, of the children whose cases have been reviewed, 82.2% have been terminated. In California, the rate is 39.7%.

"Given those discrepancies, many advocates feel Social Security should stop reviewing these cases until they figure out why," the ABA's Justicz said. "There's no reason kids in Mississippi should be losing benefits at 2½ times the rate of kids in Michigan."

Daniels argued that the populations are different and those differences come into play when looking at termination rates.

"Because they're different doesn't mean they're wrong," she said. "It just means they're different."

What lies ahead for families like Richard's is uncertainty. Appeals can last for up to a year. But his mother is looking even further down the road.

"I'm looking at making sure he can be functionally independent, be able to hold a job and be able to function in society and be a responsible citizen," she said. "That's

Childhood Disability

Summary

The 1996 Welfare Reform law included a new statutory definition of disability for children. Of the approximately one million children on the rolls in 1996, SSA identified approximately 290,000 children who needed to be reviewed under this new standard. To date, SSA has completed about 90 percent of the initial redeterminations. When announcing the regulations in February of 1997, SSA estimated approximately 135,000 children would have their benefits ceased after all appeals. To date, 139,000 have been denied at the initial level of review. Approximately 50 percent have requested an appeal. The issue has generate controversy. Some have called for the suspension of all reviews and reworking all cases. Others have called for changing the standard for eligibility determinations. Still others have called for no changes to the standard or how the standard is implemented.

Issues

The Commissioner has directed a "top to bottom review" of this issue. In addition he has requested a statistically valid 150 case sample of initial denials describing the individual decisions. The primary issues include:

Mental Retardation. Whether children with mental retardation are being improperly denied.

Appeals/Benefit Continuation. Whether families understand their appeal rights and whether they are being discouraged from requesting that benefits be continued during the appeals stage.

Variances Among States. Whether states are implementing the new standard differently as a result of some states being significantly above or below the national average. In addition to a national analysis of state variance rates, the major issues that are being examined include:

Maladaptive Behavior. Whether some states are ignoring maladaptive behavior as part of a case review.

Failure to Cooperate. Whether states are following proper procedures before denying a case because of being nonresponsive.

School Records. Whether school records have been properly retrieved by states, since many of the reviews took place over the summer.

Consultative Exams. Whether consultative exams have been done well by states as part of the case development.

Record Type: Record

To: Elena Kagan/OPD/EOP

cc: Cynthia A. Rice/OPD/EOP, Laura Emmett/WHO/EOP
Subject: Children's SSI report

It turns out that Ken Apfel has decided to change the content of the children's SSI report -- he wants to review ALL the children that have been denied, not just the groups targeted earlier (mental retardation, low-performing states). We can talk about this if you like. It will be somewhat harder to argue in the media that SSA did a good job if we are re-reviewing everything. Also, the Republicans will not like it, although our response is that we are not changing the standard, which they view as the most important thing. OMB is wondering if this is necessary, and so we are meeting with SSA tomorrow on it. I am not inclined to second guess this decision -- it's their report, this decision is widely known within SSA, and I certainly wouldn't want to be in the position of arguing from here for fewer reviews.

So I'll have to rewrite the memo. The report won't be released until late next week or even the week of Christmas. I'm keeping Sylvia's office informed.

Diana —
I agree with you on
all counts - both that
the full re-review isn't
necessary and that
we shouldn't stand in
its way.
Elena

cc: Bruce

PHOTOCOPY
MISC. HANDWRITING

Statement of Congressmen Clay Shaw
Reform of the SSI Children's Program
September 17, 1997

Congressman Jim McCrery and I are pleased to be here today to release some new information about the SSI children's program reforms that were passed as part of last year's welfare reform law.

These reforms were designed to preserve SSI benefits for disabled children who need extra help while boosting sagging confidence in an important public program that had exploded in size and expense. You will recall that the number of children on SSI exploded from 300,000 in 1989 to more than 900,000 in 1995. Government experts told us that, unless reforms were made, the rolls would swell to 1.9 million by the year 2000.

While the number of children receiving SSI will continue to grow even after reform, during the welfare reform debate all sides agreed that changes were needed to prevent abuse, including the use of eligibility standards that the General Accounting Office said suffered from "fundamental flaws." Let me repeat: every major bill -- Republican, bipartisan, and Democrat -- proposed the same basic changes that are now law.

Jim McCrery will speak in greater detail about both the GAO report and the additional information from the Social Security Administration we are releasing today. Let me just say that, when Congress passed the welfare reform law, I promised we would monitor its implementation and respond with changes as needed. These early reports tell us the SSI children's reforms are right and are being implemented correctly. This is good news for the American people, who want the welfare reform law to work.

m/ssi/statement

GAO
United States
General Accounting Office
Washington, D.C. 20548

Health, Education and Human Services Division

B-278046

September 16, 1997

The Honorable William V. Roth, Jr.
Chairman, Committee on Finance
United States Senate

The Honorable E. Clay Shaw
Chairman, Subcommittee on Human Resources
Committee on Ways and Means
House of Representatives

Subject: Supplemental Security Income: Review of SSA Regulations Governing Children's Eligibility for the Program

The Congress made the Supplemental Security Income (SSI) eligibility criteria for disabled children more restrictive in Public Law 104-193, the Personal Responsibility and Work Opportunity Reconciliation Act, enacted in August 1996 in order to help ensure that only needy children with severe disabilities be eligible for benefits. From the end of 1989 through 1996, the number of children receiving SSI disability benefits more than tripled, from almost 300,000 to more than 1 million. This growth occurred after the Social Security Administration (SSA) initiated outreach efforts and issued two sets of regulations that made the eligibility criteria for children less restrictive, particularly for children with mental impairments.[1]

One regulatory change, implemented in December 1990, revised and expanded SSA's medical listings for mental impairments by incorporating functional criteria into the listings and adding such impairments as attention deficit hyperactivity disorder. The other regulatory change, implemented in February 1991 in response to the Sullivan v. Zebley Supreme Court decision, added an individualized functional assessment (IFA) to SSA's disability determination process as a basis for finding children eligible for SSI. Children who had previously been denied because their impairments did not meet or equal SSA's medical listings could now be found eligible if the IFA determined that their

[1]Social Security: Rapid Rise in Children on SSI Disability Rolls Follows New Regulations (GAO/HEHS-94-225, Sept. 9, 1994).

impairments substantially limited their ability to act and behave in age-appropriate ways.[2]

On February 11, 1997, SSA issued interim final regulations tightening the eligibility criteria for children to receive SSI disability benefits.[3] The regulations, which became effective on April 14, 1997, implement legislative changes to the SSI disabled children's program made by Public Law 104-193. You asked us--under our responsibility to report on the effect of the legislative changes on the SSI program--to review the eligibility criteria in the new regulations to determine their consistency with the law, focusing in particular on the provisions describing how severe a child's impairment must be in order for the child to qualify for benefits.[4]

In addition to analyzing the regulations themselves and SSA's regulatory analysis documenting its rationale for the new severity level, we reviewed the public comments on the regulations and interviewed SSA officials. In summary, we found the agency's regulations to be consistent with the law and well supported.[5]

ELIGIBILITY CRITERIA IN REGULATIONS ARE CONSISTENT WITH THE LAW AND WELL SUPPORTED

Public Law 104-193 enacted several provisions that made the eligibility criteria for disabled children more restrictive: (1) It changed the definition of

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[2]The medical listings for childhood impairments are regulations containing strict medical criteria for evaluating physical and mental impairments.

[3]In light of the congressional mandate to issue regulations needed to carry out the new statutory provisions as expeditiously as possible, SSA determined that there was good cause to waive the notice of proposed rulemaking procedures. Instead, in accordance with the Administrative Procedure Act, SSA issued interim final regulations with a request for public comments. SSA stated that it would issue revised rules if necessary.

[4]Section 232 of Public Law 104-193 requires GAO to report on the effect of these changes to the SSI program.

[5]GAO reported to the Senate Finance Committee and the House Ways and Means Committee that the regulations comply with the procedural steps required by sections 801(a)(1)(B)(i) through (iv) of title 5, U.S. Code. (See GAO/OGC-97-23, Feb. 26, 1997.)

childhood disability from an impairment comparable to one that would prevent an adult from working to an impairment that results in "marked and severe functional limitations," (2) it eliminated the IFA as a basis for determining eligibility for children, and (3) it removed maladaptive behavior from consideration when assessing a child's personal/behavioral functioning. Thus, such behavior would be considered only once–in the assessment of that child's social functioning–when determining whether the child had a mental impairment severe enough to meet or equal the medical listings.[6]

To implement the new law, SSA issued interim final regulations that defined an impairment that results in "marked and severe functional limitations" as one that meets or medically or functionally equals one of SSA's medical listings. For a child to be determined eligible for benefits under this new and stricter standard of severity, his or her impairment must generally result in marked functional limitations in two areas of functioning, such as social and motor skills, or an extreme limitation in one area. Under the previous IFA standard of severity, a child was generally found eligible if his or her impairment resulted in moderate functional limitations in three areas of functioning or a marked limitation in one area and a moderate limitation in another area. SSA also eliminated the IFA and removed the duplicate consideration of maladaptive behavior from the mental listings.

During the public comment period for the draft regulations, SSA received more then 175 written comments from individuals and organizations, many of which expressed the view that the new eligibility standard in the regulations is more severe than the law requires. More recently, media reports have criticized the stringency of the new regulations. Many of the critics of the new standard of severity stated that an impairment that results in a marked limitation in one area and a moderate limitation in another is severe enough to meet the new statutory definition of disability for children.

SSA rejected the "one marked, one moderate" level of severity as the standard. In its regulatory analysis, SSA gave several reasons for concluding that the law and legislative history made clear that the Congress meant to establish a stricter level. First, the Congress eliminated the "comparable severity" standard

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[6]In taking legislative action, the Congress considered our findings on the subjective nature of the IFA process and the need to improve eligibility determinations for children with disabilities. See Social Security: New Functional Assessments for Children Raise Eligibility Questions (GAO/HEHS-95-66, Mar. 10, 1995).

of disability, which had established an additional evaluation beyond the listings, and it eliminated the IFA, which was created for evaluating impairments that were less severe than those in the medical listings. Further, a "one marked, one moderate" standard of severity would have retained one of the standards under which children were found eligible under the IFA, which SSA stated would violate the law. Finally, SSA interpreted the conference report accompanying the act as indicating the congressional intent that the listings would be the last step in the disability determination process for children.

We found the interim final regulations to be consistent with the law. We believe SSA was well within its authority in establishing the new level of severity, and its rationale for doing so was well supported.

RESULTS OF REDETERMINATIONS TO DATE ARE IN LINE WITH EXPECTATIONS

The new eligibility criteria also apply to children already receiving SSI benefits. Public Law 104-193 requires SSA to redetermine the eligibility of children on the rolls who may not meet the new eligibility criteria because they received benefits on the basis of maladaptive behavior or the IFA. Recipients can elect to continue benefit payments during the appeal process. SSA identified 288,000 children as potentially affected by the changes in the eligibility criteria. In its regulatory analysis, it estimated that 135,000 children (46.9 percent) would lose benefits under the new eligibility criteria contained in the interim final regulations.

Through September 6, 1997, SSA has reviewed the eligibility of 246,211 of the 288,000 children. Of these, 116,670 (47.4 percent) were found eligible to continue to receive benefits and 129,541 (52.6 percent) were found ineligible. Those continuing to be eligible include 86,595 children found eligible after initial redeterminations done by the state disability determination services (DDS), 1,751 children found eligible by the DDSs upon appeal, and 28,324 children who had been awarded benefits on the basis of an IFA but whose impairments were now found through a file review to have been severe enough at the prior determination to qualify under the listings. For these latter cases, SSA modified its records to show that the awards were based on the listings and continued benefits to these children without further review. The 129,541 ineligible children include 6,624 who were found ineligible for reasons other than disability and 122,917 who were found ineligible after redeterminations, including 966 found ineligible by the DDSs upon appeal.

Because the number of children deemed to be ineligible by this review does not yet reflect the results of all appeals, we do not yet know what the final outcome on all these cases will be. Children initially deemed by a DDS to be ineligible have 60 days to request the DDS to reconsider their case. If they continue to receive an unfavorable result, they can appeal to an SSA administrative law judge, and, finally, to federal court. To date, 46.7 percent of the children with initially terminated benefits for whom the 60-day appeal period has expired have appealed for a DDS reconsideration. Although SSA states that the early results of the redeterminations cannot be projected to the total number of redeterminations required by the law, we believe the early results are in line with SSA's expectations.

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We discussed a draft of this letter with SSA officials responsible for these regulations. They agreed with our findings and made other technical comments, which have been incorporated where appropriate.

If you have any questions about the information we have presented, please contact me on (202) 512-7215. Other major contributors are Cynthia Bascetta, Ellen Habenicht, and Daniel Schwimer.

Jane L. Ross
Director, Income Security Issues

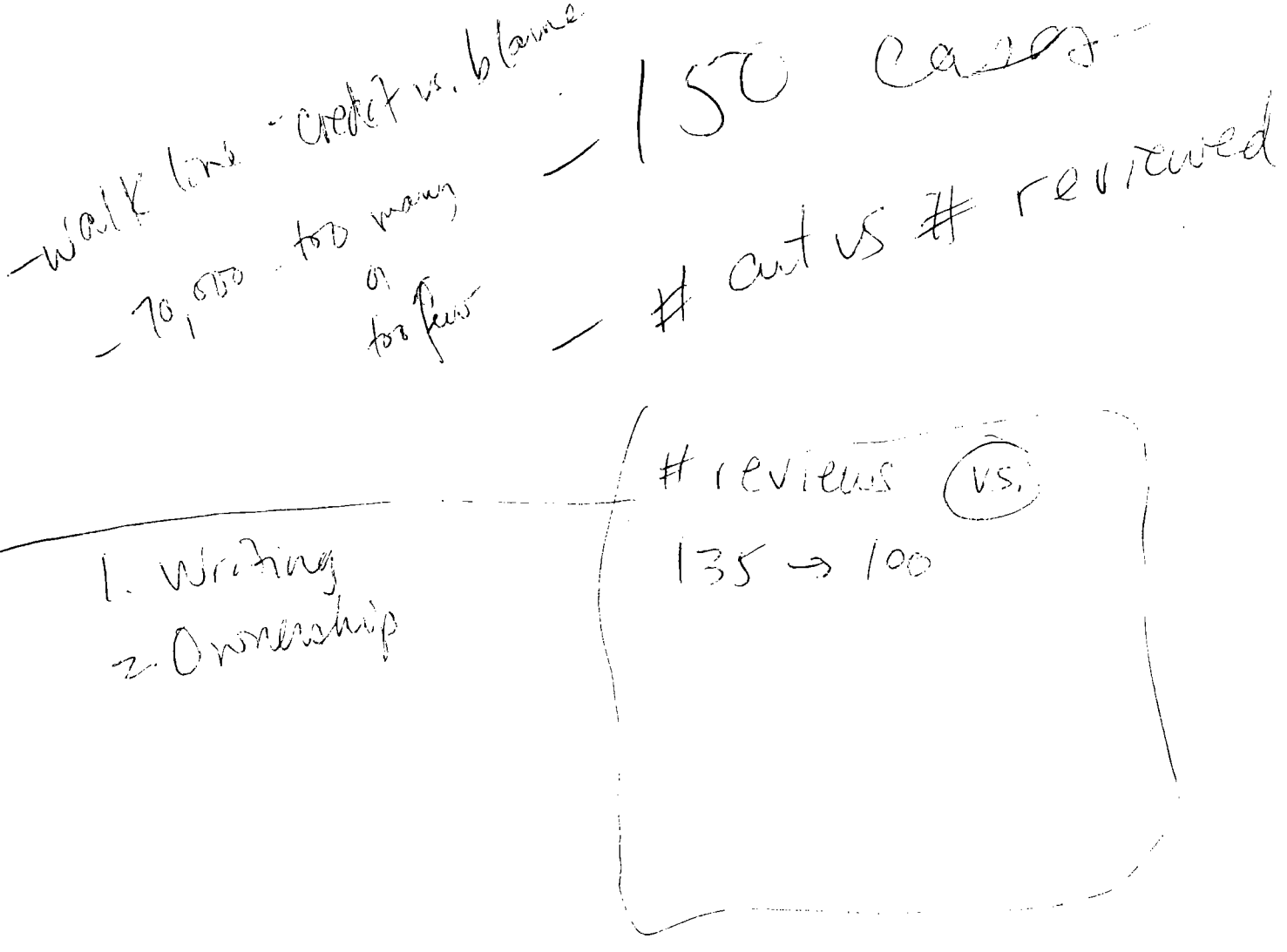
(207019)

Speech vs. Cognitive ruling???

redeterminations in some states, and appeal rights.

The big remaining issue is that the report is not written well. It does not provide clear answers to the most obvious questions, and it is overly defensive in many places.

SSA Action: SSA will review all 42,000 cases terminated that had a diagnosis of MR, to ensure that all those decisions were made properly. (Haven't they already done that based on the 8%?) Dropped 42,000, because it's 31,000 -- how to explain??



~~23~~ Mental (74) ~~68~~ 11

~~16~~ FTC 16% 24

~~8~~ Physical (11%) ~~19~~ 16

~~4~~ 18

151

−24

127

110 Mental = 87%

13 Physical = 13%

(2)

(3)

(1)

38 - ADHD ✓

7 - asthma ✓

12 - BIF ✓

(87) 7 - Cond disorder ✓

51 - Learning Dis ✓

10 - MR ✓

~~4~~ - Speech delay ✓

1010

24 - FTC

125

3 - None ✓

~~10~~ 12 - Adjustment, affective, dev delays/disorder, Personality, Post-Trauma Stress, Relat'l Disorder, ODD ✓

138

2 - Dysthymia

(P4) 2 - Epilepsy

2 - Obesity

(P5) 7 { 1 - Anencephalus; 1 - Disorder of Muscle Liga; 1 - Disorder of Back; 1 - Hydrocephalus; 1 - Organic Mental Disorder; 1 - Trichotillomania - hair pulling; 1 - Ventricular tachycardia

9% 91% 127

~~12~~ physical 8%

24 FTC 16%

115 mental 76%

151

Var Ment

7 - Cond

12 -

2

21

Nelson Reyneri
12/04/97 11:24:15 AM

Record Type: Record

To: Diana Fortuna/OPD/EOP

cc:
Subject: Re: SSI

While I think smaller is better, I understand the need to have Elena there. I'm fine with it and think Sylvia will be as also. Please let me know if she will attend so I can let Syvia know.

Here's my draft memo to Sylvia. Please let me know of:
1) any changes I should include
2) can you expand on the three parts of the report
3) can you discuss the memo to POTUS
4) do you have thoughts on the outstanding issues

Thanks a million

DRAFT

December 4, 1997

MEMORANDUM FOR: **SYLVIA MATHEWS**
Deputy Chief of Staff

FROM: **NELSON REYNERI, JR.**
Special Assistant to the Deputy Chief of Staff

SUBJECT: **SSI REPORT**

This memorandum updates you on the status of SSA's report of their top review of the Supplemental Security Income (SSI) childhood disability program.

Status

As you may recall, the Personal Responsibility and Work Opportunity Reconciliation Act of 1996 (PRWORA) led to redetermining the disability eligibility of

approximately 288,000 out of the 1 million children who receive the benefits. SSA had earlier predicted that 135,00 of the 288,000 children would end up losing their benefits. In their report, they conclude that the final number of children losing their benefits will be closer to 100,000. SSA completed their review Commissioner Aphel wants to get it out ASAP

Diana Fortuna, Richard Green (OMB) and Lauren Oliven Silberfarb (OIRA) and I met earlier this week and reviewed the report. While we think they did a pretty good job with respect to fulfilling Aphel's promise of a top down review of the program, the presentation of the report (executive summary) needed considerable rewriting. Specially, they needed to tighten up their core message, i.e., they need to do a better job in their executive summary of clearly presenting what the problems were, whey they existed and what they've done to fix them.

There are three basic areas that the report focused on:

1) Mental retardation
2) Quality of case processing
3) Appeals and requests for benefit continuation

Diana Fortuna will be at the 1:15 meeting to explain the issues within the three areas in the detail you request.

After our internal meeting, the same group had a two hour conference call with a number of key SSA officials to review the report. We shared with them our concerns, going into detail in each of three areas as well as sharing with them the need to be well prepared for a roll out of the report (Q&A's, charts and graphs, etc). They have promised to redo the executive summary, incorporating these concerns.

Aphel is scheduled to be out in California next week, but can possibly rearrange his schedule to permit him to return. While we wanted to have everything ready for by the end of this week, they did not think they could have made the necessary changes by then. Thus, we are shooting for a time next week since everyone understands that this should not be released to close to Christmas.

Remaining Issues

I think some of the questions that remain are the following:

1) what's the status of the revised report?
2) does it address WH/OMB concerns?
3) what's the roll out strategy; do they have the materials ready?
4) are they ready to address constituency groups' issues; Congress?
5) what's the status of the informational memorandum for the President
6) do you have any next steps or issues that remain.

I will keep you informed as progress occurs. Thank you.

PRESIDENT'S COMMITTEE ON MENTAL RETARDATION

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Administration for Children and Families
Washington, D.C. 20201-0000

PRESIDENT'S COMMITTEE ON MENTAL RETARDATION

1997 POLICY ADVISORY ON SSI

An Advisory to the Commissioner of SSA

Introduction

The members of the President's Committee on Mental Retardation (PCMR) highly commend the new Commissioner of the Social Security Administration (SSA) for his interest in and for taking immediate action regarding the Children's SSI program. The members of the PCMR are extremely pleased to learn that the Commissioner of the SSA has undertaken a review of the Children's Supplemental Security Income (SSI) program.

As stated in its Executive Order, the first of several mandated functions of the PCMR is "evaluating and monitoring the national efforts to establish appropriate policies and supports for people with mental retardation."

- **Estimates indicate that approximately 38.3% of the children who receive SSI function within the mental retardation range. (source: Annual Statistical Supplement (SSA), 1996)**

- **The Children's SSI program is instrumental in reducing the rate of admission of children with mental retardation into State institutions and other out of home placements and affords children the opportunity to live with their families.**

- **The members of PCMR remain concerned the that new rules have resulted in the discontinuance of support for over 135,000 of the 260,000 children whose status are now under review as of October 4, 1997.**

- **The reliability of the review processes is questionable in that termination rates in States have varied dramatically from the mean.**

- PCMR members are concerned that people are not adequately informed of their ability to appeal, the time limits for an appeal and the availability of legal assistance to carry out an appeal. Of Those who have appealed about 58% have won their challenges. Others may have been discouraged by unprepared and overworked SSA employees who may have discouraged appeals by providing incorrect or unintentioned misleading information in local offices and on the SSA Department's 800 number. This suggests serious evaluation of the review process, and a review of the training and supports provided to SSA staff asked to administer a complicated and confusing new set of procedures, rules and regulations.

- PCMR members are concerned that the Administration was required to implement far reaching and complex changes under extreme time pressures. The changes may have been too strict, too difficult to administer and too untested, thus resulting in the stripping of desperately needed cash from the families of children with severe disabilities. In taking such action the results suggest that those involved have had little knowledge of their rights under law and may have been subjected to review processes of unknown and suspect levels of reliability.

The members of the PCMR are offering their experience and expertise to the Commissioner as a resource to assist in the review of the Children's SSI program. The members include a rich combination of self-advocates, family members, professionals and a variety of other advocates in the field of mental retardation.

As an ex officio member, the PCMR invites the Commissioner of SSA to attend a PCMR meeting to offer a report on the status of the review of the Children's SSI program as it affects families and children with mental retardation.

Voted – 9/97

- draft back + forth
- spec Bd members/ivsen
- dropped specific states

Advisory

- The PCMR advises the Commissioner of the SSA that the most appropriate action, while the review is taking place, is to have a moratorium on all activities which lead to removing children with mental retardation and other disabilities from support provided under the Children's SSI program.

- The PCMR suggests to the Commissioner that SSA act aggressively to review for possible reinstatement of support for all children with mental retardation and other disabilities that have been removed from assistance, and whose families have not appealed since the time of implementation of the new rules for the Children's SSI program.

- The PCMR also requests a review of the basic standard regarding the high level of severity of disability required to show eligibility.

- The PCMR advises the Commissioner that it has great concern over practices in the administration of the Children's SSI program among the various States and urges substantial study of this review process to insure that people understand the requirements, their rights and that the validity and reliability of the review process is fair and equitable with regard to the eligibility of persons with mental retardation.

- The PCMR advises that SSA utilize interdisciplinary teams to conduct assessments of children for SSI qualification and for review of appeal. The PCMR will provide support to the Commissioner on the composition and practice of the interdisciplinary teams.

- The PCMR advises the Commissioner that SSA provide assurances that all teams have competency in applying their knowledge and skills and do so in a uniform manner, obtaining valid and reliable information and data for assessment of children with mental retardation for SSI support.

- The PCMR suggests that the Commissioner designate an official from the Children's SSI program to serve as a liaison to the PCMR for sharing of information on policies and supports under the Children's SSI program.

- The PCMR recommends that the Commissioner authorize a study to follow a sample of discontinued children to ascertain the effects of the loss of eligibility on these vulnerable children.

Background

The PCMR issued its initial policy advisory on Children's Supplemental Security Income (SSI) in 1995 expressing concern that nearly 98,000 children with mental retardation could be adversely impacted or dropped from SSI support by proposed legislative changes to the Supplemental Security Income Program (SSI) for Children. The PCMR advisory recommended caution in making any changes in the Children's SSI program.

A second policy advisory issued in 1996 addressed both Medicaid and the Children's SSI. The portion on the Children's SSI supported the same recommendation as the 1995 issuance.

If easy, OK

If hard, no

1) rephrase to say Ken 's right

2) mtg

2pm Staff Secretary

Comms concurs re sing

cc Ellen

MEMORANDUM TO:

FROM:

SUBJECT: SSA Report on Implementation of Children's SSI Cutoffs

DATE: December 5, 1997

As you know, the welfare law tightened the definition of childhood disability for SSI, and required the Social Security Administration to redetermine the eligibility of approximately 288,000 children (out of one million children now on the rolls). Advocates charge that SSA has done a poor job on these reevaluations, causing eligible children to be dropped from the rolls. At his confirmation hearing, Commissioner Ken Apfel promised a "top to bottom" review of SSA's process. This memo summarizes that report, which is nearing completion and will be released in about a week.

Overall, SSA concludes that the organization did a relatively good job in redetermining eligibility for these children. However, the report identified three areas of concern (described further in an attachment), along with actions to address them.

While any of the final decs are not yet made,

As a result of this review, SSA ~~will~~ plans to review the cases of ~~approximately~~ ≈ 50,000 70,000 children terminated from the program, out of a total of 136,000 terminations to date. All children terminated who were coded as having mental retardation will have their cases reviewed. SSA ~~will also~~ also plans to review all terminations in the ten states with the lowest accuracy rates (D.C., Mississippi, Oregon, Pennsylvania, Idaho, Maryland, North Carolina, Washington, Tennessee, and California). Finally, SSA will offer all 75,000 families who did not appeal SSA's termination decision a new opportunity to do so.

The report will include a lower projection of the number of children who will ultimately lose SSI after all appeals are completed -- 102,000 children, compared to SSA's original projection of 135,000. This drop of ~~33~~ 35,000 is caused by a reestimate of the baseline (~~23~~ about 100k,000 cases) and the actions announced in this report (10,000 cases). At the time the welfare law was enacted, the estimate was that 180,000 children would lose SSI. ~~35~~ 25 as well as actions already taken

great

With the report, SSA also plans to release case studies of a random sample of 150 children who have lost benefits. This document is intended to explain to the public what types of children are no longer eligible. Most of the children have mental disabilities other than mental retardation, including learning disabilities and ADHD. Over a third have improved since they were first found eligible. The majority are teenagers; only a handful are age six or younger.

Advocates will probably view the report's actions positively, but they are more concerned that about SSA's regulation interpreting the statute, which they view as needlessly strict. The report does not address this issue. The Republican leadership in Congress has been extremely supportive of SSA's actions to date, but it is ~~possible~~ likely they will criticize this report, perhaps seeing it as bending over backwards to restore benefits.

SSA Report on Childhood Disability Process

SSA's report examined three areas of concern raised by advocacy groups:

I. Mental Retardation

Advocates' Charge: Too many children with mental retardation were cut from the rolls.

SSA Finding: Of the 136,000 children terminated to date, 42,000 were "coded" as mentally retarded (MR). However, most of these children do not actually have MR, because until recently SSA's systems did not have all the necessary codes. Instead, most of these children have other mental disorders, such as learning disabilities and or "borderline intellectual functioning" (which falls short of full-fledged MR). However, some unknown subset of the 42,000 do have MR, but either their impairments are not severe enough to qualify them for SSI, or they were denied incorrectly.

approx 350? fewer?

Even with these terminations, about 360,000 children with MR will remain on the rolls, out of the total of one million children on SSI.

SSA Action: SSA will review all cases terminated that were coded as MR, to ensure that all those decisions were made properly.

II. State Variations in Cutoffs

Advocates' Charge: Errors in cutoffs appear likely, since termination rates varied widely by state, from 32% in Nevada to 82% in Mississippi. Also, SSA may not have acquired all documentation, such as school records, needed to judge a child's disability. Finally, some states were disqualifying too many families for failure to cooperate without making adequate efforts to reach them.

SSA Findings: SSA data show that on average 93% of termination decisions were both accurate and complete in terms of including all required documentation. This exceeds SSA's required level of state performance for SSI. However, 10 states had accuracy/completion rates below 90%. Another 9 states had accuracy/completion rates below the national average. (SSA's experience is that about one-third of the errors identified in these measures will ultimately prove to be accurate decisions that simply lacked documentation.) SSA found that many inaccurate decisions stem from an overly strict interpretation of the new rules for children who exhibit maladaptive behavior.

w/SSA.

Claims that SSA did not acquire all needed documentation were determined to be unfounded. mostly However, SSA found wide state variations in the percentage of children cut off because their families did not cooperate. In the four states with the highest rates, 68% of the cases did not include documentation that all required efforts to contact the family had been made.

% cutoffs did not fit

SSA then performed a regression analysis intended to determine whether wide state to state variations in overall termination rates should be expected because of legitimate factors, such as the child's age and impairment and whether the child was initially added to the rolls based on the less strict criteria eliminated by the welfare law. SSA found that these factors would lead you to expect the cutoff rate to vary from 40% in Idaho to 78% in Mississippi. While this regression analysis does not fully explain the actual state-by-state variance, it does convince SSA that the ~~vast~~ majority of the variance among states is not due to errors, but to characteristics of the children.

SSA Action: In states with accuracy/completion rates below 90%, SSA will review all cases. In states with accuracy/completion rates ~~between~~ 90% and 93%, SSA will review a sample of cases to see if additional reviews are needed. SSA will also provide more training on maladaptive behavior. In states where the rate of children dropped ~~due to failure to cooperate~~ is above the ~~national average~~, SSA will review all cases ~~with rates that dropped~~ with above average rates of cutoffs due to FTC,

III. Appeal Rights

Advocates' Charge: Too few families are appealing because SSA's notice to families was confusing, and workers discouraged appeals. Also, SSA discouraged families from requesting that benefits be continued during the appeal.

SSA Finding: SSA found that its workers did not discourage appeals. At the same time, a poll conducted by SSA confirms that many families did not understand their appeal rights.

SSA Action: All 75,000 families of children who were terminated and did not appeal will be given a new opportunity to do so. All 30,000 families of children who appealed but did not request continuation of benefits during the appeal will also be given a new opportunity to make that request. SSA will also publicize the availability of free legal services for families.

Cover plus 3 pages

ASAP

Fax to: Ken Apfel
Brian Coyne

From: Diana Fortuna

This is an internal document we may send around here this weekend as a heads-up to people. Can you give it a quick look ASAP and tell me if it seems balanced and right to you?

Thanks.

358-6076 fax
6077

Sylvia - til 6:45
when ready,
give it to her →

358 - 6016 Bob Nickerson
6000 - Ken

Close hold

FAX COVER

Income Maintenance Branch
Office of Management and Budget
Executive Office of the President
Washington, D.C. 20503

To: DIANA FORTUNA

Organization: _____

Fax Number: X 67431

From: RICHARD GREEN

Date/Time: _____

Number of Pages: Cover + 1

Notes:

Income Maintenance Fax Number: (202) 395-0851
Voice Confirmation: (202) 395-4686

DRAFT

	claims to be "screened"	claims to be "reopened"	continuances expected	5-year cost
MENTAL RETARDATION			~~c. 2,500~~ Less than 250 10,000	
Review all cases of children whose eligibility was ceased and who are coded MR	16,000	13,000 (75 IQ or below)		
Additional cases denied thru reconsideration	750	600		
Review all new applicants who were denied that show a code of MR	13,000	9,750		
Included among 68,000 pending reconsiderations -- cases of children who are coded MR	N.A.	15,000 reconsiderations		
STATE VARIANCE			~~c. 2,500~~ Less than 250 10,000	
Review all other cessation cases in States with cessation accuracy below 90 percent	12,000	3,000		
Additional cases denied thru reconsideration	550	100		
Review all other new applicant denials in States with cessation accuracy below 90%	16,500	4,100		
Review sample of cessation cases in States with cessation accuracy of 90 to 93%	4,500 "reviews"	350		
Review sample of new applicant denials in States with cessation accuracy of 90-93%	N.A.	N.A.		
Review all failure-to-cooperate (FTC) cases in States with above average FTC rate; where FTC instructions were not followed, claimants will be allowed to pursue claims	4,000 "reviews"	1,200		
Included among 68,000 pending reconsiderations -- cases from States with cessation accuracy below 90 percent		12,000 reconsiderations		
APPEALS/BENEFIT CONTINUATION				
Denials that did not appeal will get new notice with new 60-day and 10-day periods	75,000 notices	20,000 reconsiderations	~~c. 5,000~~ More than 5,000 10,000	
Appealed denials who didn't request benefit continuation get new notice with new 10-day period.	30,000 notices			