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Social Security - Children's Disability Standard [2]

Soc Sec -
Children's Disability

TABLE OF CONTENTS

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 ensure that every child receives a fair assessment of his or her eligibility for benefits.

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 children 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

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 ensuring that every child receives a fair assessment of his or her eligibility for benefits, 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:

- SSA will, through the DDSs, review all redetermination cessation cases and 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 screening 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 redetermination cessations 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

- All failure to cooperate cessations will be reviewed. (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 DDSs will do under Section 1, above, every DDS will also screen a portion of its redetermination cessations that do not have the code for MR.

- SSA will identify the proportion and types of cases that each DDS will screen. The proportion of cases a DDS will screen will depend primarily on its QA accuracy rate. DDSs with higher QA accuracy will review proportionally fewer cases than DDSs with lower QA accuracy. The cases to be screened will be cessations in those categories of cases with the greatest likelihood of error based on SSA's QA results.

- In general, the review will be a two-stage process: (1) A screening of the case file to determine whether all necessary documentation is present and that the determination was correct. If it is determined that the cessation was correct, 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.

- 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, these 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 eligibility 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.

SSA'S IMPLEMENTATION OF THE NEW SSI CHILDHOOD DISABILITY LAW

I. THE CHILDHOOD DISABILITY PROGRAM

A. Introduction

The Supplemental Security Income (SSI) program provides cash benefits to financially needy individuals who are aged, blind or disabled. Enacted in 1972,[1] the SSI program became effective in January 1974. Benefits for disabled children, i.e., individuals under age 18, have been part of the SSI program since its inception. In most States, the Social Security Administration's (SSA) finding that a child is eligible for SSI also makes the child eligible for medical assistance through Medicaid. (Note: the amendments in the Balanced Budget Act of 1997, enacted in August 1997,[2] provided for continuing Medicaid eligibility for children who lose eligibility for SSI as a result of the new definition of disability for children contained in the Personal Responsibility and Work Opportunity Act of 1996, the PRWORA.)

From January 1, 1974, when the SSI program became effective, until August 21, 1996, the Social Security Act (the Act) did not contain a separate definition of disability for children. Rather, the definition of disability for children was contained in a parenthetical statement at the end of the definition of disability for adults contained in section 1614(a)(3) of the Act:

> An individual shall be considered to be disabled for purposes of this title if he is unable to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months *(or, in the case of a child under the age of 18, if he suffers from any medically determinable physical or mental impairment of comparable severity)*. [Emphasis added.]

On August 22, 1996, the PRWORA[3] amended this definition and established a new definition of disability specifically for children. The new definition provides that a child:

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[1] Public Law No. 92-603.

[2] Public Law 105-33 (August 5, 1997).

[3] Public Law No. 104-193.

> shall be considered disabled for the purposes of this title if that individual has a medically determinable physical or mental impairment, *which results in marked and severe functional limitations*, and which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months. [Emphasis added.]

B. History

For initial claims of adults, SSA's regulations[4] set out a five-step "sequential evaluation process" for determining disability. Each step is followed in order, as outlined below.

1. Is the adult engaging in substantial gainful activity? If yes, the adult is not disabled; if no, go to the next step.

2. Is the adult's medically determinable impairment or combination of impairments "severe"? If no, the adult is not disabled; if yes, go to the next step.

3. Does the severe impairment(s) meet or medically equal the severity of a listing in the Listing of Impairments (the listings)?[5] If yes, the adult is disabled; if no, go to the next step.

4. Despite having a severe impairment(s) that does not meet or medically equal the severity of a listing, does the adult still have the "residual functional capacity" to do his or her past relevant work? If yes, the adult is not disabled; if no, go to the last step.

5. If past relevant work is precluded, does the adult retain the capacity to do any other kind of work that exists in significant numbers in the national economy, considering his

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[4] 20 C.F.R. § 416.920.

[5] The listings contain examples of medical conditions and medical findings that are so severe that disability can be presumed for anyone who is not performing substantial gainful activity and who has an impairment that "meets" the criteria of a listing. Since the listings cannot include every possible impairment or combination of impairments a person could have, SSA's rules also provide that an impairment or a combination of impairments can "equal" or be "equivalent to" the severity of a listing. There are separate listings for adults and children, although SSA sometimes uses the adult listings for childhood cases. The listings are in the regulations in appendix 1 of subpart P of 20 CFR part 404.

> or her residual functional capacity and the vocational factors of age, education, and work experience? If yes, the adult is not disabled; if no, the adult is disabled.

Until 1990, if a child was not working (performing substantial gainful activity) and his or her impairment(s) was "severe" and met the duration requirement (i.e., had lasted or was expected to last for 12 months or was expected to result in death), SSA decided whether a child was disabled based on the listings, as in the third step of the process for adults. SSA did not provide additional evaluation steps past the listings step for children, as was done for adults, because it was considered inappropriate to apply the vocational (i.e., work-related) rules used for adults whose impairments do not meet or equal a listing. In the case of *Sullivan v. Zebley*, the Supreme Court struck down this approach to determining eligibility in children.

C. *Sullivan v. Zebley*

On February 20, 1990, in the case of *Sullivan v. Zebley*,[6] the Supreme Court decided that the "listings-only" approach used to deny children's SSI claims did not carry out the "comparable severity" standard because the listings as then applied did not provide for an assessment of a child's overall functional limitations. The Court found that, under the comparable severity standard, children claiming SSI benefits based on disability were entitled to an individualized assessment comparable to adults who had severe impairments that did not meet or medically equal a listing. The Court found that, while adults who were not disabled under the listings still had the chance to show that they were disabled at the last step of the sequential evaluation process, no similar opportunity existed for children.

The Court also criticized various aspects of the way in which the listings were used in evaluating childhood disability claims. It stated that the policies for establishing whether a child's impairment(s) was "equivalent in severity," or "equal to," a listed impairment "exclude[d] claimants who have unlisted impairments or combinations of impairments that do not fulfill all the criteria for any one listed impairment." The Court was also concerned that all children be given an opportunity to have their particular functional limitations assessed in establishing equivalence, including the effects of their symptoms.

D. The Childhood Rules That Resulted From *Zebley*

As a result of the *Zebley* decision, SSA revised the rules used to evaluate childhood disability claims under SSI. Interim final

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[6] 493 U.S. 521 (1990).

regulations were published in the *Federal Register* on February 11, 1991, with a request for public comments.[7] Following consideration of the public comments, SSA published final regulations on September 9, 1993.[8]

In these regulations, "comparable severity" was defined in terms of the impact a medically determinable impairment or a combination of impairments had on a child's ability to function "independently, appropriately, and effectively in an age-appropriate manner." The rules also provided that each child whose impairment(s) did not meet or medically equal the requirements of a listing could show that his or her impairment(s) "functionally equaled" a listing. If a child's severe impairment(s) did not meet, medically equal, or functionally equal a listing, the child could still be found disabled at a step past the listings based on an "individualized functional assessment" (IFA), an evaluation of the impact of the impairment(s) on the child's ability to function.

The new "functional equivalence" rules also evaluated the impact of a child's impairment(s) on his or her functioning. They were intended, among other things, to address the Supreme Court's concerns about the use of the listings in childhood cases. The policy of functional equivalence was based on the fact that it is the *functional limitations* a child has that make the child disabled, regardless of the particular medical cause. For example, a child who uses a wheelchair is disabled because of an inability, or seriously limited ability, to walk, regardless of whether the cause is from an injury or an impairment the child had at birth.

Although there were several methods for deciding functional equivalence, the primary method required consideration of functioning in broad areas of functioning, such as cognition/communication, social functioning, personal/behavioral functioning, and task completion (concentration, persistence, and pace). A child's impairment(s) "functionally equaled" a listing if the child had "marked" limitations in two areas of functioning or "extreme" limitations in one area. The terms "marked" and "extreme" were terms used to define the severity of limitations in an area and were defined in the regulations or other instructions.[9] These rules, since they took into account a

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[7] See *Federal Register* 56 FR 5534 (1991).

[8] See *Federal Register* 58 FR 47532 (1993).

[9] Under the new rules implementing the PRWORA, SSA still uses the standard of "marked" limitations in two areas of functioning or "extreme" limitations in one, and the terms are defined in

child's actual functional limitations, provided a more comprehensive assessment of a child's impairments than the pre-*Zebley* rules.

If a child's severe impairment(s) was not of listing-level severity (i.e., did not meet, medically equal or functionally equal a listing) SSA would go to the next step and conduct an IFA. The IFA at the next step also assessed the functional impact of a child's impairment(s) in broad areas of functioning, called "domains and behaviors," such as cognition, communication,[10] and motor abilities. A child was generally found disabled using the IFA if he or she had "marked" limitations in one domain of functioning and "moderate" limitations in another domain, or "moderate" limitations in three of the domains. (The term "moderate" was also defined in SSA regulations and other instructions.)

Thus, under the rules that resulted from the *Zebley* decision, SSA considered functioning at both the listings step and the IFA step of the sequential evaluation process.

Although the PRWORA eliminated the IFA, many other features of the regulations resulting from *Zebley* and other existing regulations were not affected by the new law. Among these rules were many of the provisions for evaluating functional equivalence, which took on added significance under the PRWORA, and rules for considering functioning appropriate to a child's age, the rules for considering the effects of a child's symptoms (such as pain), and rules for the consideration of "other factors," factors such as the effects of medication, functioning in school, and the need for assistive devices which adjudicators must also consider.

SSA's current regulations and other instructions. The word "marked" in the new definition of disability in the PRWORA, "marked and severe functional limitations," does not have the same meaning as the term "marked" in the listings and functional equivalence. In the current regulations, SSA defines the *phrase* from the PRWORA, "marked and severe functional limitations," as a single term providing the statutory definition of disability and continues to define the term "marked," used for evaluating severity in the mental disorders listings and functional equivalence, as a separate term.

[10] Under the policy of functional equivalence, cognition and communication were considered together in one area of functioning called the "cognitive/communicative" area. In the IFA, they were separate domains.

E. Resulting Growth in the Rolls

Prior to the regulations required by *Zebley*, there had been a modest growth in the number of children receiving SSI disability benefits. From 1980 to 1990, the number of children on the rolls increased from 228,000 to 340,000. In contrast, the number of children on the rolls nearly tripled between 1990 and 1996, increasing from 340,000 to approximately one million children. Related program costs rose during that time from $1.2 billion annually to over $5 billion annually.

There were several causes for this increase, including:

- New provisions of SSI legislation enacted by the Congress in 1989 that required SSA to make outreach efforts to locate children who could qualify for SSI;
- Updated listings published in late 1990 for evaluating mental disorders in children;
- New regulations published in response to *Zebley*;
- Readjudication of *Zebley* class member cases and outreach mandated by the *Zebley* court order; and
- An increase in the number of children living below the poverty line.

F. Public Reaction

The rapid increase in the number of children on the rolls raised concerns among members of Congress, the Administration, the media, and the general public. Allegations were made that children were being "coached" to manipulate the disability process and that benefits were being paid to children with "mild" disorders. As a result of the allegations, SSA, the Office of Inspector General (OIG) for the Department of Health and Human Services, and the General Accounting Office (GAO)—the last two at the request of various members of Congress—conducted studies to determine the veracity of the allegations and the extent of any abuses.[11] None of the studies found any significant amount of such abuse.

There were many other activities during the period prior to enactment of the PRWORA. Notable among them was the establishment of the National Commission on Childhood Disability in 1994, which issued its report to Congress in October 1995. While there were differences of opinion about the extent of change needed, the report called for tightening the evaluation criteria for children. Another significant report was issued by the Childhood Disability Committee of the Disability Policy Panel, National Academy of Social Insurance, "Restructuring the SSI Disability Program for Children and Adolescents" in May 1996. Among other recommendations, it called for the elimination of "maladaptive behavior as a separate domain in the functional assessment in the childhood mental disorders listings and the IFA" and a revamping of the IFA using criteria that were more appropriate for children with physical impairments. Although it called for retaining the IFA, the report suggested that SSA should "strengthen, and in some ways tighten, the eligibility criteria for future SSI applicants."

Against a backdrop of increasing public and congressional sentiment against the IFA rules, and the payment of benefits to children whose impairments were considered by some to be too mild to confer eligibility, Congress took legislative action in the PRWORA.

II. THE PERSONAL RESPONSIBILITY AND WORK OPPORTUNITY RECONCILIATION ACT OF 1996

Responding to concerns raised about the rapid growth in the childhood disability program and the other concerns already noted,[12] the PRWORA provided a new definition of disability for

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[11] See, e.g., SSA's report, "Findings From the Study of Title XVI Childhood Disability Claims," May 1994; the GAO report, "Rapid Rise in Children on SSI Disability Rolls Follows New Regulations," GAO/HEHS-94-225, September, 1994, which concluded most of the growth in the rolls was attributable to children with mental impairments, both under the revised listings and the new IFA standards, not because of the IFA standards in themselves; and the OIG reports, "Concerns About the Participation of Children With Disabilities in the Supplemental Security Income Program," A-03-94-02602, October, 1994, and "Supplemental Security Income: Disability Determinations for Children with Mental Impairments," A-03-94-02603, January, 1995.

[12] See H.R. Rep. No. 651, 104th Cong., 2d Sess. 1386 (1996), *reprinted in* 1996 U.S. Code, Cong. and Ad. News 2183, 2445.

children claiming SSI benefits based on disability, and directed SSA to make significant changes in the way childhood disability claims are evaluated. The new law established a definition of disability for children separate from that for adults, no longer based on an impairment of "comparable severity" to one that would be disabling in an adult. Rather, the new definition provided that a child shall be considered disabled if he or she has a medically determinable impairment or combination of impairments that meets the statutory duration requirement and "which results in marked and severe functional limitations."[13]

The President had strongly opposed earlier House legislation that would have removed a majority of the approximately one million children from the SSI rolls, and proposed that the legislation include provisions guaranteeing continuing Medicaid eligibility to children who lose eligibility for SSI under the new disability standard, a provision that was finally enacted in the Balanced Budget Act of 1997. The President signed the PRWORA on August 22, 1996.

Under the PRWORA, a child's medically determinable impairment or combination of impairments must cause more serious impairment-related limitations than the post-*Zebley* rules required.[14]

Specifically, the new law eliminated:

- The comparable severity standard,
- The IFA, and
- References to maladaptive behaviors in the personal/behavioral area of functioning in SSA's childhood mental disorders listings.[15]

The law further required SSA to:

- Notify no later than January 1, 1997, beneficiaries who were eligible for SSI benefits on August 22, 1996, and whose

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[13] Section 1614(a)(3)(C)(i) of the Act.

[14] See H.R. Conf. Rep. No. 725, 104th Cong., 2d Sess. 261, 328-329 (1996), *reprinted in* 1996 U.S. Code, Cong. and Ad. News 2649, 2649, 2716-2717; H.R. Rep. No. 651, 104th Cong., 2d Sess. 1385-1386 (1996), *reprinted in* 1996 U.S. Code, Cong. and Ad. News 2183, 2444-2445.

[15] See Listing of Impairments, prior sections 112.00C2 and 112.02B2c(2).

eligibility might be affected by the PRWORA, that their eligibility might be redetermined;

- Redetermine the eligibility of such beneficiaries using the new definition of disability for children no later than one year after the date of enactment;[16]
- Redetermine the eligibility of beneficiaries who are eligible for SSI in the month before the month in which they attain age 18, using the adult initial eligibility criteria, during the one-year period beginning on a beneficiary's 18th birthday;[17] and
- Conduct continuing disability reviews (CDRs):[18]
    - Not later than one year after birth for children whose low birth weight is a contributing factor material to the determination of disability;[19]

      and
    - Not less than once every three years for beneficiaries under age 18 with impairments that are considered likely to improve. At the Commissioner's option, SSA

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[16] The Balanced Budget Act of 1997 extended the date by six months, to February 22, 1998, and also provided that SSA could, at any time, redetermine the case of any child if the Agency discovered a child's case that should have been redetermined under this section.

[17] The Balanced Budget Act of 1997 changed this provision. The law now provides that SSA may perform an age-18 redetermination during the one-year period after the child's 18th birthday or in lieu of a continuing disability review (see footnote 18) whenever SSA determines that a case was subject to redetermination.

[18] SSA periodically reviews the cases of all disability beneficiaries to determine if their conditions have medically improved to the extent that they are no longer eligible for benefits. This review is known as a "continuing disability review" (CDR).

[19] The Balanced Budget Act of 1997 changed this provision. The new law provides that the Commissioner may determine that a CDR is not necessary at age one if the Commissioner determines that the child has an impairment that is not expected to improve by age one.

> may also perform a CDR with respect to individuals under age 18 whose impairments are unlikely to improve.

Finally, the legislation required the representative payee of a child whose continuing eligibility is being reviewed to present evidence at the time of the CDR that the child is, and has been, receiving treatment that is considered medically necessary and available for the condition that was the basis for providing SSI benefits, unless SSA determines that providing such evidence is unnecessary or inappropriate considering the nature of the child's impairment(s). If the representative payee does not comply with this requirement without good cause, SSA may, if it is in the child's best interests, suspend payment of benefits to the payee and pay benefits to another payee, or to the child directly.

On February 11, 1997, SSA published interim final regulations with a request for comments implementing most of the childhood disability provisions of the PRWORA.[20] Relying on express statements of congressional intent,[21] the regulations interpreted the statutory standard of "marked and severe functional limitations" in terms of "listing-level severity" and emphasized the importance of functional equivalence.[22]

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[20] *See* 62 Fed. Reg. 6408 (1997).

[21] *See* 62 Fed. Reg. at 6409, 6413 (1997).

[22] *See* 62 Fed. Reg. at 6409, 6413 (1997). For example, the conferees stated:

> The conferees intend that only needy children with severe disabilities be eligible for SSI, and the Listing of Impairments and other current disability determination regulations as modified by these provisions properly reflect the severity of disability contemplated by the new statutory definition. In those areas of the Listing that involve domains of functioning, the conferees expect no less than two marked limitations as the standard for qualification.

H.R. Conf. Rep. No. 725, 104th Cong., 2d Sess. 328 (1996), *reprinted in* 1996 U.S. Code, Cong. and Ad. News 2649, 2716. The House Report contains similar language. *See* H.R. Rep. No. 651, 104th Cong., 2d Sess. 1385 (1996), *reprinted in* 1996 U.S. Code, Cong. and Ad. News 2183, 2444. The conferees also made statements regarding the use of functional equivalence:

> The conferees also expect SSA to continue to use criteria in its Listing of Impairments and the application of other determination procedures, such as functional equivalence, to

However, as already noted, the regulations retained a number of rules that resulted from the *Zebley* decision and other rules that aid in effective adjudication of cases. For example, the new rules continued to include consideration of the impact of a child's impairment(s) on his or her functioning under the listings and functional equivalence, somewhat expanded to permit better evaluation of physical impairments, and stressed the need to consider "other factors." In accordance with the statute's mandate, the regulations also deleted references to "maladaptive behaviors" from the former personal/behavioral area of functioning in the childhood mental disorders listings and deleted the IFA.

Of the approximately one million children on the rolls, roughly 288,000 were subject to redetermination of eligibility under the PRWORA. With the publication of the regulations, SSA estimated that benefit eligibility after all appeals would end for a total of 135,000 of these children.[23]

> ensure that young children, especially children too young to be tested, are properly considered for eligibility for benefits.
>
> The conferees recognize that there are rare disorders or emerging disorders not included in the Listing of Impairments that may be of sufficient severity to qualify for benefits. Where appropriate, the conferees remind SSA of the importance of the use of functional equivalence disability determination procedures.
>
> Nonetheless, the conferees do not intend to suggest by this definition of childhood disability that every child need be especially evaluated for functional limitations, or that this definition creates a supposition for any such examination. Under current procedures for writing individual listings, level of functioning is an explicit consideration in deciding which impairment, with certain medical or other findings, is of sufficient severity to be included in the Listing. Nonetheless, the conferees do not intend to limit the use of functional information, if reflecting sufficient severity and is otherwise appropriate.

H.R. Conf. Rep. No. 725, 104th Cong., 2d Sess. 328 (1996), *reprinted in* 1996 U.S. Code, Cong. and Ad. News 2649, 2716.

[23] See 62 FR 6417-6418, February 11, 1997.

III. IMPLEMENTATION

A. Screening and Notification

Soon after the passage of the PRWORA, SSA identified approximately 288,000 children who could potentially be impacted by the new law. The Agency reviewed about 54,000 of their claim files at its headquarters and identified over 28,000[24] children who could be found disabled under the new law, and for whom a redetermination was unnecessary.[25] In November and December 1996, SSA notified the families (or other payees) of about 264,000 children that the children were potentially subject to redetermination under the new law, as required by the PRWORA. The notice was shared with advocates for comment prior to being finalized.

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[24] This number includes overt 23,500 cases that were identified before any notices were sent and over 4,500 cases that were still being reviewed when the notices were sent in November and December 1996, and which were subsequently found to meet the requirements of the new law. Thus, the number of children who received notices was the difference between the original 288,000 identified and the first 24,000 children who were continued in payment status, or 264,000 children.

[25] The 288,000 cases identified as potentially requiring redeterminations included two groups of cases in which SSA computer records did not show definitively whether the claims should be redetermined. The first group included children who had been found eligible by ALJs and for whom SSA's data did not include coding of the basis of the allowance; for example, whether the cases were allowed because of an IFA. The cases were subject to redetermination only when review showed that they had been allowed based on an IFA or based on maladaptive behaviors in the former personal/behavioral area of functioning in the mental disorders listings. The second group of cases had been allowed at the listing level and involved four "maladaptive behavior impairments" (attention deficit/hyperactivity disorder, conduct disorder, oppositional defiant disorder, and personality disorders). SSA reviewed this group to determine whether the children would have been found to have impairments that met or equaled a listing without consideration of maladaptive behaviors in the former personal/behavioral area of the mental disorders listings. If so, benefits were continued; if not, the cases were sent to the State agencies (also called Disability Determination Services, or DDSs) for redetermination.

B. Publication of Regulations and Other Instructions

SSA published the interim final regulations with a request for comments in the *Federal Register* on February 11, 1997, within six months of the passage of the PRWORA.[26] The comment period ended April 14, 1997. "Interim final" means that the regulations were final rules that SSA implemented upon publication, as compared to "proposed" rules, which cannot be used until they are published as "final" rules. However, SSA may revise them in the future after considering the public comments.

SSA received comments on the regulations from 174 individuals and organizations. SSA is considering the comments and will respond to them through the rulemaking process.

SSA also developed and issued operating manual instructions and several temporary instructions to its Field Offices (FOs), the DDSs, and the Office of Hearings and Appeals (OHA) in time for the national training and implementation of the PRWORA.

C. National Training

Given the changes outlined by the PRWORA, SSA conducted extensive training for its employees and the DDSs before starting the redetermination process. Upon publication of the interim final regulations, SSA piloted nationwide training with 10 States using the Interactive Video Teletraining (IVT) system. This four-hour "train-the-trainer" session, presented on February 18, 1997, featured a one-hour videotape and written materials (trainer and student manuals). The presenters were experts from SSA headquarters in Baltimore, Maryland, including some who were intimately involved in the writing of both the current regulations and the prior rules. The 10 States then participated in the Centralized Implementation Review described below under *Monitoring and Evaluation*.

After the Centralized Implementation Review, SSA revised the training based on its findings. On March 18, SSA conducted

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[26] It should be noted that the PRWORA provided that the SSI provisions affecting children were to be implemented immediately, even though regulations had not been promulgated. Since SSA adjudicators need regulations and operating instructions in order to process cases, the Agency adjudicated only those new claims that were not affected by the PRWORA and held other claims until the interim final regulations were published and all adjudicators were trained. It should also be noted that, under the statute, redeterminations could not be processed until potentially affected children and their families were notified, and the notices were not sent until November and December, 1996.

nationwide training on the revised rules and procedures, again over the IVT and with the same presenters, to trainers in all DDSs, OHA, and all SSA quality assurance (QA) review components. Also observing were a number of advocates for children with disabilities. Shortly afterwards, all DDS examiners and medical staff, OHA administrative law judges (ALJs) and staff, the Appeals Council, QA reviewers, and all other affected SSA staff completed training.

D. Monitoring and Evaluation

From the beginning of the implementation, SSA planned a number of steps to attempt to provide continuous, timely guidance to adjudicators in the DDSs, QA components, and OHA.

- Centralized Implementation Review

  After their pilot training in February, the 10 participating DDSs used the new rules to decide over 700 cases, which were then sent to Baltimore for review. DDS examiners and medical consultants from the participating 10 States, SSA Regional Office (RO) reviewers from each of the 10 regions, including QA reviewers, and ALJs came to SSA headquarters to review and discuss the claims, the policy, and the training. This in-depth review enabled SSA to identify areas of policy that may have been subject to misinterpretation early in the adjudicative process and to greatly improve subsequent training before implementation began. It also enabled adjudicators and quality reviewers representing each of SSA's 10 regions to carry a consistent understanding of proper adjudication back to their home components while providing SSA with insight about what was needed to clarify the training.

- Early Information Systems Reviews

  After the national training, each of SSA's 10 RO disability quality branches (DQBs), which perform the regular QA reviews of States within their jurisdiction, implemented "early information systems" (EIS) reviews of DDS determinations. The EIS reviews were in addition to the regular QA reviews.

  Although not as statistically valid or precise as SSA's regular QA reviews, the EIS has become a standard Agency practice since it helps to alert management quickly to potential problems in a DDS's application of new disability policy and procedures.

- Quality Assurance Reviews

  Throughout the implementation period, SSA has conducted regular QA reviews of continuance and cessation decisions to determine performance accuracy.[27] Error rates are measured in terms of the number of cases reviewed that are returned to a DDS for corrective action.[28] While some errors are, in fact, incorrect decisions, cases are most frequently returned to correct deficiencies in documentation that may or may not result in a change in the decision itself.

  SSA's regulations provide a threshold for performance accuracy of 90.6 percent. The overall national accuracy rates for childhood disability redeterminations for the period June-October, 1997, were 91.5 percent for continuances and 93.4 percent for cessations. (In fiscal year 1996, the accuracy for new childhood claims was about 95 percent for both allowances and denials.)

  Whenever a quality problem is detected in a DDS, samples are increased for that DDS to assure that any problem is being addressed. SSA is currently reviewing an additional total of 1,000 cases per month taken from 13 States.

  Whenever QA data raises issues about DDS practices, SSA takes action to address them. This summer, SSA RO staff conducted extensive discussions with DDS administrators, examiners and medical consultants about quality findings.[29] SSA and DDS personnel also participated in numerous meetings and conferences where issues in childhood redeterminations were discussed. SSA also conducted case reviews and training during onsite visits to the States.

- Other case reviews

  SSA has conducted a number of case reviews to address various problems or concerns that have arisen during the processing of cases. For example, the Agency:

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[27] Separate samples are drawn for each type of determination.

[28] Under SSA regulations, low decisional quality means accuracy below 90.6 percent. See 20 CFR § 416.1043(d).

[29] For example, RO staff in all 10 regions have visited DDSs within their jurisdiction to do case workshops, review problem cases, and to discuss quality issues. Twenty-six DDSs have been visited by RO staff for this purpose. RO staff have also discussed quality issues with virtually all States by conference call and in regional meetings.

- Studied a group of cases from States that had high, low, and average continuance rates to see whether there were obvious differences in adjudication or clear errors to account for different rates of favorable determinations among the States.

- Studied cases that had been ceased because of a "failure to cooperate."

- Studied cases to address concerns that, in an effort to meet the original August 22, 1997, deadline for completing the redeterminations, the DDSs overused consultative examinations, obtained substandard consultative examinations and failed to obtain evidence from schools.

E. Public Information Activities

At the national, regional and community levels, SSA worked to inform affected individuals, public agencies, legal aid organizations, advocates for the disabled and the general public about the changes in the SSI rules for children. SSA has worked to keep them informed about the implementation of the PRWORA and other issues, such as the right to appeal and the right to request benefit continuation.

Presentations were made at meetings and conferences of major organizations, such as the Children's Defense Fund, the Child Welfare League and the Council for Exceptional Children. SSA staff answered questions at conference exhibits and provided timely information to children, parents and caregivers.

SSA has also engaged in a regular dialogue with advocates for children with disabilities and has been involved in numerous activities to investigate, correct, and respond to allegations and concerns they have raised about problems they have perceived in the implementation process. These advocates include representatives of The Joseph P. Kennedy, Jr., Foundation, The American Bar Association's (ABA's) "Children's SSI Project," The Arc of the United States (formerly The Association for Retarded Citizens), The Bazelon Center for Mental Health Law, The SSI Coalition for a Responsible Safety Net, and Community Legal Services of Philadelphia.

Informational mailings were sent to governors of all States and to the leaders of major disability organizations. Information about childhood disability was posted to SSA's Internet web site, including information about free legal services offered by the ABA's "Children's SSI Project." RO and FO staff have appeared on local cable television, and conducted seminars for State and local governments, local school systems, and the teachers and parents of children in special education classes. SSA's Press Office continues to provide information to the media to inform the public about their rights and SSA's progress in implementing the law.

F. Processing of Cases

Full implementation of the PRWORA began after initial notices were sent to affected families, new regulations and operating instructions were published, and adjudicators were trained. Beginning in March, 1997, SSA FOs began contacting families to get current information about their children to help the Agency decide whether eligibility continued. Families were interviewed to obtain information about their children's current medical conditions, sources of medical treatment, and other information, such as information about the schools the children attended.

The FOs then forwarded this information to the DDSs, which then developed current medical and functional evidence and redetermined the cases. In some cases, FOs and DDSs recontacted the families before the redetermination was completed. For example, DDSs recontacted some families to schedule consultative examinations or to find out more information from parents about their children. FOs also recontacted some families, especially those that did not respond to a letter or phone call asking them to come in for an interview. These are standard procedures followed in all cases, including initial claims.

Basic data on redeterminations. By November 1, 1997,[30] SSA had reviewed the claims of over 263,000 of the 288,000 children who were potentially subject to redetermination under the PRWORA and redetermined the claims of about 235,000 children at the initial level of review. Almost 93,700 (about 40 percent) of the initial redeterminations continued eligibility, while over 141,300 (about 60 percent) found that the children were no longer disabled under the new law. After counting those continuances that were accomplished without a formal redetermination and the cessations that had been reversed on appeal by November 1, about 127,500 children have had their eligibility continued and about 135,800 have had their eligibility ceased.

SSA initially estimated that 135,000 children would lose eligibility after all appeals as a result of the PRWORA and its implementing regulations. Although SSA has already determined that 135,800 children do not have impairments that meet the new definition of disability, this figure represents only initial determinations. On appeal to the reconsideration and ALJ hearing

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[30] For consistency, data through November 1, 1997, have been used throughout this report.

levels, some children will likely have their eligibility reinstated. There are a variety of reasons for this, including that appeals provide the claimant with an opportunity to present new evidence and to be seen and questioned, as appropriate, by the decisionmaker.

An initial determination has been made in approximately 93 percent of the redetermination workload. At the present rate, the remaining cases should be completed by the early 1998.

In earlier discussions with representatives of the advocacy organizations, SSA made a commitment to review any allegedly "egregious" cases that are brought to the Agency's attention. A small number of such cases (fewer than 50) have been submitted and are now under review.

Initial Determination and Appeal Rights and Benefit Continuation. All children whose cases were redetermined and their families or other representative payees received notices explaining the disability determination. If the determination was that disability continued, eligibility simply continued. However, if the determination was that eligibility ended under the new law, the notice provided information about how to appeal the determination and, importantly, how to request that benefits continue during the appeals process. In developing these notices, SSA sought comments on the draft notices from some leading advocates for the rights of disabled children and revised the final notices to reflect a number of their comments.

Throughout the notification and redetermination process, when concerns were raised about the clarity of information, SSA responded with revised instructions and retraining. These changes were made over time as case processing proceeded; therefore, children who were found ineligible earlier in the process may not have received the same explanations as those who were found ineligible later in the process.

Under SSA regulations, claimants have 60 days from the date they receive the notice explaining the determination to request a "reconsideration" of their initial determinations. However, to request benefit continuation in cases in which SSA makes a determination that a child's impairment(s) has ceased, does not exist, or is no longer disabling (a medical cessation determination), claimants must make a separate request no later than 10 days after the date they receive the notice. In both cases, SSA rules permit exceptions for "good cause." Claimants who do not appeal within 60 days or request benefit continuation within 10 days can still appeal or continue to receive benefits during appeal if they show a good reason under SSA's rules for failing to meet either of the deadlines.[31]

Although claimants can request that benefits be continued during the course of the appeal, the statute provides that the payments made during the appeal are an overpayment that is subject to repayment if the child is ultimately found to be not disabled under SSA's rules. However, under the applicable statute and regulations, a claimant who asks for waiver of repayment of the overpayment and who appeals in good faith is entitled to waiver consideration. SSA assumes that the appeal was made in good faith unless the individual fails to cooperate in connection with the appeal. If the individual has cooperated during the processing of the appeal and needs substantially all of his or her current income and resources to meet ordinary and necessary living expenses, or the other criteria for waivers apply, SSA will waive recovery of the overpayment. Because limited income and resources are a requirement for SSI eligibility, most claimants who appeal in good faith and request waiver are not required to repay their overpayments.[32]

Reconsideration of the Initial Determination. Like the initial redeterminations, reconsiderations are also made in the DDSs, but by different decisionmakers. Unlike the initial redeterminations, the reconsideration may include two steps, including a face-to-face disability hearing. First, a special reconsideration staff in the DDS does a "paper review" of a case to determine whether the child can be found eligible based on the information in the case file. This staff may request new evidence, including CEs, just as at the initial stage.

If the determination on "paper review" is favorable to the child, the process ends and the child's eligibility is continued. However, if on paper review eligibility cannot be continued, the case is referred to a Disability Hearing Officer (DHO) who will provide the claimant with an opportunity for a face-to-face disability hearing. Even if the claimant does not request a face-to-face disability hearing, the DHO will review the claim and issue the reconsideration determination. The DHO may also request new evidence, including CEs.

To date, few reconsideration determinations have been made. Current data show that out of nearly 68,000 requests for reconsideration, only about 9,300 reconsideration determinations

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[31] See 20 CFR §§ 416.996(c)(2) and 416.1411.

[32] See section 1631(a)(7)(B)(ii) of the Act; 20 CFR § 416.996(g)(2).

have been issued. The chart on the next page shows the results of reconsideration determinations as of November 1, 1997.

Reconsiderations of Childhood Disability Redeterminations

As of November 1, 1997

Requests for Reconsideration	67,946	
Considered at "Paper Review" First step of reconsideration process.	38,392	
Continued on Paper Review Cases cannot be ceased at the first step of the reconsideration process.	4,644	12.1 percent (of cases considered)
Still Pending Paper Review	29,554	

Cases Sent to Disability Hearing Officer (DHO) Second step of reconsideration process.	33,748	
DHO Reconsideration Determinations as of November 1, 1997	4,632	
Continued	792	17.1 percent (of cases considered)
Ceased	3,840	82.9 percent
Still Pending DHO Determination	29,116	

Total Reconsideration Determinations (Paper Review and DHO)	9,276	
Continued*	5,436	58.6 percent
Ceased	3,840	41.4 percent

* Continuance rate data are too early to predict final results. If the same results of paper reviews and disability hearings continue through all reconsideration determinations, the

continuance rate at the reconsideration level would be 27.1 percent.

Appeals After Reconsideration. If a claimant is dissatisfied with the reconsideration determination, he or she may appeal to the next level, which provides opportunity for a hearing before an ALJ.[33] Claimants again have 60 days from the date they receive the reconsideration notice in which to appeal, and 10 days from the date they receive the notice in which to choose to continue to receive benefits pending the ALJ's decision, with provision for good cause for later filing.[34] Claimants who received benefit continuation at reconsideration must make another election to receive benefit continuation at the ALJ hearing level. Claimants who did not request benefit continuation during their appeals for a reconsideration may still request benefit continuation at the time they ask for an ALJ hearing. Very few cases have reached this level of appeal.

When a Child Loses Eligibility. Under the PRWORA, no child lost eligibility for cash benefits before July 1, 1997, even if the redetermination was made before that date. Also, the amendments in the Balanced Budget Act of 1997 provided for continuing Medicaid eligibility for children who lose eligibility for SSI as a result of the new definition of disability for children contained in the PRWORA.

G. Case Characteristics.

Mental disorders are the most frequent basis for finding children eligible for SSI. Most children (77 percent) who were subject to redetermination were diagnosed with a mental disorder. About 30 percent of the children subject to redetermination were shown in SSA's data with the diagnostic code for mental retardation.

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[33] Claimants may also elect not to have a hearing and to receive a decision from an ALJ based only on the evidence in the case file. Most claimants ask for a hearing.

[34] Benefit continuation in these cases is based on the provisions of section 1631(a)(7) of the Act. Statutory benefit continuation offered in cases involving a medical cessation determination differs from benefit continuation offered in other cases. Under the statute and SSA's regulations, 20 CFR § 416.996(b), a claimant must elect to receive statutory benefit continuation, and continued benefits can be paid through the month before the month of the ALJ's decision. Benefit continuation in other cases based on 20 CFR § 416.1336 ("Goldberg-Kelly" benefit continuation) is made automatically if the claimant files the appropriate appeal within 10 days after the date he or she receives the notice, without a separate election, unless the claimant declines benefit continuation. However, benefits may be paid only through the first level of appeal, a much shorter period of time.

In addition, because impairments involving the consideration of maladaptive behaviors in the personal/behavioral area of functioning were a primary focus of the redeterminations under the PRWORA, another 30 percent of the children who were subject to redetermination had one of the primary disorders that are most likely to be accompanied by maladaptive behaviors.

Among the other impairments (23 percent), the most common are:

- Asthma—about 2,300 subject to redetermination (less than one percent of the redeterminations),
- Epilepsy—about 1,700 subject to redetermination (less than one percent of the redeterminations),
- Cerebral palsy—about 1,500 subject to redetermination (less than one percent of the redeterminations), and
- Other nervous system disorders—about 1,250 subject to redetermination (less than one-half of one percent of the redeterminations).

The vast majority of eligible children who have these impairments were allowed under the listings and were not subject to redetermination under the PRWORA. Many of the relatively small number of children with these other impairments who were originally allowed based on an IFA had less serious forms of their impairments than children with the same impairments who were found disabled under the listings.[35] All children who were allowed based on an IFA, including children with these disorders, were subject to redetermination under the PRWORA.

H. Summary of Issues.

The remainder of this report presents discussions of the key issues surrounding the following subjects and the steps SSA plans to take to address them.

1. Cessations of eligibility of children who are shown in SSA records as having mental retardation.

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[35] However, even among the redeterminations, many of these children are being found still eligible. The continuance rates are as follows: Asthma, 24 percent; epilepsy, 45 percent; cerebral palsy, 64 percent; other nervous system disorders, 58 percent. SSA expected that more than a third of all the children subject to redetermination would simply have improved to the point at which they were no longer disabled. Also, many of the mental and physical impairments in this group of children are expected to improve with treatment and the passage of time.

2. Quality of case processing.

3. Failure of some claimants to appeal cessation determinations or to request benefit continuation during appeal.

The following sections address each of these issues. At the end of each section are "Next Steps"—a list of plans the Agency has to address the issues when action is necessary.

In some cases, the next steps involve reviews of cases that were previously decided in the States, and potential reopening and revision of prior determinations. Before any actions to review and, if warranted, to reopen cases are taken, SSA will first provide additional training and necessary written instructions to its adjudicators in the areas in which problems were found. The training and instructions will reemphasize the correct application of current policies and procedures in the appropriate areas. SSA will continue to ensure that there is appropriate QA review of the issues and continue to take corrective action on these or any other issues if they are found.

THE ISSUES

ISSUE #1

MENTAL RETARDATION

Background

Mental retardation (MR) is a mental disorder characterized by significantly subaverage general intellectual functioning (e.g., as shown by a valid IQ of 70 or below) accompanied by significant limitations in adaptive functioning.[36] 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, 407,000 were shown with SSA's diagnosis code for MR. The vast majority of these children (80 percent) were *not* subject to a redetermination because they have impairments that

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[36] See, e.g., the *Diagnostic and Statistical Manual of Mental Disorders,* Fourth Edition (DSM-IV), of the American Psychiatric Association (1994): "The essential feature of Mental Retardation is significantly subaverage general intellectual functioning . . . accompanied by significant limitations in adaptive functioning . . ." (DSM-IV, p. 39). Also, *Mental Retardation: Definition, Classification, and Systems of Supports*, 9th Edition, American Association on Mental Retardation, 1992 (the AAMR manual): "*Mental retardation* refers to substantial limitations in present functioning. It is characterized by significantly subaverage intellectual functioning existing concurrently with related limitation in two or more . . . adaptive skill areas . . ." (AAMR manual, p. 1). Similarly, the *Manual of Diagnosis and Professional Practice in Mental Retardation,* " ed. John W. Jacobson and James A. Mulick, American Psychological Association (1996), p. 13 (the APA manual).

Adaptive functioning refers to how effectively individuals cope with common life demands and how well they meet the standards of personal independence expected of someone in their particular age group . . ." (DSM-IV, p. 40). There is also a requirement that MR must first be manifested during the "developmental period," defined as prior to age 22 in the APA manual and SSA's adult mental disorder listings, and prior to age 18 in other authorities, including the DSM-IV and AAMR manual. However, the children discussed in this report are all individuals who have not attained age 18.

meet a listing. Once a child is properly classified with MR, SSA will generally find the child disabled under the listings if:

a. The child's IQ is 59 or below,[37] or

b. The child's IQ is in the range of 60 to 70 (considered a "marked" limitation in cognition) and the child has a second "marked" limitation of functioning in another area of functioning (e.g., social functioning) because of MR,[38] or

c. The child's IQ is in the range of 60 to 70 and the child has another physical or mental impairment (in addition to the MR) that causes an additional and "significant" limitation of function.[39] "Significant" in this case does not mean "marked" but something more minor.

The 80 percent of eligible children whose MR meets a listing (over 325,000 children) were not affected by the PRWORA, and their cases were not reviewed as part of the redetermination process. The remaining 20 percent, approximately 79,500 children, were subject to a redetermination because they were originally found eligible based on an IFA.

Concerns:

Concerns center around two issues: The precision of SSA's coding data and whether the redeterminations were being made correctly.

A substantial number of children have been found ineligible who have a primary diagnosis code for MR. However, the MR code has been used for other impairments since it was first established. This is because SSA requires its DDS adjudicators to enter a diagnosis code into the computer system in all cases but does not have codes for all possible impairments. In such cases, SSA instructs its adjudicators to choose a code for a "closely

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[37] Listing 112.05C.

[38] Listing 112.05E.

[39] Listing 112.05D. In addition, listings 112.05A, 112.05B, and 112.05F provide criteria for adjudicating cases in which the results of standardized intelligence tests are unavailable (such as when a child's young age or condition precludes formal standardized testing) or in which a child has "marked" limitations in two areas of functioning regardless of whether scores on standardized tests fall within the precise ranges in the listings.

analogous" impairment. Accordingly, SSA knows that many of the children who eligibility was ceased on redetermination did not have MR, and were never thought to have had it, even though they were, and perhaps still are, included in the MR data.

The MR code was often used for two other disorders. First, many children allowed under the IFA had what is called a "learning disability" or "learning disorder."[40] SSA instituted a code for this group of disorders in February, 1994, but before that most of these children would have been assigned the code for MR; undoubtedly, many of these children received the MR code even after SSA instituted the new code.

The second disorder frequently coded as MR is called "borderline intellectual functioning" in the DSM-IV.[41] This diagnosis is given to children who have IQs from 71-84 (between one and two standard deviations below the mean) *and* who do not have the significant deficits of adaptive functioning required for a diagnosis of MR.[42] SSA recently instituted a code for borderline intellectual functioning to better identify this group of children.[43]

There is also concern that the eligibility of children who have MR is being ceased incorrectly.

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[40] The most commonly used tests of intelligence typically yield more than one IQ score, testing various aspects of intelligence; for example, verbal IQ, performance IQ, and a composite, full scale IQ. SSA policy is to use the lowest score. Many children who do not have MR, especially children with learning disabilities, will have one IQ score in the 60-70 range, even though they do not have MR.

[41] The DSM-IV does not recognize borderline intellectual functioning as a mental disorder (DSM-IV, p. 684) but SSA does because it is an abnormality in cognition that can be demonstrated by medically acceptable laboratory techniques; i.e., standardized intelligence tests.

[42] It is possible for a child with an IQ score greater than 70, in the range defined by borderline intellectual functioning, to have MR. The critical factor is whether the child has significant deficits in adaptive functioning. (Also, see footnote 37, concerning children with IQ scores of 70 or below who do *not* have MR.)

[43] On October 10, 1997. SSA expects that, as with any such coding change, there will be a learning curve before adjudicators use the code in all cases to which it applies, so it should be some time before there are data based on the new code.

- First, there is concern that the eligibility of children with IQs in the range of 60 to 70 is being ceased erroneously because of misapplication of the listings. The concern is that many children with MR who have IQs in the range of 60 to 70 who also have other impairments that are "significant" should be found to have impairments that meet listing 112.05D, but that adjudicators may be overlooking this listing.[44]

- Second, there is concern that the eligibility of children with MR who have IQ scores *above* 70 is being ceased because of adjudicator failure to consider the range of error inherent in all test scores, called the Standard Error of Measurement (SEM).[45]

SSA believes that in most cases that are ceased and that show the code for MR, the children do not have 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.[46] SSA does not believe that there are many children who fall into this category; however, the

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[44] Advocates have submitted nine cases to illustrate "egregious" errors in evaluating children who are alleged to have mild MR. However, reviews by experts in SSA headquarters show the same tendency among the advocates as alleged among adjudicators to accept IQ scores without considering the other criteria necessary to establish the diagnosis of MR. In seven of the nine cases, the children did not have MR, despite having at least one IQ score of 70 or below. In the two remaining cases of confirmed MR, eligibility had already been continued on reconsideration.

[45] The SEM is a method of expressing the reliability of a test score in terms of a range. For example, for one SEM, an IQ of 70 may be considered within a range of 65 to 75 (plus or minus five points) with a known degree of confidence. Thus, in effect, some children with IQ scores above 70 may have cognitive functioning consistent with an IQ of 70 or below, just as some children with scores of 70 or below may have cognitive functioning consistent with an IQ above 70. SEMs vary from test to test and even within tests that take more than one measurement.

[46] See, e.g., the APA Manual, Appendices to Chapter 1, pp. 39-53.

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.[47]

What the Data Show

1. Basic data.

SSA sent notices to about 79,500 children whose cases had the code for MR explaining that their cases would be redetermined.

As of November 1, 1997, SSA had redetermined 73,950 (93 percent) of the 79,500 cases. SSA determined that eligibility continued under the new standards in about 31,525 (43 percent) of these cases, and that eligibility did not continue in about 42,425 (57 percent) of the cases.

2. Changes in diagnostic codes.

Significantly, of the 42,425 cases ceased, 24,720 (58 percent) were not diagnosed with MR at the time of cessation. In about 9,460 of the cases in which the diagnosis code changed (almost 40 percent of the 24,720), the original MR code was changed to the code for learning disability at cessation.

In addition, central case reviews have shown that many cases involving borderline intellectual functioning were coded for MR. As a result, it is not known how many children whose cases originally had the code for MR, or whose cases had the code for MR at cessation, actually exhibited borderline intellectual functioning.

In contrast to the children whose eligibility ceased, 79 percent of the children originally showing the code for MR whose eligibility was continued on redetermination retained the code for MR. This shows that children who retained the diagnosis of MR were significantly more likely to be continued than those who did not.

3. Age.

Whether the MR diagnosis code changed or not, the younger the child, the more likely these children were to be continued. Children five years old and younger were continued at a 61 percent rate. This compares to continuance rates of 47.3 percent for children ages six to 11, 41.5 percent for

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[47] See, e.g., the AAMR manual p. 18, and DSM-IV, p. 44.

children ages 12-15, and 28.6 percent for children ages 16 and 17.

4. QA Data.

QA data show that the return rate for MR continuances is slightly lower than the return rate for all redetermination continuances.[48]

QA data also indicate that the return rate for MR cessations is slightly higher than the return rate for all redetermination cessations, although it is above the 90.6 percent accuracy threshold for quality in the regulations.

Key Findings:

1. SSA data and internal studies demonstrate that in a large number of cases with the code for MR, the children did not have MR, and were never thought to have MR, but were only shown in SSA's records with this diagnosis code. These claims were significantly more likely to result in cessation than claims of children who retained the code for MR at the time of the redetermination.
2. QA data show that cessations of cases with the code for MR have documentational and decisional deficiencies. This means that, regardless of the correct diagnosis, the eligibility of some children with the code for MR was potentially ceased incorrectly.
3. Although this report addresses only redetermination cases, many of the same problems in findings 1 and 2 exist in the cases of children whose claims were adjudicated after enactment of the PRWORA and who were denied.
4. Cases with a valid IQ of 60 through 70 may include some children with MR whose eligibility should have been continued or established. Cases with valid IQs from 71 to 75 include the upper end of one "standard error of measurement" on several of the most commonly used cognitive scales and may include some children with mild MR who could meet the definition of disability.

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[48] As already noted in the discussion of QA earlier in this report, the fact that a case has documentational deficiencies means only that it does not have sufficient evidence to support the determination. It does not necessarily mean that the determination will be changed when additional evidence is obtained.

Actions to Date:

SSA issued a DDS Administrators' Letter on August 28, 1997, highlighting several important points for adjudicators to remember when interpreting the results of standardized intelligence tests in childhood disability cases.

SSA established a separate code for children with borderline intellectual functioning.

Next Steps:

1. For all DDSs, there will be a review of:

    a. All cases of children whose eligibility was ceased at the initial level under the PRWORA and that show the code for MR, and

    b. All denials of initial applications adjudicated on or after August 22, 1996, that show the code for MR.

    In general, the review will be a two-stage process.

    i. 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.

    ii. 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.

    However, *all* cases of children with the code for MR and who have a valid IQ score of 75 or below that were ceased on redetermination or denied on or after August 22, 1996, based on an initial application will be reopened, developed as necessary, and receive a revised determination, if appropriate. 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.

2. Before beginning the reviews, SSA will provide additional training to its adjudicators addressing the issues regarding the evaluation of MR raised in this report. The training will consider what SSA has learned from all of the efforts

leading up to Commissioner Apfel's top-to-bottom review, including data analysis, study results, and other case reviews, to ensure an effective refresher training program and meaningful review of the cases.

ISSUE #2

QUALITY OF CASE PROCESSING

Background

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 the differences in case characteristics among State workloads to see how these factors impacted results, the quality of case development procedures, and the overall accuracy of determinations.

I. REGRESSION ANALYSIS

Regression analysis can show if differences in case characteristics can help explain the differences in redetermination continuance rates among the States. With a regression analysis, SSA can identify the characteristics of cases that are associated with the finding of continuing eligibility and produce a mathematical formula that can be used to predict the likelihood of a continuance based on the characteristics of each case. The mathematical formula allows for comparisons of different State workloads by adjusting for differences in the characteristics of cases in each State's workload. To the extent that not all case characteristics or other factors accounting for variation in outcome are known or tracked, regression analysis will be unable to explain all of the variations.

SSA's administrative records were used to identify case characteristics for the regression analysis. Examples of such case characteristics included:

- The child's age at the time of redetermination,
- The child's impairment at the time of the original award,
- The year of the original award,
- The adjudicative level of the original award, and
- Whether the original award was based on an IFA.

In addition to these case-specific characteristics, SSA included two other variables that might affect outcomes:

1. The proportion of children in each State at or below 200 percent of the poverty level who were receiving SSI disability payments, and

2. The proportion of children in a State who were required to have their SSI eligibility redetermined.

During the years following the Supreme Court ruling in *Zebley*, filing and award rates varied substantially among States. The first variable has been shown to account for differences among States in their original awards of SSI childhood eligibility. The second variable considers the fact that some States often used IFAs as the basis of award, even when children could have been allowed based on meeting or equaling one of the listings. These States tended to have a higher proportion of the SSI children subject to redetermination. They would also be expected to have higher redetermination continuance rates because many of the children had more severe impairments when they were first found eligible than children in other States who were found eligible based on an IFA.

Once the formula was developed, the characteristics of each State's redetermination workload were evaluated by the formula and an "expected" continuance rate was predicted for each State. The "expected" continuance rate and the actual continuance rate for each State were then compared to determine how much of the difference between a State's actual continuance rate and the national continuance rate was accounted for by case characteristics evaluated in the regression formula.

The results of the analysis were that the differences in case characteristics among States definitely led to a difference in expected continuance rates. For many States, much or all of the difference between the individual States' continuance and cessation rates and the national continuance and cessation rates was accounted for by case characteristics considered in the regression analysis. However, there were differences in results among States in processing the redeterminations that were not explained by the regression analysis or QA data. It is unknown whether limitations in the variables available for the analysis would account for the unexplained differences or whether other factors not identified in this analysis contribute to the unexplained differences.that the differences in case characteristics among States definitely led to a difference in expected continuance rates among the States.

This was to be expected because of the limitations in the number of variables used in the formula. The ability of any statistical approach to predict outcomes depends upon its ability to accurately measure the key factors associated with the result being predicted. However, one of the key factors in assessing childhood disability—the severity of the child's impairment(s) and the resulting functional limitation(s)—is not available in SSA's automated administrative records. Lacking this data, SSA could not expect the statistical approach to be very precise in predicting which children would be found to have continuing disability.

Despite these limitations, the national formula provides useful insights into the variability among State continuance and cessation rates. The two charts on pages 40 and 41 show the results of the regression analysis together with QA data for each DDS. In the first chart, the States are ranked by continuance accuracy; in the second, by cessation accuracy. The second, third, and fourth columns show data for the regression analysis. The second column shows each State's actual continuance rate.[49] The third column shows the State's "expected" continuance rate based on the regression analysis. The last column shows the difference between the actual and expected continuance rates and should be read as a percentage; for example, "0.04" means the State's continuance rate was four percent higher than "expected" from the regression analysis, while "-0.04" means the State's continuance rate was four percent lower than "expected" from the regression analysis. The charts show that in both cases there is no correlation between a DDS's accuracy rating and whether its rate of continuance was higher or lower than "expected" based on the regression analysis.

Key Findings:

1. Since the regression analysis produced different "expected" rates based on the characteristics evaluated, differences in continuance and cessation rates among States are to be expected.

2. For many States, much or all of the difference between the individual States' continuance and cessation rates and the national continuance and cessation rates is accounted for by case characteristics considered in a regression analysis.

3. There are differences in results among States in processing redeterminations that are not explained by the regression analysis or QA data. It is unknown whether limitations in the variables available for the analysis would account for the unexplained differences or whether other factors not identified in this analysis contribute to the unexplained differences.

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[49] This applies to the second table as well. Even though the States are ranked by *cessation* accuracy, the purpose of the analysis was to determine whether differences in *continuance* rates could be explained by case characteristics.

CHILDHOOD REDETERMINATIONS

Ranked by CONTINUANCE Accuracy

	QA Continuances: Accuracy Rate	Actual Continuance Rate	Expected Continuance Rate	Difference Continuance Rate
Montana	100.0	0.23	0.55	-0.32
Missouri	100.0	0.29	0.42	-0.12
Oklahoma	100.0	0.26	0.29	-0.03
Rhode Island	100.0	0.34	0.42	-0.08
Vermont	100.0	0.47	0.43	0.05
Texas	100.0	0.22	0.42	-0.20
Oregon	100.0	0.62	0.45	0.17
Alaska	100.0	0.47	0.63	-0.16
Maine	99.3	0.44	0.44	0
Utah	99.1	0.41	0.49	-0.09
Massachusetts	99.0	0.50	0.44	0.07
Hawaii	98.9	0.67	0.36	0.31
Ohio	98.6	0.39	0.39	0
Wisconsin	98.6	0.39	0.38	0.02
Georgia	98.5	0.33	0.29	0.04
Indiana	97.8	0.40	0.47	-0.07
Connecticut	97.6	0.48	0.52	-0.04
Iowa	97.4	0.24	0.47	-0.23
Minnesota	97.3	0.64	0.55	0.09
Arkansas	97.2	0.25	0.29	-0.04
Wyoming	97.2	0.48	0.55	-0.07
New Hampshire	97.1	0.40	0.35	0.05
Illinois	97.1	0.28	0.40	-0.12
Washington	96.9	0.54	0.52	0.03
Tennessee	96.2	0.29	0.33	-0.05
West Virginia	95.9	0.36	0.37	-0.02
Delaware	95.6	0.53	0.33	0.20

Arizona	95.5	0.62	0.49	0.12
Maryland	95.3	0.50	0.47	0.04
Alabama	94.4	0.30	0.28	0.01
Florida	94.2	0.47	0.44	0.03
Mississippi	93.9	0.18	0.24	-0.06
Kentucky	93.8	0.59	0.41	0.17
North Dakota	93.8	0.39	0.43	-0.04
North Carolina	93.4	0.58	0.55	0.03
California	92.5	0.63	0.49	0.14
Nevada	92.3	0.68	0.49	0.19
Virginia	91.3	0.51	0.56	-0.05
Colorado	91.2	0.49	0.39	0.10
South Carolina	90.7	0.31	0.36	-0.05
Kansas	88.1	0.24	0.52	-0.28
Dist Columbia	87.7	0.68	0.40	0.28
Nebraska	87.7	0.34	0.41	-0.07
South Dakota	87.3	0.58	0.35	0.22
Louisiana	86.1	0.24	0.28	-0.04
Michigan	85.4	0.62	0.50	0.12
Idaho	81.5	0.44	0.61	-0.18
New York	80.9	0.39	0.47	-0.07
New Mexico	80.8	0.35	0.41	-0.06
New Jersey	80.7	0.59	0.38	0.21
Pennsylvania	69.0	0.62	0.47	0.16
NATION	91.5	0.43	0.43	0

CHILDHOOD REDETERMINATIONS

Ranked by CESSATION Accuracy

	QA Cessation: Accuracy Rate	Actual Continuance Rate	Expected Continuance Rate	Difference
Hawaii	100.0	0.67	0.36	0.31
Louisiana	99.2	0.24	0.28	-0.04
New Hampshire	98.7	0.40	0.35	0.05
Vermont	98.6	0.47	0.43	0.05
Minnesota	98.5	0.64	0.55	0.09
North Dakota	98.4	0.39	0.43	-0.04
Nevada	98.3	0.68	0.49	0.19
Connecticut	98.2	0.48	0.52	-0.04
Delaware	98.0	0.53	0.33	0.20
South Dakota	97.8	0.58	0.35	0.22
Arizona	97.8	0.62	0.49	0.12
Montana	97.6	0.23	0.55	-0.32
New Mexico	97.3	0.35	0.41	-0.06
Oklahoma	97.2	0.26	0.29	-0.03
Utah	97.2	0.41	0.49	-0.09
Maine	97.2	0.44	0.44	0
Massachusetts	97.0	0.50	0.44	0.07
Missouri	96.9	0.29	0.42	-0.12
Nebraska	96.8	0.34	0.41	-0.07
Illinois	96.6	0.28	0.40	-0.12
Wisconsin	96.4	0.39	0.38	0.02
West Virginia	96.0	0.36	0.37	-0.02

Colorado	95.5	0.49	0.39	0.10
Alabama	95.3	0.30	0.28	0.01
Virginia	95.2	0.51	0.56	-0.05
Texas	94.9	0.22	0.42	-0.20
Wyoming	94.7	0.48	0.55	-0.07
Iowa	94.6	0.24	0.47	-0.23
Michigan	94.3	0.62	0.50	0.12
Florida	94.3	0.47	0.44	0.03
South Carolina	93.9	0.31	0.36	-0.05
Arkansas	93.7	0.25	0.29	-0.04
Alaska	93.2	0.47	0.63	-0.16
Indiana	93.0	0.40	0.47	-0.07
Kansas	92.6	0.24	0.52	-0.28
New York	92.1	0.39	0.47	-0.07
Georgia	91.6	0.33	0.29	0.04
Rhode Island	91.5	0.34	0.42	-0.08
Kentucky	91.5	0.59	0.41	0.17
New Jersey	91.3	0.59	0.38	0.21
Ohio	91.3	0.39	0.39	0
California	89.7	0.63	0.49	0.14
Tennessee	89.5	0.29	0.33	-0.05
Washington	89.3	0.54	0.52	0.03
North Carolina	89.1	0.58	0.55	0.03
Maryland	88.6	0.50	0.47	0.04
Idaho	88.1	0.44	0.61	-0.18
Pennsylvania	87.9	0.62	0.47	0.16
Oregon	87.4	0.62	0.45	0.17
Mississippi	83.0	0.18	0.24	-0.06

Dist Columbia	81.2	0.68	0.40	0.28
NATION	93.4	0.43	0.43	0

II. CASE DEVELOPMENT PRACTICES

SSA also considered the possibility that differences in case development practices contributed to differences in redetermination results by States.

The Act and SSA's regulations require claimants to provide current medical and other evidence showing the existence and severity of their impairments. Although claimants are technically responsible for providing the evidence SSA needs to make a determination, in practice, SSA often obtains this evidence for claimants. SSA refers to this process as "developing" evidence for the case. Under the law and regulations, SSA is required to develop a complete medical history for at least the 12 months preceding the month in which the application is filed before the Agency can decide that a child is not disabled;[50] for a redetermination cessation under the PRWORA, SSA develops evidence for at least 12 months preceding the month of the redetermination.

Because the children subject to redetermination under the PRWORA had been found eligible in the past, there was no current evidence in the children's case files from which to determine current eligibility. This meant that SSA had to develop evidence for almost every redetermined case starting with the implementation of the PRWORA in about mid-March, 1997.

Concerns were raised that the DDSs rushed redetermination cessations to meet the original August 22, 1997, deadline of the PRWORA. It was alleged that, as a consequence, the DDSs made many errors in the development of the cases; i.e., in obtaining evidence necessary to support their determinations. The allegations raised a number of issues related to two types of evidence in particular: Consultative examinations and school records. To address the concerns, SSA studied both issues.

The findings, described in more detail below, do not support the concerns raised. Development of CEs and of evidence from schools was properly done in the great majority of cases. Even in those instances where consultative examination and school evidence was not properly developed, there was usually other evidence in the file to support the determination.

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[50] See section 1614(a)(3)(H) of the Act (incorporating section 223(d)(5) of the Act by reference under title XVI); 20 CFR §§ 416.912(c) and (d).

A. Consultative Examinations

Consultative examinations (CEs) are medical examinations SSA purchases when a child does not have a medical source or when the child's medical source(s) cannot or does not provide sufficient medical evidence for SSA to determine whether the child is disabled.[51] The regulations and operating instructions provide guidelines for the DDSs and ROs on the management and oversight of CEs. Included are DDS guidelines for choosing CE providers, scheduling CEs, the length of CEs, monitoring the qualifications of CE providers, and ensuring the quality of CE reports. Claimant feedback on the quality of CE providers is an important part of the management of the CE program.

Four concerns were raised regarding the CE process:

- *Overuse of CEs.* Allegations were raised that, in their haste to complete the cases, the DDSs purchased CEs instead of developing evidence from treatment sources and other sources (e.g., schools).
- *Quality of Examinations.* Allegations were raised that too little time was spent by the CE providers in the examinations, and many examinations were not complete.
- *Quality of Written Reports.* Allegations were raised that the reports were incomplete, too brief, and did not provide sufficient detail.
- *Qualifications of CE Providers.* Allegations were raised that the DDSs were not using CE providers with the right specialty to perform the CEs.

What the Data Show:

Frequency of Purchase. For this report, SSA reviewed 364 CEs to determine whether the reports met the standards set out in its instructions for the DDSs. Because the study reviewed only case records, it could not measure the quality of the examinations themselves, which is not indicated in the case files.

The overall finding is that CE purchase practices were consistent with SSA's instructions. More specifically:

- The national CE rate (about 34 percent) was consistent with both adult and prior childhood experience.

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[51] See 20 CFR §§ 416.917 through 416.919t.

- CE rates were about 10 percent higher in cessation cases than in continuances (38.6 percent vs. 28.1 percent), also consistent with prior experience.

- It was clear that States did not purchase CEs as a means for *ceasing* claims. On the contrary, the higher rate of purchase of CEs in cessation cases was largely attributable to attempts by the DDSs to fully develop evidence for children who could not otherwise establish eligibility because the existing medical evidence would not support a continuance or the children did not have treating sources or a source of record.

Thus, there was no evidence that DDSs were systematically over-relying on CEs in lieu of existing medical evidence. Nor was there evidence to support the allegation that DDSs were purchasing CEs to "shortcut" full development to the child's detriment.

Quality of the Reports. Of the 364 CE reports, 278 (about 76 percent) satisfied all of SSA's standards. Furthermore, even where the CEs did not satisfy all of SSA's standards, other evidence in file was almost always sufficient to support the determination. Only 5.6 percent of the cases had to be returned to the DDSs for corrective action related to a deficient CE.

Qualifications of CE Providers. There were no indications that CE providers with inappropriate specialties were being used. Of the 364 CE reports, 274 (75 percent) were performed by psychologists and psychiatrists, consistent with the fact that the largest category of redeterminations comprised children with mental impairments. The second highest category of CEs was performed by speech/language pathologists (29 CEs, about eight percent).

B. Obtaining and Using Evidence From Educational Sources

Evidence of functioning is critical to the determination whether a child is disabled under the PRWORA and SSA's regulations, unless the claim can clearly be allowed or continued on medical evidence alone. Information from educational personnel (e.g., teachers, counselors, school psychologists) and school records detailing scores on standardized tests, grades, attendance and other information may be important evidence about how well a child functions. SSA's rules stress the importance of requesting this evidence, if the child is in school and the medical evidence alone is not sufficient to support a favorable determination. Of course, sources other than schools (including medical sources) can and do provide evidence of a child's functioning.

Concerns:

Early in the implementation process, advocates predicted that the DDSs would soon be unable to obtain school records as the summer recess began. It was also alleged that in the summer, when many of the redeterminations were completed, DDSs redetermined cases without this often-critical evidence in order to meet the original August 22, 1997, deadline.

What the Data Show:

In discussions with States, it is clear that the States had planned ahead, undertaking various initiatives to make the evidence available before the schools closed for the summer. Some States negotiated arrangements with their departments of education to gain access to the records while schools were closed. DDS medical relations officers interviewed teachers to obtain information about their students. In some States, the DDSs arranged for school records to be sent electronically. Some States hired teachers on a piecework basis to copy records from school files. Parents, too, were asked to assist and obtain copies of their children's school records.

SSA also conducted a "probe" study of this issue to determine if school records had been retrieved. The study included 214 cases for which SSA was able to review the entire case file.

- School records were included in 84 percent of the cases for which SSA had complete files. Further, 84 percent of the cases adjudicated in the July-September period contained school records.

- In six percent of the 214 cases, the file did not contain school records because there was sufficient evidence to support a continuance without obtaining information from the child's teacher or other educational sources.

- Another four percent of the 214 cases were cessations without school records in which other evidence was sufficient to document the child's functional abilities.

- In an additional three percent of the 214 cases, no school records were in file but the child was not of school age (i.e., age three or younger).

- Therefore, in the remaining three percent of the 214 cases, there were no school records in file and no apparent reason for their omission.

- Of the 214 cases for which the complete file was available for review, only 17 (eight percent) were returned to the

DDSs to obtain school records. Fourteen of these cases already contained some school records but needed additional records.

The three most common types of school records were: Questionnaires from teachers or teacher assistants, Individual Education Plans (IEPs), and reports of psychological testing performed by school psychologists.

Key Findings:

1. SSA studies of redetermined cases did not support the allegations regarding case development, including consultative examinations and school evidence.

2. There are no other data to support the allegations, either from QA or from various studies conducted in SSA headquarters since implementation began.

Next Steps:

No actions specific to this issue.

III. FAILURE TO COOPERATE

A child's eligibility may be ceased on the basis of a "failure to cooperate" (FTC) when his or her parent (or other payee) or, in some cases, the child himself or herself,[52] does not respond to a notice initiating the disability redetermination or fails or refuses without good cause to attend a consultative examination after SSA makes repeated attempts to get cooperation.

SSA has special instructions regarding FTC in childhood claims to ensure that children's rights are protected because in most cases children are not in a position to pursue their claims independently.[53] When a parent or other payee is not providing the required information or is not cooperating, the special procedures require additional attempts to contact the claimant or representative 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. SSA developed these procedures in 1993 with the plaintiffs' attorneys in the *Zebley* case.

Concerns:

As early as June, SSA recognized that, even though the national rate of FTC determinations was within historical ranges, a number of States had an unexpectedly high number of FTC determinations. SSA began steps to investigate the causes of the high rates and to take corrective actions where necessary.

What the Data Show:

At least some people chose not to cooperate because they did not wish to pursue their claims; for example, when their children's medical conditions had improved. Unlike initial applications, in which the claimant first approaches SSA, the redeterminations were automatic. However, there is also study information that raises concerns.

Nationally, FTC cessations make up 4.8 percent of all initial redeterminations. This rate compares favorably with the 5.2 percent FTC rate in SSI CDRs. However, on a State-by-State basis, there were wide variations in the numbers of FTC

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[52] In a very small number of cases (fewer than 500), benefits are paid directly to individuals under age 18. Examples include children who have been emancipated by courts and children who are within seven months of reaching age 18.

[53] See Program Operations Manual System (POMS) DI E25205.015, issued November, 1993.

cessations. Rates ranged from less than one percent in the lowest States to 9.5 percent in the highest States.

To investigate the causes of the high rates, and to determine whether they reflected errors, SSA studied a sample of cessations based on a failure to cooperate. This study found that in 68 percent of cases either all of the contacts required under the special childhood procedures that had been in effect since 1993 had not been made or the efforts were not documented in the case file. In about 40 percent of the cases that contained these deficiencies, the States had correctly followed the instructions for adult claims but had not made the extra efforts required by the childhood instructions.[54]

Key Findings:

1. Although the national rate of redetermination cessations based on a failure to cooperate is within acceptable ranges, there are wide variations among the States.
2. Based on SSA study findings, there were many deficiencies in redetermination cessations based on a failure to cooperate, especially in the early months of implementation of the PRWORA.
3. SSA has provided additional written instructions and training to its FO personnel and clarified DDS instructions. However, these actions had only a prospective effect.
4. Many redetermination cases that were ceased on the basis of a failure to cooperate have already been reworked using the correct procedures.

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[54] This finding has led to a theory that a lack of a specific cross-reference to the special childhood procedures in the POMS SSA issued for the redeterminations led adjudicators to use only the adult procedures. In fact, the new instructions included a cross-reference to a group of existing childhood instructions that included the special FTC instructions (POMS DI 25201.001ff-DI 25225.001ff.), although they did not single out the special FTC instructions. While the lack of a specific cross-reference may have had some effect, it must be stressed that the special childhood procedures had been in use for 3½ years and were not changed by the PRWORA instructions. It also does not account for the number of cases in which the instructions for adults were not correctly followed. However, SSA added a specific cross-reference to the childhood operating instructions in August.

Actions to Date:

As a result of its investigations, SSA has taken several remedial actions, including the issuance of clarifying instructions and training in September to FO personnel. In addition, the FTC cessations in several States have been reviewed to correct any deficiencies.

Next Steps:

1. All failure to cooperate cessations will be reviewed.[55] The case reviews will ensure that all contacts and followups required in the special instructions for children's cases have been made and that these actions have been documented in the case files.
2. When the reviews show deficiencies in following the special childhood failure-to-cooperate instructions, claimants who wish to pursue their claims will be given an 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.

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[55] Many redetermination cases that were ceased on the basis of a failure to cooperate have already been reworked using the correct procedures and will not be reworked again under this action.

IV. ACCURACY OF CASES

While SSA continues to be interested in understanding and explaining differences in cessation and continuance rates among the States, the primary concern is that the determinations are correct.

What the Data Show:

Nationally, the accuracy of both continuance and cessation determinations is above 90.6 percent (the regulatory threshold for accuracy). QA data for continuances for the period June-October, 1997, show a national accuracy rate 91.5 percent; data for cessations show a national accuracy rate of 93.4 percent. 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.

The QA sample for cessations is larger than the sample for continuances. The larger QA cessation sample allows for identification of patterns. In DDSs with overall cessation QA problems, the largest number of returns is in cessations involving mental impairments other than MR. This is to be expected because the majority of redetermined cases are cases involving mental impairments. Furthermore, cases involving mental impairments are among the most difficult to adjudicate.

Maladaptive Behavior Cases

In December, 1996, there were about 95,000 children receiving SSI benefits based on an impairment likely to have involved maladaptive behaviors in the prior personal/behavioral area of functioning.[56] This represented about 10 percent of all children on the SSI rolls.

Over 16,500 of these children's benefits continued because they were not affected by the PRWORA. In these cases, the children still had impairments that met or equaled listings without consideration of the prior personal/behavioral area of functioning. The remaining 78,500 cases were subject to

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[56] In particular, children with four mental impairments were significantly affected by the changes to the listings and the elimination of the IFA. The first three were "disruptive behavior" disorders: Conduct disorder, oppositional defiant disorder, and personality disorders (a category comprising several types of mental impairments). The fourth was ADHD. However, maladaptive behaviors can occur with other kinds of mental impairments.

redetermination under the PRWORA, about 30 percent of all children subject to redetermination.

Cases involving maladaptive behaviors account for about 29 percent of all redetermination cases already adjudicated (about 68,900 out of 235,000) and are about 31 percent of all cessations (about 43,200 out of almost 141,300 cessations on November 1, 1997).

Of the cases requiring redetermination because of a targeted diagnosis, two-thirds were originally allowed based on an IFA and would have been redetermined even if maladaptive behaviors had not been a factor.

Of the maladaptive behavior cases in which eligibility was found to have ceased after redetermination, about a third were changed at the time of cessation to a diagnosis code for an impairment that did not involve maladaptive behaviors, usually another mental impairment. Cases with a new diagnosis ceased at a lower rate (58 percent) than cases that retained a code for one of the "maladaptive behavior" diagnoses (65 percent).

There are indications from SSA central reviews that there is some inconsistent handling of redetermination cessations involving mental impairments other than MR.[57] The PRWORA required elimination of certain references to maladaptive behaviors in SSA's Listing of Impairments, but the legislative history makes it clear that the intent was not to preclude all consideration of such behaviors, only to prevent "double-weighting." Concerns had been raised that Agency adjudicators could misinterpret the intent of the changes in the law regarding maladaptive behaviors to mean that such behaviors, or certain impairments, should be ignored. SSA has reviewed some cases in which children with serious psychiatric disorders lost eligibility because adjudicators failed to recognize the medical significance of the behaviors and to make the correct diagnosis or to obtain the correct kinds of evidence.

Cognition and Speech

A concern has been raised that, in the policy for functional equivalence, the single area of functioning that includes cognition and communication disadvantages children with both

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[57] SSA provides feedback to the DDSs on the cases it reviews. This also helps to clarify the issues for the adjudicators, serving an educational function.

cognitive and speech impairments.[58] On October 29, 1997, SSA met with several speech/language professionals and pediatricians to discuss their individual views on this issue. Medical experts provided several examples of speech-related communication disorders which they viewed to be separate from cognitive disorders. Although all of the examples met or equaled one of SSA's current listings, there was still concern that some children might be disadvantaged.

There is little specific data regarding the combination of separate disorders affecting cognition and speech. There is some information from SSA's central case reviews, prior experience under the IFA, and the comments of the speech/language professionals and pediatricians that raise concerns about the evaluation of speech disorders. Data for cases that have the diagnostic code for "speech and language delays" show that, of about 5,100 cases with this diagnostic code redetermined by November 1, 1997, about 49 percent were continued and 51 percent were ceased. Of the ceased cases, only 327 changed diagnosis to MR at the time of cessation, less than one percent of cases ceased with a diagnosis code for MR. Likewise, only 1,250 cases that were originally coded MR changed to the code for speech and language delays at the time of cessation, less than three percent of cases originally coded for MR that were ceased.

Key Findings:

1. For the nation and most States, accuracy of both continuances and cessation redeterminations is above 90.6 percent. However, some children may have had their eligibility ceased incorrectly.

2. There is some inconsistent handling of redetermination cessations involving mental impairments other than MR.

3. The retention of the prior area of functioning for "cognitive/communicative" limitations in the interim final rules does not seem to have had any negative effect on children with MR. Concern has been expressed, however, on behalf of children who do not have MR but whose separate impairments of cognition and speech may not be appropriately evaluated. There is some indication in the data and from

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[58] At least one advocate has asserted that SSA "combined" the areas of cognition and communication in the 1997 interim final rules for functional equivalence. This is inaccurate. Cognition and communication were separate domains under the IFA but have been evaluated in a single "cognitive/communicative" area for determining functional equivalence since the policy of functional equivalence was first promulgated in 1991. See former POMS DI 25215.010D.2.c (November, 1991).

central case reviews 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.

Next Steps:

1. In addition to the reviews of cases with the code for MR that all DDSs will do under Issue 1, above, all DDSs will also screen a portion of their redetermination cessations that do not have the code for MR.

2. SSA will identify the proportion and types of cases that each DDS will screen. The proportion of cases a DDS will screen will depend primarily on its QA accuracy rate. DDSs with higher QA accuracy will review proportionally fewer cases than DDSs with lower QA accuracy. The cases to be screened will be cessations in those categories of cases with the greatest likelihood of error based on SSA's QA results.

3. In general, the review will be a two-stage process: (a) A screening of the case file to determine whether all necessary documentation is present and that the determination was correct. If it is determined that the cessation was correct, no further action will be taken. (b) 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.

4. 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.

5. 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.

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

7. 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. The training will consider what SSA has learned from all of the efforts leading up to Commissioner Apfel's top-to-bottom review, including data analysis, study results, and other case reviews to ensure an effective refresher training program and meaningful review of the cases.

8. 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.

9. 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.

ISSUE #3

APPEALS AND REQUESTS FOR BENEFIT CONTINUATION DURING APPEAL

Background:

Explanations Provided To Claimants. Throughout the implementation process, it has been SSA's policy to explain to claimants:

- The changes in the PRWORA,
- How the changes might affect eligibility for benefits,
- When benefits will terminate if the child is determined to be ineligible, and
- Their appeal rights, including how to ask for a reconsideration and the right to request continued benefits on appeal.

SSA has provided this information in the notices advising children and their families of an unfavorable redetermination. In developing the notice advising of unfavorable redeterminations, SSA sought comments from some of the leading advocates for the rights of disabled children.

Likewise, SSA policy is to explain appeal rights when a claimant inquires about an unfavorable childhood disability redetermination. This includes an explanation of the claimant's right to appear in person at a reconsideration disability hearing and the claimant's right to request benefit continuation during the appeal for a reconsideration.

Explanations Regarding Benefit Continuation. In each case, after explaining benefit continuation rights, SSA obtains a signed statement from the claimant showing whether he or she elected or waived benefit continuation on appeal. The claimant is given a copy of the signed statement to keep.

Since July 30, 1997, the statement has included revised, standardized language. This language is required in all childhood redeterminations that are appealed. Among other things, the statement explains that, even though payments received during the appeal will be an "overpayment" if the child is still found ineligible after the appeal is decided, the claimant has a right to ask SSA to waive repayment of the overpayment. It also explains the circumstances under which waiver may be granted. SSA developed this revised statement in response to concerns expressed by several advocates.

"Good Cause" for Late Filing. When a claimant files an appeal or request for benefit continuation after the required deadline, SSA

procedures provide for the FO to determine whether "good cause" exists for the late filing. If the claimant has good cause for missing the date for requesting appeal or continued benefits during appeal, the FO will treat the request as though it had been filed timely.[59]

Information About the Availability of Representation. Under the Act and regulations,[60] SSA is required to advise claimants how to obtain information about options for accessing representation in notices of determination that are not wholly favorable to claimants who do not already have attorney representation. SSA is also required to tell claimants that a legal services organization may provide free legal services if they qualify. The redetermination cessation notice includes language explaining these policies but does not itself contain references to specific legal services providers.

However, the FOs and teleservice centers (Tics) maintain a referral list of legal services organizations (e.g., local bar associations, legal aid societies, and law schools with legal aid programs), and community organizations that provide non-attorney representation in their service areas. These lists are available to *any* claimant who expresses an interest in being represented. FO managers are responsible for keeping this information up-to-date. FOs do not recommend particular representatives or types of representatives, but only provide the claimant with the entire list.

Since August, 1997, FOs have also been instructed to include on the lists any State or local toll-free numbers for the ABA's "Children's SSI Project."[61]

Concerns:

Concerns have been raised that some SSA employees were discouraging claimants from filing appeals or from requesting benefit continuation, and that FO, TSC, and program service

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[59] For more information about good cause, see the section on *The Processing of Cases* earlier in this report.

[60] See section 1631(d)(2)(B) of the Act; 20 CFR § 416.1506.

[61] As of this writing, the ABA's "Children's SSI Project" does not maintain a national toll-free number, but 36 State chapters and the District of Columbia maintain at least one such number. (In some States, there are two or more numbers that together cover all of the State.) In 11 States, there are no toll-free numbers. In the remaining four States, toll-free numbers cover only portions of the States.

center employees were not providing referral information to claimants about the availability of free legal services, particularly the ABA's "Children's SSI Project." In addition, procedures in effect when the redeterminations began did not require a full explanation of the overpayment waiver process.

Also, despite the fact that SSA sought input from advocates regarding the content of the notice of disability redetermination, they expressed concerns about the cessation notice itself. They note that it is a lengthy, complex document that may be difficult for some parents and caregivers to understand.

On the other hand, the law requires an explanation in the notice of the reasons for the determination. Also, much of the notice conveys important information, required by the statute and principles of due process, about the claimant's legal rights and steps that must be taken to preserve these rights.

In addition, there were concerns that some claimants who needed appeal forms mailed to them so that they could return them by mail would have been unable to satisfy the 10-day response requirement for receiving benefit continuation. While such circumstances would constitute good cause for late filing, it is possible that some individuals might not have requested benefit continuation if they thought they had missed the deadline and did not understand the information about good cause provided with information about appeals.

What the Data Show:

The data show that, through November 1, 1997, requests for reconsideration have been filed in about 50 percent of unfavorable redeterminations in claims whose 60-day appeal period has expired. This rate by itself does not suggest a problem; it exceeds the 41 percent appeal rate on denials of SSI applications and is consistent with the appeal rate for children who receive unfavorable determinations on CDRs,[62] which is about 52 percent. Almost 64 percent of the people who have appealed filed within 10 days—about three out of every five—and also requested benefit continuation. Data on appeal rates by State also do not demonstrate any State-specific problems, although the number of cases is limited in smaller States.

To test the concerns discussed above, SSA conducted two polls. First, SSA telephoned social services organizations, public agencies, major umbrella advocacy organizations, and legal aid

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[62] See footnote 18 for an explanation of continuing disability reviews.

services in five regions. The five regions represent over 81 percent of the redetermination workload.

SSA found that most social services organizations and public agencies believe the Agency is doing an "adequate" to "admirable" job of educating interested groups and the public about the appeals process, and that there has been improvement over time. While some agencies voiced concern about the appeal rate, some thought it was at least partly due to parental acceptance of the fact that the child is not as severely disabled as required by the new law, rather than to any misunderstanding or discouragement from SSA personnel. Some of this response may have been influenced by recent amendments to the law. SSA has had feedback that some parents were most concerned about continuing SSI eligibility so that their children would continue to qualify for Medicaid. However, the amendments in the Balanced Budget Act of 1997 provided for continuing Medicaid eligibility for children who lose eligibility for SSI as a result of the new definition of disability for children contained in the PRWORA.

A few organizations reported isolated instances in which they thought SSA employees had discouraged claimants from filing appeals. However, they also indicated that these situations were corrected locally when brought to the FOs' attention. Some organizations did believe that the cessation notice was confusing to claimants.

While several legal aid offices said SSA was doing a good job of explaining the appeals process, benefit continuation, and good cause, there were also concerns about the length and complexity of notices and concerns that, as noted previously, some SSA employees discouraged appeals and benefit continuation.

The second poll, a survey of over 400 claimants who filed appeals but were not receiving benefit continuation, found significant confusion and misunderstanding of the process. For example:

- Half the people said they believed they had requested benefit continuation. Of this group, 92 people (43 percent) thought that their request was timely.

- About one-fourth (99) said that they did not request benefit continuation because they did not want to incur overpayments, and most these individuals alleged that they received no explanation that overpayments might be waived under appropriate circumstances.

- Of 40 claimants who stated they were denied continuing payments because they filed after the 10-day deadline, 36 said that they were not told of the provisions for "good cause" for late requests.

Also, SSA recognizes that a flaw in the automated notification process resulted in dual notices to some claimants, causing the potential for further confusion about the deadlines for responding.

Key Findings:

1. SSA found a few isolated incidents of SSA employees actively discouraging claimants from exercising their rights to appeal or to continue to receive their SSI payments during appeal.

2. There is anecdotal and survey evidence indicating that many individuals who did not appeal and some claimants who appealed but did not request benefit continuation did not fully understand their rights. Some of these individuals would have appealed or requested benefit continuation if they had more fully understood their rights.

3. Beginning in the summer of 1997, SSA took several steps to clarify its instructions and to retrain its adjudicators on these issues. However, these steps had only a prospective effect and had no impact on claimants whose eligibility had already been ceased and who had not appealed, had not requested benefit continuation during appeal, or had not been found to have "good cause" for late filing of an appeal or a request for benefit continuation. In addition, SSA received reports that some staff continued to use the prior procedures for a period of time after instructions were issued.

4. It is likely that some of the same concerns discussed in this section in relation to redetermination notices apply to notices of denial of initial applications of children filed on or after August 22, 1996.

Actions to Date:

In response to some of the concerns, SSA issued a series of operating instructions to FO staff during the summer emphasizing various aspects of good cause and waiver of overpayments to be stressed during appeal interviews.[63] All FOs also received "refresher training" in September.

In August, SSA directed all FOs to enter toll-free telephone numbers for the ABA's "Children's SSI Project" referral service on their TSC information and referral screens.[64] In addition, SSA made the various State toll-free numbers available on its Internet site. It also sent a letter to the governors of all 50 States offering to provide a list of children whose eligibility was ceased on redetermination or whose redeterminations were still pending so that their States could help them or refer them to other assistance programs. To date, all 50 States have requested this information, and 45 have received their lists.

Next Steps:

1. 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.

2. 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.

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[63] See emergency teletype, E-97-110, 7/30/97, already discussed; E-97-118, 8/13/97, a Program Circular with clarifications of the appeals process and discussion of waiver of the potential overpayment in continuing benefits cases; E-97-119, 8/14/97, a Program Circular that discussed good cause; and E-97-133, a teletype that replaced the 8/13/97 Program Circular, clarifying that the "good cause" provision applies to *changed* election of benefit continuation as well as late election.

[64] The Informational/Referral Screen is a computer screen that contains information to help TSCs answer telephone inquiries about specific FOs and public service agencies in an FO's service area.

3. If claimants whose eligibility 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.

4. 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.

5. Finally, SSA is working with the ABA to include ABA toll-free telephone numbers as an attachment in SSA decision notices in those States where such numbers 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.

Social security –
children's disability standard

Week Ending 11/1/97

NATIONAL WORKLOAD STATUS CHILDHOOD REDETERMINATIONS

SSI Children

SSI Childhood Recipients	998,280		
Original Redetermination Workload	288,000		
Continuances Screened Out Before Notices	23,658		
Total Notices Sent	264,342		
Additional Continuances Screened Out After Notices	4,666		
Cases Redetermined at Initial Level	235,038		
Cases Continued	93,691	39.9%	
Cases Ceased	141,347	60.1%	[at this rate 170,000 children will be terminated]
Ceased Cases that Appeal Within 60 Days	59,384	50.5%	[versus a 91% appeal rate after 2 weeks]
Cases Redetermined at Reconsideration Level	9,276		
Cases Continued [i.e. reversing the initial termination]	5,436		= 59% reversal rate (vs. historical average 10–15%).
Cases Ceased	3,840		
Cases Terminated for Non-Disability Reasons	6,989		
Total Continuances of Cases Decided (Redeterminations Plus Screen-Outs)	127,451	48.4%	
Total Cessations Through the Redetermination Level (includes cases screened out)	135,911	51.6%	

Note: Early data from appeals are not representative and should not be used for projections.

[221,000 other new claimant children have been denied at application stage, see Table 2, p.3 at end]

+ a 27% (100,000 case) drop in new applicants; only 15% was planned & budgeted!

Star-Telegram / Sunday, November 9, 1997

We'll need all those saved dollars to dry the tears

MOLLY IVINS

AUSTIN — Because of the wonders of welfare reform, almost 140,000 poor, disabled children have now had their Supplemental Security Income benefits cut off for failure to meet strict new standards of what constitutes a disability. And who are these poor children who were freeloading so greedily at the welfare trough? So far we've found kids who suffer from cerebral palsy, hydrocephalus, schizophrenia, bone disease, severe manic depression, severe retardation, and an entire catalogue of crippling mental and physical afflictions that would wring tears from a stone. These are the children the Republicans in Congress claimed were "faking" and had been coached by their parents to "act crazy."

Opal White of Houston is taking care of three grandchildren, 13, 11 and 7. On Aug. 7, 1993, their mother committed suicide in front of them. "They been diagnosed with mental depression, one is schizophrenic, one hear voices and the other is suicidal," White said Thursday. "They have been under psychiatric care since December of '93. It's been hard: I tried to take them to MHMR, but I didn't have the legal guardianship then. In May of '94, at the school, they tried to make the one boy make a Mother's Day card. He told them he didn't have a mother, but they say, well, make the card for a grandmother or any mother, and he tore up the whole school and the law escorted him to the hospital."

Teresa Colwell of Denison has two sons, both born hydrocephalic, a condition also known as "water on the brain." Robert, the younger boy, has been cut off; he suffers seizures and is in a special-ed class. "I had an appeal; I asked for a hearing on it," said Colwell, "and they told me, 'Well, your other son will be next.' I don't understand why the government is cutting off children like my children; the problems they've got will never leave them. Now he might have to have the shunt to drain the water off. My husband is a disabled veteran, and I can't keep a steady job because the kids need to go to the doctor so much. They have had so many tests I can't keep track, and medications too."

The children are being cut off without any consultation with the doctors who treat them or any examination of the children. Most of the time a letter simply arrives announcing the cut-off. Many of the families do not know how to appeal, and some do not even know that an appeal process is available to them. The standards being applied differ from state to state. Mississippi has cut off 82 percent of the children being reconsidered under the new standards; Texas, 80 percent; Washington, D.C., only 36 percent. Another case of justice depending on geography.

The State Bar of Texas has a toll-free hot line to help SSI families get legal representation: (888) 281-6511. It has been flooded with calls.

The predictable result of this stupid and cruel policy is that poor families, living on the margin at the best of times and struggling to care for their damaged children, will be forced to institutionalize them. Mental hospitals and state schools for the retarded will be flooded with new patients; and, of course, institutionalizing someone is incredibly expensive. Disabled kids on SSI get $400 a month.

Michelle Bonner of Clarksville has an 8-year-old son with cerebral palsy. "He was born four months premature; he had a cyst on his brain when I carried him, and the only reason he was born alive is because he was delivered early. They kept him in the hospital two months, but they didn't diagnose the cerebral palsy until he was 1 year. I knew there was something wrong; I told the doctor, 'He's not doing anything he should be doing.' The doctor who diagnosed him informed me about SSI, and there was never any difficulty with it until now.

"He has limited mobility in his right arm and right leg, his speech is slurred, he talks like a 4-year-old and he has trouble holding utensils. He holds them like a baby, with a fist. But he tries. He is quite a good little trooper. He's a brave boy.

"I was so shocked. They wrote me this letter saying under their conclusion he was not disabled. Well, you can look at him and tell there's something wrong with him. The doctor says his speech might improve, but he's got one eye that's really bad; he already had surgery on it, and it needs another surgery.

"I had just now got on my feet. I'm getting a divorce, and I was hoping to find a specialist for him, maybe at the Scottish Rite in Dallas, to get a brace for his leg. I thought maybe with a brace he could walk better. And now this. They said I had 10 days to appeal, but I had to file it in writing. I called and said, 'Send me the papers to appeal.' But they said I had to file the papers there, and it's 30 miles over to Paris and I couldn't get there. When I called to say could I mail the papers back, they said it was too late."

The government says it will save $5 billion over five years by removing these children from SSI. Aren't we proud of them for making this vast saving? We could buy two or three more rain-challenged Stealth bombers with that kind of money.

Molly Ivins is a columnist for the Star-Telegram. You may write to her at 1005 Congress Ave., Suite 920, Austin, TX 78701 or via e-mail at mollyivins@star-telegram.com.

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The Atlanta Journal-Constitutic

EDITORIAL

Congress picks myth over reality about kids

America's disabled children are denied benefits in a misguided effort to fix a system that wasn't broken.

Is a troubled 11-year-old with an IQ of 79 and the reading skills of a first-grader in more need of help than a 7-year-old who has average grades but is HIV-positive? State workers across the country, including in Georgia, have to render these Solomon-like decisions as a result of a change enacted last year in federal disability law. It is a reform gone awry, and it hurts the citizens with the least voice and voting power.

Armed only with anecdotal evidence, Congress concluded that chicanery riddled the $10 billion-a-year assistance program for low-income households with disabled children. That conclusion was rebutted by four government studies, but the *facts* didn't matter. Congress decreed that $8 billion be cut from the program over the next six years by denying assistance to kids whose disabilities were not "marked and severe."

As a result of that reform, federal disability assistance averaging $439 a month is being cut off from poor children with chronic conditions such as mental retardation, diabetes and cerebral palsy.

The task of interpreting "marked and severe" fell to the Social Security Administration. Last spring, the administration began reexamining the records of the 1 million disabled children receiving the aid, known as Supplemental Security Income or SSI. The agency targeted 135,841 kids to lose SSI this year, including 3,500 Georgia children.

But as reports in Georgia and elsewhere demonstrate, Social Security is applying too harsh a standard in its interpretation, and as a result is stripping benefits from children whose families need assistance in dealing with their health problems.

One Georgia child — now part of a class action suit — is an 8-year-old from Tallapoosa. He has cerebral palsy but does not use the extensive bracing or wheelchair required by the tough new mandates. He was initially removed from the SSI rolls, then reinstated through an appeals process.

Nationwide, 8,321 children have been removed from the rolls, have filed appeals, and have had their appeals decided. Of that number, 4,869, or 58.5 percent, have won their appeal and been reinstated. However, only half the families that are removed from the rolls appeal, leading advocates to worry about the fates of these other children.

Expanded in 1972 to cover disabled children, SSI was intended to help poor families pay for living modifications, rent, food, transportation and therapies. The funds could also be tapped to offset the lost wages of parents forced to remain at home to care for their child. It is the type of program that distinguishes a caring society from a cold and callous society.

Over the past six years, the SSI price tag for children tripled, largely in response to a 1991 Supreme Court decision. In a suit brought by disability advocates, the high court ruled that the government was using a tougher standard for determining whether children should be covered than it used for adults.

Under liberalized standards ordered by the court, the government began to consider not only a child's medical problems, but also the effect those conditions had on the child's ability to walk, eat and take part in other activities of daily living. As the eligibility window widened, so did the potential for cheating.

The most flagrant abuse involved an Arkansas couple allegedly collecting $61,000 a year in SSI for all 11 of their children. Media accounts claimed that kids simply had to act crazy to be enlisted for SSI benefits. These and other reports enraged legislators, who responded with deep cuts in SSI.

But the anecdotal accounts of widespread fraud were never borne out by any systematic audit. A General Accounting Office study in 1994 found that two out of every three children who applied for SSI benefits were rejected. An examination by the Social Security Administration of the records of 617 children receiving SSI benefits determined that only three awards — .005 percent — failed to meet the criteria.

The mental impairment category was supposedly the area most flagrantly abused, but while some children with only behavioral problems had been approved for SSI, the majority of children in that category were clearly mentally retarded.

When Kenneth Apfel took office a month ago as head of the Social Security Administration, one of his first actions was to order a thorough scrutiny of new SSI policies. That review is necessary and overdue. If too many children with mild disabilities have been admitted to SSI over the past six years, the danger now is that too many others with serious ailments are paying the consequences.

■

E-mail: sunday@ajc.com

Social Sec - children's disability standard

[redacted]

Record Type: Record

To: Elena Kagan/OPD/EOP

cc: Cynthia A. Rice/OPD/EOP, Laura Emmett/WHO/EOP
Subject: SSI meeting with Sylvia on Monday

Monday at 1pm, Ken Apfel will present his tentative plans for the "30-day top-to-bottom review" of SSA's reevaluation of children under the new disability standard, which he promised at his confirmation hearing last month. Here is a briefing of what they will say and my comments.

Overall, it's pretty good but will still disappoint advocates. However, it is hard to satisfy them without reopening major issues that shouldn't be reopened.

Ken's report will end up taking more like 6-7 weeks -- it looks like late next week or early the next.

- SSA will agree to re-review the cases of 17,000 mentally retarded children dropped from the rolls. Apparently the number of such cases has been overstated at 40,000 because SSA coded many cases as MR inappropriately. Nevertheless, they are concerned about why they have dropped 17,000, since children who meet a clinical diagnosis of MR should remain eligible.
- In response to reports from advocates that staff discourage families from appealing, or from exercising their right to continue benefits during an appeal, SSA will send new notices to the 75,000 children denied to date whose families did not appeal or did not exercise their right to continuing benefits, explaining their rights to them. SSA will also announce it has retrained its workers on this issue.
- In response to charges that the variation in cut-off rates among states demonstrates that the new standard is being implemented inconsistently, SSA will announce that it has rational explanations for most of the variations. (Nationwide 43% of kids reviewed were cut off, but that varies from 18% to 65% depending on the state.) However, in 6-8 states where they aren't uncertain, they will re-review all the cases.
- Advocates charge that some states are cutting off too many kids because of "failure to cooperate," when in fact the states are not trying hard enough to work with families who may have trouble understanding the notice. In response, SSA will re-review all 10,000 of these cases.
- Generally, SSA has refused to consider changes to the underlying reg as part of this 30-day process, because they will have a more elaborate process for that, and because they do not want to stir false hopes that they will reconsider the underlying standard -- which is what the advocates want most. However, SSA is considering announcing **one** minor change to the reg as part of the 30-day review. It has to do with splitting cognitive and communication impairments into two separate categories, allowing more children to qualify.

All of these are good actions, and they are reasonably significant. However, the advocates will still be disappointed because it doesn't change the underlying reg, and also because they were hoping Ken would agree to a moratorium on case reviews while all this work is being done. SSA is strongly opposed to a moratorium, arguing it will send too hopeful a signal and allow a backlog to start to build up, but I am not totally convinced on their reasoning.

On numbers, SSA originally estimated they would cut off 135,000 kids. The actual rate is running somewhat below that. With these changes, SSA expects that the number of kids cut off would drop to 100,000. I'm not sure strategically whether to make a big deal of that when this is released -- that would please the advocates, but could annoy congressional Republicans. On the other hand, the Republicans have been extremely supportive of everything we have done so far, so maybe a bit of criticism from them wouldn't be awful at this point, especially since these are just procedural, not policy changes.

I'm pretty sure OMB is fine with this from a money and policy standpoint.

Finally, you sent me a note from the advocate Jonathan Stein complaining that HCFA is implementing the provision to grandfather Medicaid for these children that we got in the balanced budget act unfairly: by allowing states to require children to reapply. I haven't quite untangled this, but if we can make it better, perhaps it could be part of the report.

P.S. I should note that the President said on September 10 in a meeting with advocates that he was asking SSA for a report on all this in 30 days. When Ken said the same thing but with a later start point, we told advocates we would fold it all into one report. So this report would presumably go to the President and the world simultaneously. The alternative of sending it first to us and then to the world does not seem smart.

Social security —
Children's disability standard

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.

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.

Cognition/Communication. Whether communication limitations should be separated from cognition in regulations, or whether aspects (i.e.,speech) should be separated in sub-regulation (SSA ruling).

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 for 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.

Social Security –
children's disability standard

[redacted]

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cc: Cynthia A. Rice/OPD/EOP, Laura Emmett/WHO/EOP
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Social Sec –
Children Disability
Standard

COMMUNITY
LEGAL
SERVICES, INC.

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PHILADELPHIA, PA 19102
215-981-3700
FAX 215-981-0434

October 13, 1997

Ken Apfel
Commissioner
Social Security Administration
500 "E" St., SW
Washington, DC 20254

Dear Ken,

My recent letter to Arthur (cc to you) on SSI child disability data suggests that you may not be getting the data that you need to provide the comprehensive remedies needed for the program. For example,

1. Reconsideration reversals: Have you been told what the closest "historical" recon reversal rates have been? Although there is no easy direct precedent, historically recon reversals are about 10% over the 40 year history of the DI program and 25 year history of the SSI program (give or take a few percentage points).

So, even if the reversal rate drops to 50%, or 40%, or 30%, it is still extraordinary and unprecedented bespeaking systemic errors when compared to any "historical" index.

What I find disturbing is that at our meeting you made no mention of this, only the agency defenses that the numbers are small, and are coming down. Interestingly, the weekly "status report" , although referring to "historical" levels elsewhere, doesn't for recon reversals. If you are not getting past recon reversal data, this becomes not only our problem but yours as well. You cannot function with people around you defending the status quo.

2. Appeal rates: The "status reports" say that the appeal rate for children (about 49% now, but we have yet to be given real numbers), is at "historical" levels. But the only direct precedent are the appeals for readjudication which took place in 1991 and thereafter from the Zebley class notices when 91% (or 338,255 children appealed out of 369,680 who received notices) appealed.

Again, I ask have you been told of this 91% appeal rate? If not, why not? Then the question why 91% then and 49% now? The notices were better; we helped write them and to include our "800" number. There was outreach including personal public appeals from then Commissioner Gwen King. And local offices weren't hostile to appeals as many clearly are now, setting up lots of obstacles.

3. New initial allowance rates: Why weren't you briefed before our meeting? Under the new law over 300,000 new initial child claims were decided vs. about 225,000 redetermination decisions, clearly the majority of determinations made.

The similar problem exists of enormous variations in state initial allowances exists, see, e.g., Miss. 15%, La. 18%, etc. as well as a very low national average rate of 32% compared to 42% for the pre-Zebley period when a similar Listings policy was extent.

Our concerns are here twofold: that you get the data you need that might not be forthcoming in reports coming to you, and that we get the data we believe we need and have asked for.

Among the data we have yet to receive, data also requested by Mrs. Eunice Kennedy Shriver are:

-- cessation numbers and rates of children reviewed when turning 18 (these are IFA <u>and</u> Listings children, so termination rates in the 50-60% range, akin to IFA cessations, means serious trouble as a <u>majority</u> of these are people who have received SSI because they met the Listings);

-- breakdowns of data <u>within</u> the large mental disorders category (where, e.g., Listings level children with "maladaptive behavior" were also reviewed with IFA children);

-- race and ethnicity data (also requested by Sen. Mosely-Braun);

-- actual numbers of appeals taken per state and numbers of appeals with benefits continuing pending appeal.

Sincerely,

JONATHAN M. STEIN
General Counsel

P.S. If you have time on Tuesday, while in Philadelphia, give a call as I'd love to speak with you in person (981-3742).

Soc Sec – Children's Disability

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)

Social Sec: Children's Disability Standard

COMMUNITY LEGAL SERVICES, INC.

1424 CHESTNUT STREET
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Diana —
Could you look into This?
It seems absurd to require
a reapplication for Medicaid.
Elena

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

NHeLP **National Health Law Program, Inc.**
1101 14th Street, NW, Suite 405 ◻ Washington, DC 20005 ◻ (202) 289-7661 ◻ Fax (202) 289-7724
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

Jonathan Stein
Community Legal Services, Inc.

Richard P. Weishaupt

Richard P. Weishaupt
Community Legal Services, Inc.

Marty Ford

Marty Ford
The Arc

Marilyn Holle

Marilyn Holle
Protection and Advocacy

Herb Semmel

Herb Semmel
National Senior Citizens Law Center

Chris Koyanagi

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
(215) 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

Social Security —
children's Disability
Standard

[redacted]

Record Type: Record

To: Bruce N. Reed/OPD/EOP, Elena Kagan/OPD/EOP, Cynthia A. Rice/OPD/EOP, Jacob J. Lew/OMB/EOP
cc: See the distribution list at the bottom of this message
bcc:
Subject: Re: President's Committee on Mental Retardation on Children's SSI

FYI, it looks like the President's Committee on Mental Retardation has decided that a meeting with Ken would be more productive than issuing a report.

Diana Fortuna

[redacted]

Record Type: Record

To: Bruce N. Reed/OPD/EOP, Elena Kagan/OPD/EOP, Cynthia A. Rice/OPD/EOP, Jacob J. Lew/OMB/EOP
cc: See the distribution list at the bottom of this message
Subject: President's Committee on Mental Retardation on Children's SSI

Bill White of Public Liaison and I just learned that the President's Committee on Mental Retardation wants to issue a report in the next few days saying that SSA is mishandling its redeterminations of children's eligibility for SSI under the new standard. The draft report pretty much repeats all the criticisms that the advocates have been making -- SSA's review process is not reliable, questionable, suspect; employees are unprepared and overworked; we should have a moratorium on case reviews; and SSA's interpretation of the statute itself should be reviewed.

The President's Committee is housed at HHS, but its committee members are presidential appointees who are experts in mental retardation. Several have ties to the Kennedy family; the Committee itself was begun by President Kennedy. They have apparently already voted to issue a report.

Since Ken Apfel is in the middle of the 30-day review of these issues that he promised at his confirmation hearing, Bill and I have suggested to the Committee's executive director that perhaps a meeting with Ken would be an alternative to issuing a public report. He's going to get back to us. A second alternative that we have not yet suggested is that the report could simply recommend the items Ken should be looking at in his review, without repeating the litany of criticisms of SSA.

Message Copied To:

William H. White Jr./WHO/EOP
Barry White/OMB/EOP
Keith J. Fontenot/OMB/EOP
Richard E. Green/OMB/EOP
Laura Emmett/WHO/EOP

Social Sec - Children's Disability Standard

▶ **Diana Fortuna**
09/11/97 11:43:36 AM

Record Type: Record

To: Joshua Silverman/WHO/EOP, William H. White Jr./WHO/EOP
cc: Elena Kagan/OPD/EOP, Cynthia A. Rice/OPD/EOP, Richard E. Green/OMB/EOP
bcc:
Subject: Re: SSI

If you think it would be helpful to us to say this, and the risk of putting him in the story is minimal, then I think that's fine to talk about what happened yesterday. What do you think, Bill? It may be a bit confusing that there are two 30-day reviews (the President's, which started yesterday, and Ken's, which will start the day he's confirmed). Maybe we can merge them if Ken is confirmed very soon. But the main message is that the President is concerned about this and has asked SSA to report to him on it. Here's a draft talking point.

The President believes that it is critical that the process for redetermining the eligibility of 288,000 children for SSI benefits be conducted fairly and consistently, and he knows that there are concerns about that process, such as the variations among the states in the results of those redeterminations. He understands that Ken Apfel, whom he has nominated to be Commissioner of Social Security, said yesterday that he will conduct a top-to-bottom review of SSA's process within 30 days after he is confirmed. In addition, as the President told representatives of the disability community yesterday in a meeting at the White House on a number of topics, he has asked the Social Security Administration to report to him on their process in 30 days. [The report is presumably due to us on October 10.]

[Here's one on whether our reg is too strict, but I would avoid getting into this if possible and just focus on the process:] When the law was enacted, SSA examined the evidence and interpreted the law to create a standard that was consistent with its best reading of congressional intent. SSA does not believe that a more liberal interpretation is legally possible.

Another talking point if you need it: The Administration is pleased that, as part of the balanced budget, we were able to grandfather Medicaid benefits for all these children, so that none of them will lose health insurance.

Joshua Silverman

[redacted]

Record Type: Record

To: Diana Fortuna/OPD/EOP
cc:
Subject: SSI

soc sec - children's
disability standard

COMMUNITY
LEGAL
SERVICES, INC.

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

September 24, 1997

John Callahan, Acting Commisssioner
Social Security Administration
500 "E" St., NW
Washington, DC 20254

Re: SSA's "Random Sample/ Case Studies"
Report on Childhood Disability

Dear John,

We write to ask that you rescind or revise the above report dated 9/3/97 and recently released to the media and Congress in light of major misrepresentations in it that distort the picture of what is happening to disabled children terminated from SSI. These misrepresentations unfortunately undercut what appears to be a genuine effort of Ken Apfel to address serious problems in the program.

The first all-capitalized words, "RANDOM SAMPLE", at the top of the report, is simply untrue. A conscious selection of cases was made at regional DQB offices of cases that were then sent on to headquarters. This was not the automated, true random sampling that carries with it a social science legitimacy. (The cases originally came from a randomly obtained QA pool, but then personal, subjective decisions were then made as to what cases would be sent to HQ.)

Also untrue was the critical preamble description that the former IFA test qualified disabled children "if they had only <u>moderate</u> [emphasis in text] limitations in three areas of functioning." (Page 2 of 3.) This misrepresentation of the IFA test totally excludes the children qualifying under your agency regulations with "one marked and one moderate" limitations. The 40 cessations the listed continues this misrepresentation by not including even one child with "one marked and one moderate" losing SSI.

It is a disservice to these children and to the Congress and the public not to show that the present test is intended and does in fact disqualify children with one "marked" problem in addition to the at least one other. (The glossary by failing to define "moderate" leaves its meaning nebulous, even though your agency had defined it as a child with "considerable" problems in functioning. Again the message in amplified that no serious disabled children are being cut.)

The agency to be fair must level with the public as some SSA staff have done privately or to select audiences that children with some very serious problems are being cut. Thus although Ken Apfel candidly told the Senate Finance Committee on Sept. 10, 1997 that his "biggest concern was mentally retarded children" being terminated, not one of the 40 cessations is a MR child. And with 50% of the 40 cessations listed being ADHD, I daresay that there is no basis to suggest that 50% of the children reviewed or cut are ADHD, an additional misrepresentation that plays directly to the worst stereotypes of the SSI program.

The report could have further reported that none of the cessations evinced fraud, coaching, or a gaming of the system, the main catalytic allegations that brought us these changes. As well the report could have distinguished those cessations where there was apparent medical improvement so as to not to falsely credit an overly strict new test with this result as the simple imposition of CDR reviews, without an overly strict test, could have produced this result.

The agency owes the public an honest rendering of what is going on. The primary misrepresentations in this report need prompt correction, and we trust that this will be forthcomingcfrom you shortly.

Let me further take this opportunity to say that since our September 3, 1997 meeting we have not received word of the promised meeting with OPIR and quality assurance staff, nor have we received the information that we and Mrs. Shriver have requested in light of your stated practice of openness with us. Also, I have received but one response to the almost three dozen cases presented to you. (The decision to terminate the double amputee young woman from New York was reversed, but the problem with other excessive terminations of others turning 18 years of age, most of whom were Listings awards, still stands.)

Sincerely yours,

JONATHAN M. STEIN
General Counsel

cc: Ken Apfel, Commissioner-designate
Sheila Mathews, Deputy Chief of Staff, The White House
Elena Kagan.' Domestic Policy Council, the White House
Arthur Fried, Chief Counsel
Judy Chesser, Deputy Commissioner
Susan Daniels, Associate Commissioner
Mrs. Eunice Kennedy Shriver
Marty Ford, The Arc
Rhoda Schulziner, Bazelon Center for Mental Health Law
Dr. Joel Alpert, Vice-President, Amer. Acad. of Pediatrics

soc sec – children's disability

[redacted]

Record Type: Record

To: Nelson Reyneri/WHO/EOP
cc: Elena Kagan/OPD/EOP, Cynthia A. Rice/OPD/EOP, Laura Emmett/WHO/EOP
bcc:
Subject: Re: Meeting with SSA on children's SSI 30-day review

SSA should come in with the list of problems that the advocates have raised, and for each one they should tell us what the preliminary results of their review is -- i.e., advocates say that variations among states in the percentage of kids cut off means that the rules are being applied inconsistently; SSA's review found.....

I assume you're including OMB in the meeting.

Nelson Reyneri

Nelson Reyneri
10/22/97 10:14:10 AM

Record Type: Record

To: Diana Fortuna/OPD/EOP
cc: See the distribution list at the bottom of this message
Subject: Re: Meeting with SSA on children's SSI 30-day review

Will do. Please let me know if there are others we need to invite, as well as your thoughts to how best to focus the meeting, eg, what are the key topics for discussion.

Message Copied To:

Elena Kagan/OPD/EOP
Cynthia A. Rice/OPD/EOP
Laura Emmett/WHO/EOP
June G. Turner/WHO/EOP
Sylvia M. Mathews/WHO/EOP

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

Social Security -
Children's Disability
Standard

September 24, 1997

John Callahan, Acting Commisssioner
Social Security Administration
500 "E" St., NW
Washington, DC 20254

Re: SSA's "Random Sample/ Case Studies"
Report on Childhood Disability

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Also untrue was the critical preamble description that the former IFA test qualified disabled children "if they had only <u>moderate</u> [emphasis in text] limitations in three areas of functioning." (Page 2 of 3.) This misrepresentation of the IFA test totally excludes the children qualifying under your agency regulations with "one marked and one moderate" limitations. The 40 cessations the listed continues this misrepresentation by not including even one child with "one marked and one moderate" losing SSI.

It is a disservice to these children and to the Congress and the public not to show that the present test is intended and does in fact disqualify children with one "marked" problem in addition to the at least one other. (The glossary by failing to define "moderate" leaves its meaning nebulous, even though your agency had defined it as a child with "considerable" problems in functioning. Again the message in amplified that no serious disabled children are being cut.)

The agency to be fair must level with the public as some SSA staff have done privately or to select audiences that children with some very serious problems are being cut. Thus although Ken Apfel candidly told the Senate Finance Committee on Sept. 10, 1997 that his "biggest concern was mentally retarded children" being terminated, not one of the 40 cessations is a MR child. And with 50% of the 40 cessations listed being ADHD, I daresay that there is no basis to suggest that 50% of the children reviewed or cut are ADHD, an additional misrepresentation that plays directly to the worst stereotypes of the SSI program.

The report could have further reported that none of the cessations evinced fraud, coaching, or a gaming of the system, the main catalytic allegations that brought us these changes.
As well the report could have distinguished those cessations where there was apparent medical improvement so as to not to falsely credit an overly strict new test with this result as the simple imposition of CDR reviews, without an overly strict test, could have produced this result.

The agency owes the public an honest rendering of what is going on. The primary misrepresentations in this report need prompt correction, and we trust that this will be forthcomingcfrom you shortly.

Let me further take this opportunity to say that since our September 3, 1997 meeting we have not received word of the promised meeting with OPIR and quality assurance staff, nor have we received the information that we and Mrs. Shriver have requested in light of your stated practice of openness with us. Also, I have received but one response to the almost three dozen cases presented to you. (The decision to terminate the double amputee young woman from New York was reversed, but the problem with other excessive terminations of others turning 18 years of age, most of whom were <u>Listings</u> awards, still stands.)

Sincerely yours,

JONATHAN M. STEIN
General Counsel

cc: Ken Apfel, Commissioner-designate
Sheila Mathews, Deputy Chief of Staff, The White House
Elena Kagan. Domestic Policy Council, the White House
Arthur Fried, Chief Counsel
Judy Chesser, Deputy Commissioner
Susan Daniels, Associate Commissioner
Mrs. Eunice Kennedy Shriver
Marty Ford, The Arc
Rhoda Schulziner, Bazelon Center for Mental Health Law
Dr. Joel Alpert, Vice-President, Amer. Acad. of Pediatrics

Week ending 9/13/97

NATIONAL WORKLOAD STATUS
CHILDHOOD REDETERMINATIONS

SSI Childhood Recipients	998,280		
Original Redetermination Workload	288,000		
Continuances Screened Out Before Notices	23,658		
Total Notices Sent	264,342		
Additional Continuances Screened Out After Notices	4,666		
Cases Redetermined at Initial Level	216,381		
Cases Continued	88,091	40.7%	
Cases Ceased	128,290	59.3%	total (# will exceed 150,000!)
Percent of Ceased Cases that Appeal Within 60 Days		46.2%	
Cases Redetermined at Reconsideration (Appeal) Level	3,368		
Cases Continued	2,119		→ a 63% reversal rate at recon. of terminations appealed to first stage of appeal.
Cases Ceased	1,249		
Cases Terminated for Non-Disability Reasons	6,624		
Total Continuances of Cases Decided (Redeterminations Plus Screenouts)	118,534	48.4%	

Note: Early data from appeals are not representative and should not be used for projections.

9/13/97

The New York Times

Founded in 1851

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

Mercy for Disabled Children

President Clinton's nominee to head the Social Security Administration, Kenneth Apfel, promised at his confirmation hearing this week to undertake a 30-day review of the Administration's rules for determining which disabled children qualify for Federal aid. Mr. Apfel's pledge is welcomed because the Administration's interpretation of last year's welfare law appears unduly harsh. The law tells the Administration to tighten eligibility standards for receiving cash assistance under the Federal disability program Supplementary Security Income. The question is whether the Administration tightened too much too quickly, stripping desperately needed cash from the families of severely crippled children.

Under the old law, children could qualify for disability payments if they suffered from a single extreme disability, like an I.Q. below 60, or from a combination of less extreme problems, like an I.Q. in the 60's along with cerebral palsy, rendering the child incapable of functioning like other children of the same age. Congress concluded that these functional standards were lax and, despite Government studies to the contrary, many critics also believed the standards were subject to fraud and abuse.

The Administration interpreted some loose language in last year's law and the accompanying conference report to mean that only children with extreme disabilities could qualify. It expects the new rules to knock out about 135,000 of the 260,000 children whose status will be reviewed. In answer to critics who charge that the new rules are overly harsh, the Administration points out that it expects to disqualify 50,000 fewer children than the Congressional Budget Office expected.

But Jonathan Stein of Community Legal Services in Philadelphia, an advocacy group for low-income families, points to chilling anecdotes. Under the new rules a child suffering from cerebral palsy, learning problems and depression was disqualified, as was a mentally retarded child infected with the AIDS virus and suffering from chronic multiple infections. Social Security officials say these decisions, if wrong, do not reflect bad rules but rather aberrant judgments that are the unavoidable consequence of reviewing hundreds of thousands of cases in a matter of months.

Even if that were true in these particular cases, there are compelling reasons for the Administration to rethink its rules. For starters, key senators from both parties, including John Chafee of Rhode Island and Tom Daschle, the minority leader, have written the Administration to challenge its interpretation of the welfare act.

Nowhere, they point out, does the act say that children must have extreme disabilities to qualify for cash aid. Many senators say that the 1996 law called for eligibility criteria tougher than the old law's, but less tough than the Administration's. Another disturbing fact is that about 70 percent of the families that have appealed decisions to strip them of disability aid have won their challenges. That suggests the review process is riddled with error. Unfortunately, too few families take advantage of their right to appeal.

Mr. Apfel, once confirmed, needs to quickly decide if further reviews should be put on hold while his office checks what Congress intended, why the vast majority of challenged disqualifications are reversed on appeal and why too few families appeal decisions to throw them off S.S.I. He also needs to know why states appear to be instituting the Administration's rules differently. Only after these questions are answered will Mr. Apfel know whether the Administration has abandoned thousands of disabled children for no good reason.

A24 WEDNESDAY, AUGUST 20, 1997

The Washington Post

AN INDEPENDENT NEWSPAPER

A Case of Overkill

TWO LARGE federal programs give cash each month to the families of low-income children. The one called welfare mainly supports children with only one parent in the home. The other, of roughly equal size, is for children who may have both parents present but are disabled.

The second program, less well-known, was relatively small until the 1990s, when it suddenly grew threefold. The growth was partly the result of congressional action but also the handiwork of advocacy groups, which pried the program open first with a lawsuit that led to a favorable Supreme Court decision, then through a series of administrative proceedings. Many of the children newly admitted had mental as distinct from physical disorders. By the mid-1990s the cost of the program—supplemental security income, or SSI, for children—was $5 billion a year, and critics had begun to charge, mainly on the strength of anecdotal evidence, that some of this was the result of abuse. Parents and others—state officials—were taking advantage of the eased eligibility standards to shift into the all-federal program children who, while needy, were not disabled.

As part of the welfare bill in the last Congress, Republicans, and a limited number of Democrats insisted on cracking down. The question became how to write the rule—how to differentiate between children who did and didn't belong in the program so as to screen out the one group without denying benefits to some part of the other. In the end a bipartisan group in the Senate prevailed over harder-liners in the House, and Congress took refuge in some relatively general, not to say vague, language, the effect of which was to kick the problem over to the administration. It would decide in regulations which children would remain eligible and how many would be dropped.

The regulations it issued were unaccountably tougher than the legislation required. So, at least, say the senators who were the principal authors of the final language. All sides agree that about 70 percent of the children in the program clearly qualify and deserve to remain. The other 260,000, more or less, are the ones whose status is in dispute. Their cases now are being reviewed, and early results suggest that as many as two-thirds will end up being dropped. The advocacy groups say a significant number of these are genuinely disabled.

The administration's choice in this issue was whether to err on the side of kicking out too many children or too few. In our view, it made the wrong decision for reasons never well explained. If in the early 1990s too many children were added too readily to the rolls, the pendulum now has swung the other way. This sort of thing has happened before with disability programs. The responsible officials in both branches came to regret it. We think they will again.

The Hartford Courant

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9-4-97

A harsh disability benefit policy

As part of last year's welfare reform legislation, Congress and President Clinton decided to tighten eligibility criteria for Social Security benefits for disabled children. The goal was to save $4 billion to $5 billion over the next five years while curtailing fraud — such as parents coaching children to fake disabilities.

Cracking down on fraud and abuse is a good idea. But it appears that the Clinton administration has established far stricter regulations than the 1996 law requires and is denying benefits to children who should get them.

The administration should review the eligibility requirements to determine whether it is cutting off families who need help. Congress should prod if there is resistance in the executive branch.

The Supplemental Security Income payments average $436 a month for a child. There is also federal assistance to pay for treatment and social services, to make structural changes in houses to accommodate disabilities and to offset wages for parents who stay home to care for their disabled children. The children who get benefits are all from low-income families.

After the law passed, the administration notified 264,000 of the 1 million children on the disability rolls that their cases would be reviewed. So far, the government has decided to cut off benefits for 95,000 children, more than expected.

Advocates claim that children with major disabilities, including some with uncontrollable diabetes or AIDS, have been notified that their benefits will end. They've been cut off even though they seem to meet the new general standard laid out in the welfare reform law that says children will get benefits if they have "marked and severe functional limitations."

State officials working with the federal government are making most of the calls on terminating benefits — without ever interviewing or seeing the children! How would they know if a child has been coached to deceive? How are they able to detect fraud?

Children on such assistance should be thoroughly evaluated before a decision is made to take away benefits.

"USA TODAY hopes to serve as a forum for better understanding and unity to help make the USA truly one nation."
—Allen H. Neuharth
Founder, Sept. 15, 1982

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Today's debate: WELFARE REFORM

Harsh law hurts children

OUR VIEW **Overly strict new standards for disability payments go further than Congress intended. Rein them in.**

A year after the historic passage of welfare-reform legislation, President Clinton has proclaimed, "The debate is over."

Not quite. Welfare recipients have accepted the new notion that adults who collect benefits should be required to work. And more than 1 million have exited welfare rolls since last August.

But no agreement exists on how much is too much reform for some of the nation's most vulnerable — disabled children.

New federal reports show that in the name of welfare reform, nearly 107,000 poor, disabled children have had their federal aid axed. Within the next six months, some 30,000 more cutoffs are expected.

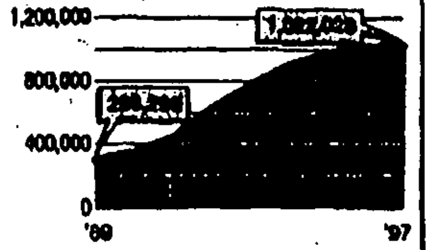
Federal case reviewers concede these kids have substantial, documented disabilities. And there's no evidence their families have scammed the government in the past.

But under strict new guidelines expected to save the government up to $5 billion by 2002, these children's disabilities aren't deemed "marked and severe," the new standard required to qualify for aid.

Children facing the greatest risk of losing their $436 average monthly checks are 264,000 nationwide with "functional limitations," including mental retardation, uncontrolled diabetes or asthma. Nearly 60% of these have been denied the federal payments that are set on an income formula and help to buy food, shelter, therapy, and living modifications and replace lost income of family caregivers.

Kids on disability

More children qualified for federal disability payments as courts recognized the need to expend the number of medical conditions that qualify for aid. Under welfare reform, that trend is expected to be reversed.



Source: Social Security Administration

By Marcy E. Mullins, USA TODAY

Fueled by tales of program abuses, Congress ordered a crackdown on disability payments. The goal: to research rumors that many disabilities were fake.

Since then, three separate government investigations tried but failed to turn up evidence of any serious program fraud.

Despite these findings, the Clinton administration imposed an overly strict interpretation of the new law.

A bipartisan group of senators has written Clinton complaining that instead of the program tuneup they'd envisioned, the administration has implemented a "radical overhaul" that fails to "adequately protect children with severe disabilities."

Next week, advocates for the disabled are scheduled to meet with the Social Security Administration to argue that the new standards need to be revised.

They are right. Welfare reform's intent was to right wrongs, not to penalize unfairly children with serious disabilities.

Compassion is our goal

OPPOSING VIEW **We want to protect kids. But Congress passed the law, and Congress has to modify it.**

By John Callahan

The Social Security Administration recognizes the importance of the Supplemental Security Income program to children, and we are working to fairly and accurately implement the provisions of last year's welfare-reform law that tightened eligibility requirements. Evaluating whether a child meets a new, more restrictive definition of disability is an enormous task. We do not underestimate the difficulty of implementing both the spirit and letter of the law.

Just over 1 million children with disabilities receive SSI. The new law tightened the definition of disability for children. When the review process is completed, we expect about 135,000 children to lose SSI benefits, substantially less than earlier estimates of 185,000 when the legislation was enacted. Our lower estimate is due, in large part, to the many safeguards the administration put in place to ensure that those children with severe impairments continue to be eligible for the program.

We know, too, that children who do not meet the new, stricter statutory standard still have impairments that are very real and may need multiple services to grow to healthy adults. That is why the administration sought, and Congress passed, legislation to permit the continuation of medical coverage for those children who do not meet the tougher, congressionally mandated standard.

The agency's choice in reviewing the disabilities of children impacted by the new legislation was not whether to remove too many children from the rolls or keep too many on the rolls. We issued rules that were based on congressional legislative language. We believe that the regulations reflect the specific legislative intent of the 1996 Welfare Reform Act. Nonetheless, we will continue to monitor the review process and recommend changes if it becomes clear that the legislation is failing to accomplish the intent of the Congress.

Making a decision that any child with a disability is no longer eligible under a stricter, congressionally mandated standard is not an easy task. It is a complex and complicated process, and we are doing all we can to compassionately carry out an extremely difficult mandate.

John Callahan is acting commissioner of the Social Security Administration.

Social Security -
Children's Disability
Standard

Diana Fortuna
09/09/97 07:51:35 PM

Record Type: Record

To: Bruce N. Reed/OPD/EOP, Elena Kagan/OPD/EOP, Cynthia A. Rice/OPD/EOP, Laura Emmett/WHO/EOP
cc: Barry J. Toiv/WHO/EOP, William H. White Jr./WHO/EOP, Barry White/OMB/EOP, Jack A. Smalligan/OMB/EOP
bcc:
Subject: Re: Kids SSI editorial in the NY Times tomorrow

Also regarding the attached, for some reason SSA chose today to send to the Hill and make available to the press a compendium describing 80 randomly-chosen cases of children under review, 40 of whom are keeping benefits, and 40 of whom are losing benefits. I just got a copy, but haven't read it yet. SSA doesn't think it will generate any press coverage by tomorrow, although the NYTimes editorial board has it. Their intention was to rebut horror stories being circulated by the advocates about kids who are clearly still eligible. But it would have been nice to know in advance.

Apparently the NYTimes ed board does know about a case in Brooklyn where SSA erroneously cut off a child with very serious problems.

Diana Fortuna

Diana Fortuna
09/09/97 07:40:15 PM

Record Type: Record

To: Elena Kagan/OPD/EOP, Cynthia A. Rice/OPD/EOP, Laura Emmett/WHO/EOP
cc:
Subject: Kids SSI editorial in the NY Times tomorrow

I just heard from Brian Coyne that the NYTimes will run a negative editorial tomorrow on SSA's handling of the SSI kids reevaluations. It will echo Jonathan Stein's request that SSA suspend further cutoffs pending a review of their process.

Social sec - children's disability
standard

▶ **Diana Fortuna**
09/17/97 12:09:54 PM
●●●●●●●●●●●●●●●●●

Record Type: Record

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

cc: Laura Emmett/WHO/EOP
Subject: Shaw press conference on children's SSI today

Shaw and some other House Republicans are having a press conference today to say that SSA is doing a good job on the children's SSI redeterminations. Apparently there is a new GAO report saying this. SSA will keep saying what it has been saying, which is that they are committed to doing this well, they are aware of problems in some areas, and that the nominee for Commissioner has committed to a top-to-bottom review of the process after he takes office -- i.e., they won't simply bask in Shaw's praise of them.

Message Sent To:

Elena Kagan/OPD/EOP
Cynthia A. Rice/OPD/EOP
Barry J. Toiv/WHO/EOP
William H. White Jr./WHO/EOP
Barry White/OMB/EOP
Keith J. Fontenot/OMB/EOP
Richard E. Green/OMB/EOP

Disabled Children Get a Needed Review

President Clinton's nominee to head the Social Security Administration, Kenneth Apfel, promised at his confirmation hearing this week to undertake a 30-day review of the Administration's rules for determining which disabled children qualify for Federal aid. Mr. Apfel's pledge is welcomed because the Administration's interpretation of last year's welfare law appears unduly harsh. The law tells the Administration to tighten eligibility standards for receiving cash assistance under the Federal disability program, Supplementary Security Income. The question is whether the Administration tightened too much too quickly, stripping desperately needed cash from the families of severely crippled children.

Under the old law, children could qualify for disability payments if they suffered from a single extreme disability, like an I.Q. below 60, or from a combination of less extreme problems, like an I.Q. in the 60's along with cerebral palsy, rendering the child incapable of functioning like other children of the same age. Congress concluded that these functional standards were lax and, despite Government studies to the contrary, many critics also believed the standards were subject to fraud and abuse.

The Administration interpreted some loose language in last year's law and the accompanying conference report to mean that only children with extreme disabilities could qualify. It expects the new rules to knock out about 135,000 of the 260,000 children whose status will be reviewed. In answer to critics who charge that the new rules are overly harsh, the Administration points out that it expects to disqualify 50,000 fewer children than the Congressional Budget Office expected.

But Jonathan Stein of Community Legal Services in Philadelphia, an advocacy group for low-income families, points to chilling anecdotes. Under the new rules a child suffering from cerebral palsy, learning problems and depression was disqualified, as was a mentally retarded child infected with the AIDS virus and suffering from chronic multiple infections. Social Security officials say these decisions, if wrong, do not reflect bad rules but rather aberrant judgments that are the unavoidable consequence of reviewing hundreds of thousands of cases in a matter of months.

Even if that were true in these particular cases, there are compelling reasons for the Administration to rethink its rules. For starters, key senators from both parties, including John Chafee of Rhode Island and the minority leader, Tom Daschle, have written the Administration to challenge its interpretation of the welfare act.

Nowhere, they point out, does the act say that children must have extreme disabilities to qualify for cash aid. Many senators say that the 1996 law called for eligibility criteria tougher than the old law's, but less tough than the Administration's. Another disturbing fact is that about 70 percent of the families that have appealed decisions to strip them of disability aid have won their challenges. That suggests the review process is riddled with error. Unfortunately, too few families take advantage of their right to appeal.

Mr. Apfel, once confirmed, needs to quickly decide if further reviews should be put on hold while his office checks what Congress intended, why the vast majority of challenged disqualifications are reversed on appeal and why too few families appeal decisions to throw them off S.S.I. He also needs to know why states appear to be instituting the Administration's rules differently. Only after these questions are answered will Mr. Apfel know whether the Administration has abandoned thousands of disabled children for no good reason.

Social Security – Children's Disability Standard

Social security - children's
disability standard

Diana Fortuna
09/10/97 04:12:54 PM
••••••••••••••••••

Record Type: Record

To: Elena Kagan/OPD/EOP, Barry J. Toiv/WHO/EOP

cc: William H. White Jr./WHO/EOP, Julia R. Green/WHO/EOP, Laura Emmett/WHO/EOP
Subject: Children's SSI and NY Times editorial board

We are debating whether someone should alert Michael Weinstein of the NYTimes editorial board about the President's statement today at the disability meeting: he has asked SSA to report to him in 30 days about problems the advocates are reporting in SSA's review of 260,000 children to see if they meet the new SSI standard. We hear the Times will run an editorial criticizing SSA for making mistakes in these reviews, and endorse a moratorium on further reviews till SSA is sure that all problems are ironed out. SSA just told the Times that today Ken Apfel promised a top-to-bottom review of this process within 30 days after he is named commissioner. We don't know when the editorial will run; it doesn't sound like it will be tomorrow.

I am more inclined not to do so. We have been consistent in letting SSA take the lead in this story, so it may be unwise to insert ourselves into the picture at this point. Plus, he didn't call for a moratorium, which is what the Times wants -- SSA would continue to review children's cases and might be almost finished by the time the 30 days are up, as an advocate pointed out to us today.

On the other hand, if the editorial does say "the President should do something about this," the President might feel dismayed that we didn't get the word out that he has taken at least this step. (Then there is the question of who talks to them.) Views on this are welcome.

Soc Security –
Children's Disability
Standard

Diana Fortuna
09/17/97 02:44:00 PM

Record Type: Record

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

cc:
Subject: Re: Shaw press conference on children's SSI today

Good news is that a new GAO report validates SSA's regulations as being consistent with the welfare reform law, and not overly strict. So that's something objective we can point to.

Bad news is that advocates are strongly critiquing a random sample study of 80 children that SSA released and that Shaw touted today. A reader of SSA's report would certainly get the sense that SSA is making good decisions. The advocates say it is sanitized, and raise questions about whether it is truly random that don't sound wacky to me at first blush.

Message Sent To:

Elena Kagan/OPD/EOP
Cynthia A. Rice/OPD/EOP
William H. White Jr./WHO/EOP
Barry White/OMB/EOP
Keith J. Fontenot/OMB/EOP
Richard E. Green/OMB/EOP

Social Sec - Children's Disabil Act

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Cynthia/Diana —
FYI.
Elena

August 14, 1997

John Callahan
Acting Commissioner
Social Security Administration
500 "E" St., SW
Washington, DC 20254

Re: State Variances in SSI Childhood Disability Cessations

Dear John,

The crisis in SSI childhood terminations now has an uglier manifestation in the extraordinary variances in cessation rates. Equally disturbing are significant variations in use of functional equivalence and failure to cooperate decisions among the states which have no rational or apparent policy justification. Enclosed is a summary chart of cessation rates taken from SSA data as of August 2, 1997.

We offer our preliminary observations here and will provide more comprehensive recommendations at the planned September 3rd meeting. We understand that your staff is in good faith seeking answers, but let us suggest that some of the reasons hypothesized in the preamble to the data themselves are suspect, and the text excludes reasons that are not neutral and innocuous.

We view this data in the context of:

(1) A very rushed redetermination process where most of the reviews have been done in the space of 4 months when the Congress anticipated a year's duration, Aug. '96- Aug. '97, and has now given SSA 6 more months. This is manifested in disturbing patterns of inadequately developed termination decisions with no or cancelled consultative exams to fill gaps in medical evidence, and based on one or two sources, where the norm for <u>allowances</u> has been multiple sources. Quaere: Why is considerably less documentation needed for cessations than for allowances?

(2) Very few appeals have been filed and even fewer requests honored by your staff for benefits continued pending appeal. The partial corrective steps are too little, too late for over 100,000 terminated children.

(3) Serious defects exist in the very "interim final" rules being employed, as most public commentators and Senators pointed out. Almost no children terminated will benefit from any changes made in these rules that could make them fairer and legal. (You have a deadline for redeterminations, but none for interim rules revisions--a double standard where the losers are disabled children.)

As for the state differentials, a number of reasons given by SSA suggest that there may have been higher continuance rates in the earlier stages of case processing. This can <u>also</u> mean that the cessation rates and differentials will get even worse! Indeed, just between the July 19th data listings and the August 2nd report, Mississippi's cessation rate climbed from 81.7% to 82.1%, and Texas' from 76.5% to 77.7%

Your staff hypothesizes that another reason, "access of children to medical treatment and/medical evidence" will vary "greatly" from state to state. <u>But</u> this ignores the agency's legal responsibility to fully develop the medical and functional evidence wherever the child may be, including Texas, Louisiana and Mississippi. That is the raison d'etre of SSA, to provide uniform and fair evaluations of <u>all</u> claimants. If SSA allowed this inequity in medical treatment to govern--as we are certain it did in the rush to get the job done--then children, especially in these states and others need their claims to be full reviewed with a full development of the medical evidence.

The above are the reasons your staff hypothesizes. Now we present those that they did not deem appropriate for a memo getting wide public dissemination. Many states, especially in the South, but not by any means limited to the South, have a long-standing hostility to these families and to the SSI program. This hostility, which the agency has done little to counter, has tainted the redetermination process. The hostility is a complex joining of brainwashing by local and national media who have pursued irresponsible reporting of the program (see Fall, 1995 <u>Forbes Media Critic</u> article by Chris Georges for documentation); anger that (minority) families have benefited too much from the program; and a misreading of Congress, that these children did not really deserve to be on SSI (in fact Congress did not terminate the program but required new, individualized functional reviews of a minority of the children on SSI). Many of these high cessation states rejected large numbers of children in the past, including after the <u>Zebley</u> decision of 1990 and the new agency rules of 1990 and 1991. If anything, these states should have lower cessation rates given how much harder it was to qualify originally.

Unfortunately SSA has not been as open as we would have liked in the sharing of this data, now received, or in sharing with us at all plans to do supplemental review sampling to flesh out the reasons. For example, the additional sampling focuses apparently on personality disorders, conduct disorders, learning disabilities and ADHD. Yet the agency shows no apparent concern for the 100,000 IFA children diagnosed with mental retardation, as we continually see children with IQ's in the 60's (even in the 50's!) among those terminated. We would ask for much greater involvement in how the agency goes about addressing this and similar problems, including discourse with the Office of Disability and OPIR.

Another area of concern that our colleague Tom Yates in Chicago has flagged is the <u>underutilization</u> of the functional equivalence criteria and the great state variances in its utilization. The agency's preamble text to the data appears to miss this with the summary, defensive assertion that "a significant number of continuances are based on" functional equivalence. (We say defensive because of the rather gratuitous assertion that this then answers "a concern of many commenters on the interim final rules that [functional equals] would be rarely used." Commenters, more accurately, spoke to underutilization not "rarity" of use.) What the agency is now missing is the diverging frequency of use of functional equals. It is perhaps no surprise that many of the highest cessation rate states are <u>also</u> low utilizers of functional equals. Thus, functional equals as a percentage of total continuances places Texas at 13%, Illinois at 13%, Mississippi at 11%, compared to Pennsylvania where 28% of its continuances were functional equals (and Pennsylvania had a much lower total cessation rate). We are thus disturbed that this variance in functional equals utilization has not caught the concern of the agency.

The Failure to Cooperate (FTC) group of 7,670 children is especially suspect, and these children should all be reviewed immediately because each case is a child's and you must agree that since cooperation falls with an adult or agency in every case, a FTC termination is by definition unfair and unconscionable for the child. Simply doing some sampling, as is planned, to see whether an "attempt" to identify and contact another agency or adult has been made, is grossly inadequate.

Further, what will happen if the sampling shows shortcomings? Will SSA commit to a remedial process to be triggered if the sample shows a certain percentage of shortcomings or will the agency wait to see what spin it can put on whatever rate turns up? In <u>every</u> case another actual contact should be made and written reasons provided to headquarters if that new contact proves unwilling to cooperate. If non-cooperation is found, a new representative payee should be named as failure to cooperate is, by definition, an irresponsible rep payee, and the agency has the responsibility to find a new one who is willing to cooperate. We think you will find that FTC was in fact the impatience of the DDS to get the job done quickly ("quick resolution" is the phrase we have been given), and an agency failure to be flexible or understanding of a parent or agency having difficulties in responding. (Consider also that local or state child welfare agencies who are guardians may be ill-prepared to move as quickly as DDS's wanted.)

We suggest at this point that if states show (1) relatively high cessation rates, (2) underutilization of functional equals, and (3) higher use of failure to cooperate, you should suspend all decision-making and immediately start the review of all, not a sample, of children terminated.

To further discern what has happened we would appreciate receiving:

(a) a breakdown by race of the children continued and terminated in each state;

(b) a more detailed mental disorder breakdown by state and nation of children continued and terminated by sub-groupings within the very large mental disorder category; and

(c) the number of children appealing terminations in each state and the number seeking benefits continuing pending appeal. Having spoken to Mrs. Shriver and Marty Ford of The Arc, we all share the need to have this data before the September 3rd meeting with you in Washington.

Thank you for your cooperation.

Sincerely yours,

Jonathan

JONATHAN M. STEIN
RICHARD P. WEISHAUPT

cc: Arthur Fried, Chief Counsel
Joseph Gribben, Associate Commissioner, OPIR
Judy Chesser, Deputy Commissioner
Carolyn Colven, Deputy Commissioner
Susan Daniels, Associate Commissioner, OD
Brian Coyne, Chief of Staff
Ken Apfel, OMB Associate Director
Sylvia Mathews, Deputy Chief of Staff, The White House
Elena Kagan, Deputy Assistant to the President, Domestic Policy
Mrs. Eunice Kennedy Shriver
Marty Ford, The Arc of U.S.
Dr. Robert Cooke
Rhoda Schulzinger, Bazelon Ctr. for Mental Health Law
Patti Smith, National Parents Network
Thomas Yates, SSI Coalition
Deborah Weinstein/Eileen Sweeney, Children's Defense Fund
Julie Justicz, Amer. Bar Ass'n Pro Bono Center
Bruce Bower, Texas Legal Services Center
Rowena Jones, New Orleans Legal Assistance
Rims Barber, Human Services Agenda (Jackson, Miss.)

Enclosure: (August 2, 1997 listings of high cessation states)

Table: SSI Childhood Disability Redeterminations
Cessation Rates of States Above National Average
Cumulative Through 08/02/97

State (DDS)	Init Cease Rate (%)	Total Ceased
Mississippi	82.1	4,078
Montana	78.6	293
Texas	77.7	6,017
Louisiana	76.1	6,892
Kansas	75.7	1,567
Iowa	75.9	945
Arkansas	74.4	2,924
Oklahoma	72.9	730
Tennessee	69.6	2,347
Illinois	71.0	6,461
Rhode Island	68.7	424
Missouri	70.1	3,367
Alabama	69.2	2,748
South Carolina	66.8	1,793
Nebraska	65.6	441
Georgia	65.3	2,040
West Virginia	64.1	962
Alaska	54.5	60
North Dakota	61.7	71
New Mexico	64.1	508
Indiana	60.8	2,233
Ohio	60.0	3,922
Idaho	56.0	520
New York	58.4	9,898
Wisconsin	58.3	2,051
New Hampshire	56.4	119
National Totals = 55.9		95,180

Source: Social Security Administration