NLWJC - Kagan
DPC - Box 056 - Folder-014

Social Security - Children's Disability Standard [1]

social security -
children's disability
standard

[redacted]

Record Type: Record

To: Elena Kagan/OPD/EOP

cc: Cynthia A. Rice/OPD/EOP, Laura Emmett/WHO/EOP
Subject: children's ssi

Sylvia's assistant Nelson Reyneri is giving her an update today at 1:15 on where SSA is on its children's SSI report, and he asked me to come along to help. Hope this is OK with you.

Just to bring you up to speed: Basically, the content of the report looks good. It is similar to what we heard last month. SSA concludes that overall they did a good job on the redeterminations of children's eligibility, but they identified three problem areas that they will address: mental retardation, accuracy of redeterminations in some states, and appeal rights. As a result, they will review the cases of approximately 60,000 children who were cut off, and give all of the 75,000 families who didn't appeal or request continuation of benefits during an appeal a new opportunity to do so. The big remaining issue is that the report is not written well. It does not provide clear answers to the most obvious questions, and it is overly defensive in many places. So we are pointing out problem areas to them.

Timing-wise, they hope to release it next week or early the week after. Sylvia doesn't want it to go too late.

Social security - children's
disability standard

[redacted]

Record Type: Record

To: Elena Kagan/OPD/EOP

cc: Cynthia A. Rice/OPD/EOP, EMMETT_L @ A1 @ CD @ LNGTWY
Subject: SSA report on children

Ken has revised his plan again, so that they will NOT review all cases. I am just getting a copy, so I'll keep you posted.

Social security -
children's disability standard

[redacted]

Record Type: Record

To: Barry J. Toiv/WHO/EOP, LUZZATTO_A @ A1 @ CD @ LNGTWY

cc: Laura Emmett/WHO/EOP, Cynthia A. Rice/OPD/EOP
Subject: Q&A's and backgrounder on children's SSI

SSA released this report today at 5pm. I hear it went well; in fact, the Arc, an advocacy group, did a release praising SSA's actions (although still criticizing the overall standard of disability we have adopted). As I told Barry, Robert Pear is writing this story for the Times tomorrow, and he may report that SSA was prepared to go further in terms of reviewing kids whose benefits were terminated, but the White House pulled him back.

One document is Q&A's; the other is more background than you'll possibly want. Also, I forwarded you paper from SSA that is pretty good. I'm supposed to go to Florida tomorrow; if I do and you need something, Elena Kagan is up to speed, as is OMB.

ssiq&A.wpd ssabkgd.wp

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

Children's SSI Report

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

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

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

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

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

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

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

SSA Report on Childhood Disability Process
Summary for Internal Use Only

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

I. Mental Retardation

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

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

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

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

II. State Variations in Cutoffs

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

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

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

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

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

III. Appeal Rights

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

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

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

Social security –
children's disability standard

[redacted]

Record Type: Record

To: Elena Kagan/OPD/EOP, Nelson Reyneri/WHO/EOP, Cynthia A. Rice/OPD/EOP, Laura Oliven Silberfarb/OMB/EOP

cc: Laura Emmett/WHO/EOP
Subject: FYI, I did the attached chart...

describing the 151 children case study that SSA will release the same day as their report. It shows the diagnoses of kids cut off -- overwhelmingly mental disorders other than mental retardation, such as ADHD, learning disabilities, conduct disorders, etc. I think it's probably too detailed to attach to the memo to the President, but it's interesting.

151.wpd

Children's SSI Terminations -- Sample of 151 Cases

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

Social Sec –
Children's Disability
Standard

Diana Fortuna
12/15/97 08:07:00 PM

Record Type: Record

To:

cc: Laura Emmett .
Subject: SSA report on children

Message Creation Date was at 15-DEC-1997 20:07:00

Ken has revised his plan again, so that they will NOT review all cases. I am just getting a copy, so I'll keep you posted.

Social security –
childhood disability
standard

THE WHITE HOUSE
WASHINGTON

December 16, 1997

MEMORANDUM TO THE PRESIDENT

THROUGH: Sylvia Matthews

FROM: Bruce Reed
Diana Fortuna

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

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

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

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

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

In all, SSA will review the cases of 48,000 children dropped from the program. (Another 70,000 have appealed.) As a result of these actions, SSA now projects that approximately 100,000 children ultimately will lose SSI benefits.

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

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

SSA Report on Childhood Disability Process

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

I. Mental Retardation

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

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

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

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

II. State Variations in Cutoffs

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

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

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

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

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

III. Appeal Rights

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

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

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

Social security –
children's disability
standard

[redacted]

Record Type: Record

To: Elena Kagan/OPD/EOP

cc: Laura Emmett/WHO/EOP
Subject: New version of children's SSI memo for you to review

Here is a revised children's SSI memo incorporating Ken Apfel's comments. (Sylvia asked me to run it by him.)

Sylvia asked that it be completed by 2pm on Saturday. I will come in in the late morning, but feel free to page me with questions or whatever. Not clear who it will be from -- her assistant Nelson Reyneri suggested that it come via Sylvia from some combination of me, you, and him.

The other issue is OMB. They have OK'd it for accuracy at the staff level, but I suspect Jack will feel left out of the loop since he hasn't commented on it yet and his name isn't on it. It is on its way to him, so perhaps he will have comments tonight or tomorrow. Also, I hear Barry White feels the memo is premature, since the details of SSA's report are not yet final and the presentation still needs work. But Sylvia wanted to get it in this weekend because he is more likely to read it at that time.

ssa.wpd

MEMORANDUM

FROM:

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

DATE: December 5, 1997

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

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

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

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

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

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

SSA Report on Childhood Disability Process

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

I. Mental Retardation

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

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

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

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

II. State Variations in Cutoffs

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

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

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

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

SSA Action: In the ten states with the lowest accuracy rates, SSA will review all cases terminated. In states with below average accuracy rates, SSA will review a sample of cases to see if additional reviews are needed. SSA will also provide more training on maladaptive behavior. In states with above average rates of cutoffs due to failure to cooperate, SSA will review all cases terminated.

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

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Soc Sec - Children's Disability

THE PRESIDENT HAS SEEN
12-17-97

'97 DEC 16 PM7:04

THE WHITE HOUSE
WASHINGTON

December 16, 1997

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MEMORANDUM TO THE PRESIDENT

THROUGH: Sylvia Matthews

FROM: Bruce Reed
Diana Fortuna

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

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

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I. Mental Retardation

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

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

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

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

II. State Variations in Cutoffs

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

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

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

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

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

III. Appeal Rights

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

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

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

EXECUTIVE OFFICE OF THE PRESIDENT
OFFICE OF MANAGEMENT AND BUDGET

ROUTE SLIP

TO ELENA KAGAN	Take necessary action	☐
	Approval or signature	☐
	Comment	☐
	Prepare reply	☐
	Discuss with me	☐
	For your information	☑
	See remarks below	☐

FROM JOANNE CIANCI x53385 DATE 12/17/97

REMARKS

Revised SSI Kids Report

OMB FORM 4
Rev Aug 70

Soc Sec -
Children's
Disability

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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" 38,392
First step of reconsideration process.

Continued on Paper Review 4,644
12.1 percent
Cases cannot be ceased at the first step of (of
cases
the reconsideration process.
considered)

Still Pending Paper Review 29,554

Cases Sent to Disability Hearing Officer 33,748
(DHO) Second step of reconsideration
process.

DHO Reconsideration Determinations 4,632
as of November 1, 1997

Continued 792 17.1 percent
(of cases

considered)

Ceased 3,840 82.9 percent

Still Pending DHO Determination 29,116

Total Reconsideration Determinations 9,276
(Paper Review and DHO)

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	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

Talking Points

New York Times Article on SSI Children's Regulations

August 15, 1997

Main Points

- As the New York Times noted today, 95,000 children are no longer eligible for SSI benefits under the Social Security Administration's regulations.

  – The 95,000 is about half of the 180,000 cases that SSA has reviewed as of August 2, 1997

  – SSA still needs to review another 85,000 cases.

  – The initial reviews should be completed by early October.

- Those SSA regulations are designed to implement last year's welfare reform law.

- While these early figures suggest that SSA's initial estimate that 135,000 children would lose their benefits may be exceeded, you have to remember:

  – SSA cautions that this early data is not representative and should not be used for projections.

  – Moreover, a portion of these children will appeal their cases and be found eligible once their cases have gone through SSA's normal appeals process.

- To minimize the adverse effects of the law (and its regulations), the Administration convinced Congress in the recent balanced budget law to retain Medicaid coverage for those disabled children who are kicked off the SSI rolls.

  – Without such action, many of these children would have lost Medicaid as well.

Background

- Last year's welfare law, enacted on August 22, 1996, tightened the eligibility standards for childhood disability benefits in the Supplemental Security Income (SSI) program.

  -- The legislation could have been much worse.

    -- Initial Republican proposals in early 1995 would have eliminated cash benefits for 80 percent of future applicants, replacing the cash with State block grants to provide services at much reduced funding levels.

    -- In the final bill, the Administration managed to maintain the SSI childhood disability program as a cash benefit program for all those children found eligible.

- SSA released regulations on February 6, 1997, to implement the new law.

  -- These regulations were prepared by SSA under the supervision of then-Commissioner Shirley Chater.

  -- They were reviewed by OMB and the DPC as part of the normal regulatory review process.

- Soon thereafter, SSA notified 264,000 children of the nearly 1 million children receiving SSI benefits that they might be affected by the new law and that their cases would be reviewed.

- At the time the regulations were issued, SSA estimated that 135,000 children would have their benefits terminated as a result of the tighter eligibility standards.

- SSA's regulations adhered to its reading of Congressional intent, but also provided several new procedures (that the law did not specify) to ensure continued eligibility for severely disabled children.

  -- SSA estimated that, without these new procedures, approximately 190,000 children would lose benefits.

- As the New York Times noted today, 95,000 children have been found no longer eligible as a result of initial determinations.

  -- About 180,000 cases have been reviewed as of August 2, 1997, with another 85,000 cases still to be reviewed.

  -- The initial reviews should be completed by early October.

- While the majority of cases involve mental impairments, it is too early to definitively classify the nature of the disabilities of the children being effected.

– However, SSA is monitoring the results of these redeterminations.

– No children who are mentally retarded as that term is clinically defined are losing benefits.

– Children with mild learning disabilities and attention deficit disorder appear to be the types of children most affected.

Social Security - Children's disability standard

Diana Fortuna
08/14/97 07:01:55 PM

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Record Type: Record

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

cc:
Subject: Possible story tomorrow on cutoff of kids on SSI

SSA thinks there may be stories in tomorrow's NY Times or through AP on the cutoff of children from SSI. THey don't seem to know much more about it. We had assumed that the new law would cut off 135,000 children. The data I've seen to date suggests that was a pretty good guess. Some of the advocates have charged that SSA is not doing everything it could administratively to make it easier for these families to stay on the rolls. A surprisingly low percentage are appealing, and the advocates think SSA may be discouraging -- or at least not encouraging -- appeals.

Social Sec - Children's Disabil Standard

Diana -
FYI.
Elena

COMMUNITY LEGAL SERVICES, INC.

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

August 5, 1997

Senator Daniel Patrick Moynihan
SR-464
Washington, DC 20510

Re: SSI Disabled Children Terminations

Dear Senator Moynihan:

A pattern of arbitrary and unfair terminations of disabled children on Supplementary Security Income is emerging now that over 80,000 children have been terminated and over half the redeterminations completed by the Social Security Administration.

In New York State, where over 26,000 disabled children are being reviewed, over 10,000 have already received terminations of 19,000 children reviewed so far. The following six year old, upstate, NY, child is one of these 10,000:

"G. A." was born HIV-positive and began receiving SSI in 1993 under the care of his grandmother, "M. A.", now 61 years of age. He is reported to have AIDS now and is treated at the Strong Memorial Hospital; he also has mental retardation, an IQ of 62; along with developmental delays, repeated infections, and Attention Deficit Hyperactivity Disorder. Surgery for a colostomy set him back, preventing completion of the Headstart program, and he is now repeating the 1st grade in a special education class.

Young "G. A." joins many other children with indisputably severe disabilities who have been cut: a Philadelphia child, La'Shaira Cooke, with "brittle diabetes" requiring 24 hours day monitoring by the mother (the facts of which were used by SSA as an "example" of a child who would "remain eligible"); a Louisiana 10 year old, Tevis Sally, with mental retardation, depression, and a severe, perhaps organic eating disorder making him 100 lbs. overweight; an 11 year old Burlington, Vt. boy, Sam, who functions at a kindergarten level, with severe emotional/behavioral problems, a language disorder, ADHD (and a mother with breast cancer and a father paralyzed in a wheelchair); and a North Carolina child with severe, profound mental retardation, who is non-ambulatory and non-verbal.

The SSI killing fields are upon us. The causes are:

1. The Administration's interpretation of the new child disability test, which does not reflect congressional intent, particularly the moderate Senate language pressed by Sens. Chafee, Cohen and Conrad, ultimately adopted, that did not require so-called Listings-level severity as the test. Only 45,000 children would have been cut with this reasonable alternative.

2. Other defects in the "interim final" regulations criticized widely in public comments that SSA, so far, has ignored, e.g. inadequately evaluating multiple impairment children, arbitrarily conflating or ignoring "areas" of child functioning, and not applying universally accepted Standard Errors of Measurement to objective tests used.

3. Systemic problems in the review processes, e.g., rushing the reviews through without full development of the record to meet an arbitrary and now legislatively extended, August 22nd deadline (the extension coming too late for those arbitrarily cut); failure to obtain needed information from parents and to utilize Consultative Examiners where appropriate; etc.

4. With only 1 in 5 families appealing terminations, SSA has both deterred appeals through misinformation given to parents around the country that they would have to pay the SSI back if they lose (failing to adequately explain waiver of overpayment rights), and not taking steps to assist families, who are poor and not well educated, to appeal terminations such as by listing phone numbers of helpful non-profit agencies on the termination letters, making personal contact with families who could appeal, reminding DO staff to liberally construe "good cause" for a delayed appeal, etc.

Families and advocates for these children urge you to intervene now to protect the many disabled children already terminated in New York State and elsewhere and to be cut in coming months, and have the Senate Finance Committee immediately address this national crisis. Thank you for your attention to this pressing matter.

Sincerely,

JONATHAN M. STEIN
General Counsel

cc: Mark Patterson, Minority Staff Director and Chief Counsel, Senate Finance Committee
Doug Steiger, Minority Staff, Senate Finance Committee
Ken Apfel, Associate Director, OMB
Sylvia Mathews, Deputy Chief of Staff, The White House
Elena Kagan, Ass't to the President, The White House
John Callahan, Acting Commissioner, Social Security Administration
Brian Coyne, Chief of Staff, SSA Commissioner
Judy Chesser, Deputy Commissioner for Legislative and Congressional Affairs, SSA
Mrs. Eunice Kennedy Shriver
Marty Ford, The Arc

Social Security - children's
disability standard

Elena Kagan
08/02/97 06:04:39 PM

Record Type: Record

To: Sylvia M. Mathews/WHO/EOP

cc:
Subject: Re: SSI

Stein has some ideas that seem very reasonable about informing families losing SSI of their appeal rights, providing them with information on pro bono representation, allowing more good cause exceptions to appeals deadlines, etc. These should clearly be things that come from SSA rather than the White House; I would be reluctant to tell Stein even that we have asked SSA to look into them. But in fact, we have asked the key folks at SSA to take a hard look at these suggestions and to let us know what they think of them. In all honesty, we are unlikely to make real progress on these matters until Ken Apfel gets to SSA -- but Apfel will be great on issues like this.

Diana Fortuna
07/22/97 06:50:33 PM

Record Type: Record

To: Elena Kagan/OPD/EOP
cc:
bcc:
Subject: Re: SSI

Stein's memo suggests several administrative actions SSA could take to make it more likely that families take advantage of their appeal rights. These include calling families, particularly those who are appealing but not exercising their right to have benefits continue during the appeal; telling families how to get pro bono legal services; allow more "good cause" extensions to the appeals deadlines; giving state agencies the names of those cut off so they can assist them.

Some of these sound like good ideas, but they are clearly the types of things that SSA should make the call on. So we think we need to ask them what they think. I can call them if you want.

In terms of a formal response to Stein, we are simply cc'd, so originally I didn't think we needed to respond. But Sylvia's note suggests perhaps we should. If SSA takes some of these actions, I'm not crazy about taking credit for them and undercutting SSA, since among other things that will encourage him to come to us for help. If you were looking for something symbolic, we could make a more formal request of SSA to evaluate these ideas....

In my experience, pushing SSA a bit to look at suggestions like this can be productive.

Elena Kagan

Elena Kagan
07/21/97 07:32:22 PM

Record Type: Record

To: Diana Fortuna/OPD/EOP

cc:
Subject: SSI

what's my answer to this question?
---------------------- Forwarded by Elena Kagan/OPD/EOP on 07/21/97 07:34 PM ---------------------------

Sylvia M. Mathews
07/21/97 04:11:02 PM

Social Security - Children's Disability
Standard

Diana Fortuna
07/12/97 07:18:10 PM

Record Type: Record

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

cc: Cathy R. Mays/OPD/EOP
Subject: Draft response to 10 Senators on children's SSI cuts

Below for your review is a draft response from Bruce to 10 Senators who wrote the President to complain that SSA's regulation to implement the children's SSI cuts is too strict and does not reflect what Congress intended. The Senators are Conrad, Chafee, Kennedy, Harkin, Rockefeller, Jeffords, Baucus, Leahy, Dodd, and Daschle.

I took advantage of the opportunity to note that the Senate has failed to include our budget agreement proposal to grandfather Medicaid for these children.

Please let Cynthia know of any changes in my absence.

July 14, 1997

Dear Senator --:

Thank you for your letter to the President regarding the children's SSI provisions of the welfare reform law.

The Administration is working to implement the new law fairly and effectively, including the children's SSI provisions. The President has asked the Social Security Administration to ensure that the eligibility review process now underway allows eligible children to demonstrate that they meet the new definition of childhood disability, and that all appropriate appeal rights are provided to affected families. The Administration believes that SSA's regulation is entirely consistent with the Congress's intent in the welfare reform law.

As you know, as part of the balanced budget agreement, the President fought for and won inclusion of his proposal ~~to proposal~~ to grandfather Medicaid coverage for all children now on the rolls who do not meet SSI's new definition of childhood disability. The House reconciliation bill allows, but does not require, states to provide Medicaid benefits for these children, while the Senate bill does not include this proposal at all. The Administration urges the conferees to conform to the budget agreement in this critical area and guarantee continued Medicaid benefits for these 30,000 children.

Thank you for your letter on this critical issue.

Sincerely,

Bruce Reed
Assistant to the President

Social Security - Children's Disability Standard

Diana -
FYI.
Elena

COMMUNITY LEGAL SERVICES, INC.
Interoffice Memorandum

TO: JOHN CALLAHAN, BRIAN COYNE, ARTHUR FRIED, JUDY CHESSER
SUSAN DANIELS, SOCIAL SECURITY ADMINISTRATION

FROM: JONATHAN STEIN and RICHARD WEISHAUPT

DATE: JULY 17, 1997

RE: IMMEDIATE STEPS SSA COULD TAKE TO ASSIST SSI FAMILIES WITH DISABLED CHILDREN TO APPEAL TERMINATIONS

Only 10-15% of families are appealing SSI child disability terminations, which apparently has surprised those in the Administration who had assumed (and planned) that many more families would appeal. Far fewer we believe are "opting" for benefits continuing during the appeal. The latter is an absolute constitutional right, being undermined, as we have documented, by local SSA practices of discouraging this option. (This low appeals experience confirms our own earlier predictions and the recommendations we made earlier to prevent this from happening.)

Without an appeal the family obviously cannot receive fairer treatment by having a personal hearing before an adjudicator, or preventing irreparable harm from an erroneous termination. The initial redetermination process lacks any personal appearance before a decision-maker prior to the termination, a scenario that you might agree is Kafkaesque.

This is a national crisis given the fact that over 50,000 children have already been terminated with many more to come. Yet it is not too late for SSA to take immediate steps to remediate this situation, which we suggest below:

1. Personal calls/contacts to families: Every family who has been or will be terminated should be personally contacted and informed that they have a right of appeal and how they can easily exercise it. Note: Past SSA Commissioner Gwen King instituted this in the late 80's for mentally ill and homeless client adverse action decisions. The current crisis demands similar action.

2. Add to termination letters state/local "800" numbers of non-profit/pro bono groups and name these groups in letters: We have long made this suggestion, and the American Bar Association is sending the "800" numbers available in about two dozen states. Local non-profit groups available in every state are legal aid and

Protection & Advocacy offices (available from the LSC or NLADA, and the Nat'l Ass'n of P. & A. Systems, all in D.C.).

3. Honoring the constitutional right to have benefits continue pending appeal and remedying documented practices of SSA employees discouraging the exercise of this right:

a. immediately instruct SSA staff to encourage exercise of this due process right and explain that a person has a statutory right to a waiver of overpayment (law says "there shall be no adjustment...") if the parent is not at fault; this is not happening now.

b. for all those appealing without benefits continued SSA should immediately write to them informing them of this right and the new, clarified waiver rights language. (We believe, given the widespread failure to advise about the waiver right, that a Federal Court would at a minimum include this in injunctive remedial relief.)

c. SSA should also immediately instruct SSA staff that "good cause" grounds to excuse 10 day late or 60 day late appeals should be liberally construed, with illustrations specific to the lives of these families. (SSA issued this clarification for drug and alcohol addiction but has not, so far, for children's cases.)

4. Share names of terminated children with state agencies now: In conformity with the excellent and caring letter of the Acting Commissioner to Governors of May 22, 1997, informing states that names of children reviewed can be shared with states, SSA should make clear and pro-actively provide to each state now the names of all children already terminated, and, concurrently with future terminations, the names of other children who will be cut. The Commonwealth of Pennsylvania, for example, has for some weeks wanted these names, so that welfare dept. staff can call each of these families to assist them with appeals and retaining their Medical Assistance.

We would be most happy to sit down with you at the earliest convenience to address these matters. Thank you for you anticipated cooperation.

cc: Ken Apfel/Franklin Raines, Office of Management and Budget
Sylvia Matthews/Erskine Bowles, Office of Chief of Staff
Elena Kagan/Bruce Reed, Domestic Policy Council
Senator John Breaux
Senator John Chafee
Senator Kent Conrad
Senator Christopher Dodd
Senator Charles Grassley
Senator Orrin Hatch
Senator Jim Jeffords

Social Security –
Children's Disability
Standard.

► **Diana Fortuna**
07/11/97 12:38:15 AM
• • • • • • • • • • • • • • • • •

Record Type: Record

To: Elena Kagan/OPD/EOP
cc: Cynthia A. Rice/OPD/EOP, Laura Emmett/WHO/EOP
Subject: Children's SSI question

You were cc'd on a letter to Sylvia from Jonathan Stein, the disability advocate who came in with Eunice Shriver to lobby us on SSA's interpretation of the new childhood disability standard. You forwarded it to me with the following question: "Where are we on this? is there any chance at all at any point of changing our minds?"

The advocates have 2 levels of change they are seeking, which they mixed together at our meeting. The first is a very major step, to change the standard from "2 marked impairments" to "1 marked and 1 moderate impairment. This is a huge issue that we went over in incredible detail after the law was signed, and I don't think we would change our minds on it. SSA feels strongly that 2 marked is the better standard, as does OMB. When we made the decision, Bruce was very concerned that we would provoke a Republican backlash because we moderated the 2 marked standard in a way that cost a billion or two. By the way, if we were now to go all the way to their position, it would cost $4 billion over 5 years.

At the meeting, they also offered 3 more modest ideas (allowing a standard error of measurement for IQ tests; adding a new domain for children under 3; and finding a way to reflect the fact that cognitive and communication impairments are sometimes separate). The first is really just a way to lower the standard -- it would also be expensive and definitely provoke a bad reaction from the Hill. The other 2 are potentially meritorious, although they would cost something. We have asked SSA to evaluate them, including their costs; but SSA's position is that they don't want to consider changes to the standard until they get through the 260,000 cases they are reevaluating. OMB agrees. There is a certain logic to this, since they are under time pressure, and because it seems odd to start changing the rules of the game this early. And yet if these ideas make sense, the sooner you implement them the better. I will push SSA to evaluate this more, to at least cost them out, and figure out whether they could set cases on the margin aside as they go through their reevaluations.

Great

Social Security –
Children's Disability Standard

July 10, 1997

To: Bruce, Elena, Cynthia

Fr: Diana Diana

Attached is a Time Magazine story on the upcoming cutoffs of children on SSI. It's possible we'll see more stories in the coming weeks, since the cutoffs are starting this month. I hear ABC World News Tonight may do one soon.

Our guess is 135, 000 kids will lose benefits. The data from the field so far are inconclusive as to how good a guess that was. SSA is supposed to be done with its redeterminations by August 22, but both the House and Senate propose to give them a 6-month extension, which they need.

A few things to bear in mind that this story gets wrong and others may as well:

- Kids won't lose speech training and medicine if the final reconciliation agreement includes the budget agreement's plan to grandfather Medicaid for these kids. Right now, the Senate does not include this, while the House allows but does not require states to grandfather Medicaid for these kids. But we are fighting for it. (Also, special ed would probably pay for speech training.)

- The advocates raise the spector of institutionalization, but that seems very unlikely for these kids, who are not severely disabled enough to justify being institutionalized. It's harder to dismiss the risk of foster care.

With the President having moved such a distance, what is there left to fight about? Plenty, it turns out, and in the p.r. battle, Clinton seems to have the advantage. For one thing, a narrow plurality of the public say they have more confidence in Clinton than in congressional Republicans on the tax issue, according to a CNN/*USA Today*/Gallup poll released last week. Clinton's 43%-to-40% edge is a startling turnaround in comparison with shortly after the 1994 election, when the public that had handed control of Congress to the Republicans rated the party 22 points ahead of the President on handling the issue. The change partly reflects the verdict of most independent analysts, who say Clinton's measure is a better deal for the middle-class taxpayer than what the House and the Senate are offering. And when the argument turns to the details of the various proposed tax breaks, Clinton has positioned himself as the champion of hardworking parents: while he pushes his education tax credits, for instance, the same Republicans who wanted to close the Education Department will be fighting to index capital-gains taxes so that investment profits can be insulated from inflation.

The stickiest issue to resolve between Congress and the White House is the question of whether low-income workers should get the $500-per-child tax credit. Republicans will argue that refunding these Americans more than the amount they pay in income taxes is not a tax cut but welfare. So Clinton operatives are scouring key congressional districts for real-life examples of such "welfare" recipients, lining up teachers, police officers and social workers. Clinton can also point out that the Republicans themselves, in their Contract with America, advocated giving the tax credit to the working poor. It's not hard to figure out who wins that fight.

Republicans have begun to contemplate the scenario that is their ultimate nightmare: "He could get away with vetoing a Republican bill and saying he wanted his kind of tax cuts and win," says David Mason, the conservative Heritage Foundation's leading congressional scholar. "I could get in trouble with my Republican friends for saying so, but it's true." No wonder there are few G.O.P. voices still arguing for confrontation. As a Republican strategist put it, "The fact is, we're going to have to share credit with this guy. Then again, he's not on the ballot in 1998, and Republicans in Congress are." An odd consolation for a party that rode to power in 1994 by turning a congressional election into a referendum on the President. *—With reporting by John F. Dickerson/Washington*

Are The Cuts Unkind?

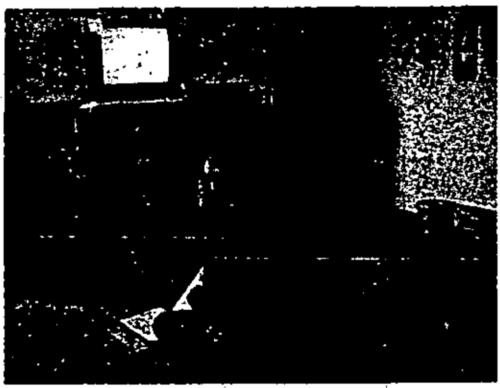
New rules may halt benefits to more than 100,000 disabled children. What will happen to them now?

SHIRLEY ESHELMAN IS PHYSICALLY DISabled, but she manages to work small miracles for her 12-year-old son Jonathan, who is emotionally disturbed and has learning difficulties. And she does so on a family income of just $241 a week. She stretches a $30-a-month grocery budget by planting a large vegetable garden outside her home in rural Middletown, Md., and by taking Jonathan to a food pantry where they volunteer in exchange for food. She sets aside money in meticulous expense ledgers for Jonathan's outings with a local teacher who teaches him socialization skills, and a little more for his twice-monthly speech therapy. But the Eshelmans' world may be on the brink of collapse because of new federal rules that could take away Jonathan's $74-a-week disability check. "It's frightening," says Eshelman, who is worried that with her two-person household's income cut almost a third, she won't be able to meet her house payments, and she and her son will end up homeless. "I really don't know what we would do."

Jonathan is one of 264,000 low-income, disabled children nationwide whose Supplemental Security Income benefits, averaging $424 a month, are being reviewed for possible termination. The reviews are being conducted under new rules, adopted in last year's overhaul of th welfare system, that significantly tighte the program's definition of disability. S far, 42% of children whose cases have bee reviewed under the new rules national have been found ineligible; some starte losing benefits last week. Jonathan's revie ended with a request for him to submit fu ther evidence of his disability—a sign, h mother fears, that he may be on the verge of being cut off.

ON THE BRINK

THE ESHELMANS of Maryland, a disabled mother and her son Jonathan, could be made homeless by new children's disability rules. Jonathan's $74 a week in benefits is nearly a third of the family's income



ANDREW LICHTENSTEIN—SYGMA FOR TIME (2)

The move to slash children's disability in part budget driven: the governmen estimates that the new eligibility rule could save $4.7 billion over six year But the program's critics contend has been abused by families whos children are not truly disabled. "Th standards are vague and easily met says Representative Jim McCrery, Louisiana Republican and supporte of the new rules. "Some people regar it as just a super welfare program The assault on children's SSI bega three years ago, when a spate of new reports carried charges that parent were coaching children to act ou mental disabilities. Among these wa a 1994 story on ABC's *PrimeTime Liv* titled "Crazy Checks," which offere anecdotal evidence of cheating i what it called "a government progra gone haywire." In time the charges were largely dismissed by four sepa rate investigations, including the Social Security Administration's own which found "no evidence" of widespread parental prompting. But these investigations received little attention, and skepticism in Congress remained strong.

What will happen to those who lose SSI? Many will have to give up treatments ranging from speech training to medicine. Others may end up homeless, since SSI families are poor and the check is a large percentage of household income. And some families may be torn apart. Organizations like the Arc, formerly the Association for Retarded Citizens, say they have been inundated with calls from parents afraid they will have to give up their children to foster care or institutionalization. "People tell us this is what's holding their family together," says Arc spokesman Marty Ford. "If you pull this card out, the whole house falls down." *—By Adam Cohen/Middletown*

Not if we get our provision to grandfather Medicaid.

Social Security –
Children's Disability
Standard

COMMUNITY
LEGAL
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June 12, 1997

Sylvia Mathews
Deputy Chief of Staff
West Wing
The White House
Washington, D.C. 20502

Re: SSI Disabled Children

Dear Sylvia,

We have recently obtained the enclosed SSA memordandum, explained in more detail by my also enclosed cover memo, which shows that there has been a reasonable policy available--a middle course between the old IFA test and the Listings of Impairments--to implement the SSI provisions of the new welfare law.

The SSA memo not only lays out this policy (cutting 45,000 children this year), but also critiques the "alternative" policy, since adopted in the "interim final" rules of Feb. 11, 1997, as one that does not follow the intent of the Congress and prevents "seriously disabled children" from now qualifying.

The host of Senators who have written to the President have criticized the "interim" rules on the same grounds as is found in this SSA policy memorandum.

I would appreciate your response, as I believe that this document may not have been made available to the White House when the decision on these rules were made earlier.

Sincerely,

JONATHAN M. STEIN
General Counsel

cc: Frank Raines, OMB Director
Elena Kagan, Deputy Assistant
to the President

Encl.

cc: Diana (return) –
Where are we on
this? Is there any
chance at all –
at any point –
of changing our minds?
Elena

COMMUNITY
LEGAL
SERVICES, INC.

1424 CHESTNUT STREET
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TO: Friends of SSI Disabled Children

FROM: Jonathan Stein, General Counsel

DATE: June 11, 1997

RE: SSA's Critique of Its Own SSI Child Disability Policy Adopted in the Feb. 11, 1997 Interim Final Rules

SSA prepared in late 1996 a memorandum that explained why the new SSI child disability policy published as "interim final" rules in February 1977 did <u>not</u> reflect the intent of Congress and would preclude "seriously disabled children" from remaining eligible under the Administration's interpretation of the SSI provision of the new welfare law. The latter eliminated the prior Individualized Functional Assessment rules, substituting in the statute a new eligibility test of "marked and severe functional limitations," and requiring the redetermination of about 260,000 IFA children under the new standard.

The document, attached, was prepared pursuant to Executive Order 12866, which requires an assessment of costs and benefits of the policy adopted and policy alternatives rejected with a rationale attached with each. The document was obtained pursuant to a Freedom of Information Act request duly filed.

The memorandum (with an April 23, 1997 cover memo explaining that the memo's "development ended on 1/27/97," two weeks before Federal Register publication of the "interim final" rules) reveals that the main policy proposed would have cut but 45,000 children among the 260,000 being redetermined this year and "save" $1.3 billion over time. (pp. 5-60) (Under this proposal close to 250,000 children would be cut or denied at application over 6 years.)

This policy was the middle course between the old IFA test and the extreme medical Listings of Impairments (e.g. requiring an IQ below 59 to qualify for mental retardation) that many Senators, including the key Senators who framed the final provision adopted, had urged the Administration to adopt. (These Senators were Chafee, Conrad, Jeffords, Harkin, Daschle, Kennedy, Rockefeller IV, Dodd, Baucus, and Mosely-Braun.)

The memo is significant in that on page 8 it offers a detailed critique of an alternative, to be adopted in the interim final rules. SSA has stated that this latter policy will cut 135,000 disabled children now, and over 6 years will cut or deny on application close to 800,000 children. Advocates believe that this is a major undercount of children to be cut, given the extreme Listings-level disability severity threshold of the new policy. We believe that a large majority of the children to be reviewed will be terminated.

The attached SSA memorandum thus reads:

> "This alternative is based primarily on a listings-level interpretation of the intent of Congress and legislative history with an expansion of the motor domain to try to cover seriously disabled children who were not the target of the legislation. <u>We do not recommend this option because we believe that Congress did not explicitly mandate a listings-level standard when it defined disability in terms of "marked and severe functional limitations". Also, the expansion of the motor domain will cover some of the seriously disabled children, it is not sufficient to cover all of those who were eligible under the previous rules for SSI benefits based on disability.</u>(The word "all" emphasized in original.)
>
> "We need to be clear about the listings we use in the disability process. <u>The listings were never intended to be more than a screening device in the evaluation process to identify many disabled individuals. They were never intended to be the sole criteria for determining disability, and they were never intended to cover all possible serious disabilities.</u> Therefore, we determined that this alternative was not potentially effective nor reasonably feasible.

This Administration analysis above, directly comports that the views expressed by the various Senators who wrote to the President following publication of the "interim final" rules. The Senators wrote: "...(T]he Administration has misinterpreted the intent of Congress in reforming the SSI program for children with disabilities....Congress never intended and did not require this [listings or equivalent] level of severity. SSA thus ignores the law, floor debate, and the history of the program." Letter of April 14, 1997 from Sens. Chafee, Conrad, Jeffords, Daschle, Baucus, Leahy, Dodd, Kennedy, Rockefeller, and Harkin.

The Administration has not as yet responded to this letter or to the plethora of critical public comments of these rules now being employed to terminate or deny children seeking aid.

Attachment

April 23, 1997

NOTE TO THE FILES:

The attached document is an assessment of the potential costs and benefits of an alternative regulatory action which was considered in the development of the interim final rules published in the Federal Register on February 11, 1997, at 62 FR 6408, which were effective beginning April 14, 1997. This alternative was not adopted by SSA.

Development of this document ended on 01/27/97, and the data contained in this document does not, in some cases, reflect the final figures used for the assessment for the alternative which was adopted.

Daniel T. Bridgewater

Daniel T. Bridgewater
Legal Assistant, SSA

Attachment

SUPPLEMENTAL SECURITY INCOME (SSI)
DETERMINING DISABILITY FOR A CHILD UNDER AGE 18
INTERIM FINAL RULES WITH REQUEST FOR COMMENTS

ASSESSMENT OF BENEFITS AND COSTS TO SOCIETY AND PRESENTATION OF MAJOR POLICY ALTERNATIVES

INTRODUCTION

The Social Security Administration (SSA) has determined that these regulations require an assessment of costs and benefits to society per Executive Order (E.O.) 12866, Regulatory Planning and Review, because they meet the definition of a "significant regulatory action." These regulations also meet the definition of a "major rule" under 5 U.S.C. 801 ff., and this assessment also fulfills the requirements of those provisions as well. In addition, SSA has determined, as required under the aforementioned statute, that these regulations do not create any unfunded mandates for State or local entities pursuant to sections 202-205 of the Unfunded Mandates Act of 1995.

E.O. 12866 includes in its definition of a "significant regulatory action" one which raises novel legal or policy issues arising out of legal mandates, the President's priorities, or the principles set forth in the E.O. Accordingly, a discussion follows of the effect of the regulations and general information on estimated costs and benefits to society.

EFFECT OF THE REGULATIONS

These interim final rules affect the SSI program under title XVI of the Social Security Act (the Act). The SSI program provides a minimum income level for aged, blind, and disabled individuals who do not have income or resources above levels specified in the Act. SSI payments are made from the general fund of the U.S. Treasury and are intended to help provide for food, clothing, and shelter. To the extent that Medicaid eligibility is based on eligibility for SSI under title XVI, these rules also affect the Medicaid program.

These rules implement the childhood disability provisions of Public Law (P.L.) 104-193, the Personal Responsibility and Work Opportunity Reconciliation Act of 1996. Sections 211 and 212 of P.L. 104-193 provide a new definition of disability for children (i.e., individuals under age 18), mandate changes to the evaluation process for children's disability claims and continuing disability reviews (CDRs), and require that disability redeterminations be performed for 18-year-olds eligible for SSI benefits based on disability as children in the month before the month in which they attain age 18.

P.L. 104-193 provides a definition of disability for children separate from that for adults. The "comparable severity" standard in the Act has been repealed and replaced with the following standard:

> (C)(i) An individual under the age of 18 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.
>
> (ii) Notwithstanding clause (i), no individual under the age of 18 who engages in substantial gainful activity (determined in accordance with regulations prescribed pursuant to subparagraph (E)) may be considered to be disabled.

The conference report that accompanied P.L. 104-193 further explained:

> 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. The conferees are also aware that SSA uses the term "severe" to often mean "other than minor" in an initial screening procedure for disability determination and in other places. The conferees, however, use the term "severe" in its common sense meaning.

Thus, the new statutory definition of disability for children requires a child's impairment or combination of impairments to cause more serious functional limitations to be considered disabling than the old law did.

Under the new regulations, the evaluation sequence for determining initial eligibility for a child filing a claim for SSI benefits based on disability is the following:

1. Whether the child is engaging in substantial gainful activity;

2. If not, whether the child has a medically determinable severe impairment or combination of impairments;

3. If severe, whether the child(s) impairment(s) meets or medically equals the severity of a listing in the Listing of Impairments, or whether the functional limitations caused by the impairment(s) are the same as the disabling functional limitations of any listing and, therefore, are functionally equivalent to such listing.

There is no longer a provision in the sequential evaluation process affording each child whose impairment(s) does not meet or equal the severity of a listing an "individualized functional assessment" (IFA) of his or her functioning. In P.L. 104-193, Congress specifically directed that SSA discontinue use of the IFA. However, these rules clarify a number of our current functional equivalence policies to ensure that childhood disability claims are properly evaluated under the new statutory standard.

In addition to the rules required to adjudicate new and pending claims, these regulations also implement childhood disability provisions of P.L. 104-193 that affect the medical improvement review standard used to evaluate the continuing eligibility of children and provisions affecting adults (who are age 18) and who were eligible as children in the month before they attained age 18.

Further provisions concerning childhood disability adjudication are summarized below with references to the relevant sections of P.L. 104-193:

- The Commissioner of Social Security (the Commissioner) was directed to remove references to maladaptive behaviors in the personal/behavioral domain from listings 112.00C2 and 112.02B2c(2) of the childhood mental disorders listings (Section 211(b)(1)).

- The Commissioner was directed to discontinue the IFA for children in 20 CFR 416.924d and 416.924e (Section 211(b)(2)).

- Within 1 year after the date of enactment, we must redetermine the eligibility of individuals under the age of 18 who were eligible for SSI based on disability as of August 22, 1996, and whose eligibility may terminate because of the new law. The cases are to be redetermined using the eligibility criteria for new applicants. The medical improvement review standard in section 1614(a)(4) of the Act and 20 CFR 416.994a, used in CDRs, shall not apply to these redeterminations (Section 211(d)(2)).

- The medical improvement review standard for determining continuing eligibility for children was revised to conform to the new definition of disability for children (Section 211(c)).

- Not less frequently than once every 3 years, we must conduct a CDR for any childhood disability recipient eligible by reason of an impairment(s) which is likely to improve. At the option of the Commissioner, SSA may also perform a CDR with respect to those individuals under age 18 whose impairments are unlikely to improve (Section 212(a)).

- We must redetermine the eligibility of individuals who were eligible for SSI based on disability in the month before the month in which they attained age 18 using the rules for determining initial eligibility for adults. We will do the redetermination during the 1-year period beginning on the individual's 18th birthday. The medical improvement review standard used in CDRs does not apply to these redeterminations (Section 212(b)).

- We must conduct a CDR not later than 12 months after the birth of the child for any child whose low birth weight is a contributing factor material to our determination that the child was disabled (Section 212(c)).

- At the time of a CDR, a child's representative payee shall present evidence that the child is and has been receiving treatment to the extent considered medically necessary and available for the disabling impairment. If a payee refuses without good cause to provide such evidence, we may select another representative payee, or pay benefits directly to the child, if we determine that it is appropriate and in the best interests of the child (Section 212(a)).

Although not included in these interim final rules, the law requires SSA to redetermine the eligibility of children who may be affected by the changes in the definition of disability within one year after enactment (August 22, 1997), with the provision that no child's benefit may be terminated before July 1, 1997. Under this provision of the law, many children already on the rolls will lose their eligibility for SSI benefits. Even though not a part of these rules, we also have considered this provision of P.L. 104-193 in our analysis of the costs and benefits of the changes we are making to the childhood disability program as a result of the law.

In most States, individuals who are eligible for SSI are also eligible for Medicaid, although many children can qualify for Medicaid without being eligible for SSI. Some children who lose their SSI eligibility will also lose their Medicaid eligibility. However, many of the children affected could still continue to be covered under Medicaid because they meet other Medicaid eligibility criteria. States are required to perform a redetermination of Medicaid eligibility in any case where an individual loses SSI and that determination could affect the individual's Medicaid eligibility.

In addition, there may be redeterminations made for food stamps, Temporary Assistance for Needy Families, and other support programs for children who lose their eligibility for SSI benefits, or who cannot qualify for SSI benefits under the new disability standard. This may shift some of the burden of meeting the needs of these children to States, localities, and charitable organizations.

Program Savings

It is estimated that due to the legislation there will be reduced program outlays resulting in the following savings (in millions of dollars) to the SSI program (over $1.3 billion total in a 6-year period):

FY1997	FY1998	FY1999	FY2000	FY2001	FY2002	Total
-$35	-$225	-$295	-$315	-$225	-$220	-$1,315

Note: Annual numbers may not add to total due to rounding.

Medicaid costs will also decrease. The decrease will be less than the effect of both of the policy alternatives.

Administrative Costs and Savings

The administrative cost of conducting the medical redeterminations of the children who might be affected by the new childhood disability standards is expected to be $140 million in FY 1997 and $85 million in FY 1998. There will be net ongoing savings of approximately $3-5 million annually.

From FYs 1999-2002, the ongoing Federal workyear savings are from fewer recipients on the rolls, i.e., from those children currently receiving benefits who will be terminated and from those children who will be denied under the stricter standards. These savings will result from fewer income and resource redeterminations, representative payee actions and maintenance of the rolls activities. The ongoing State workyear costs are for the medical reviews from the additional reconsiderations and hearings resulting from the stricter childhood disability standards.

Estimated administrative costs ($ in millions, rounded to the nearest $5 million) and workyears (rounded to the nearest 50) are:

FY1997	FY1998	FY1999	FY2000	FY2001	FY2002	Total
$140	$85	-$5	-$5	-$5	-$5	$205

Workyears

Federal	550	-50	-100	-100	-50	-50	200
State	1,100	400	50	50	50	50	1,650
Total	1,650	350	-50	-50	-50	0	1,850

Note: Annual numbers may not add to total due to rounding.

Reductions in SSI Recipients (in thousands)

Under this alternative, we estimate benefit eligibility for a total of 45,000 of those children receiving benefits at date of enactment will be terminated. The following figures show the estimated annual effect of the legislation on projected numbers of recipients of Federal SSI benefits.

FY1997	FY1998	FY1999	FY2000	FY2001	FY2002
-5	-40	-50	-50	-40	-35

POLICY ALTERNATIVES

1. Follow a Literal Interpretation of the Legislation

Under a literal interpretation of the legislation, we would only have discontinued use of the individualized functional assessment from the sequential evaluation process, deleted the "maladaptive behaviors" paragraph from the personal/behavioral area of functioning in the childhood mental disorders listings, and made only those changes mandated by the legislation, without the clarifications we have provided in the interim final rules.

We did not choose this option because we do not believe that it comports with the spirit or the intent of the law. As we explained in the preamble to the interim final regulations, the legislative history makes clear that Congress intended for us to provide benefits to needy children with severe disabilities. The Congress also singled out for special mention our policy on functional equivalence and the need to consider functional information, if reflecting sufficient severity and if it is otherwise appropriate. In an attempt to more closely reflect the spirit and the letter of the law, we decided to add a "motor" area of functioning to ensure that physical impairments are appropriately evaluated, to better explain how the policy of functional equivalence should be applied (including, the method for evaluating episodic impairments), to provide a new form for use at the initial and reconsideration levels of our administrative review process, and to make the other clarifications throughout the interim final rules. If we had done otherwise, we would have risked excluding many of the children the law was intended to cover.

Program Savings under Alternative 1 (in millions)

It is estimated that due to the legislation there would be reduced program outlays resulting in the following savings (in millions of dollars) to the SSI program (over $6.6 billion total in a 6-year period):

FY1997	FY1998	FY1999	FY2000	FY2001	FY2002	Total
-$165	-$965	-$1,290	-$1,485	-$1,280	-$1,445	-$6,625

Note: Annual numbers may not add to total due to rounding.

Medicaid costs would also decrease under alternative 1. The decrease would be greater than the effect of the chosen alternative and alternative 2.

Administrative Costs and Savings under Alternative 1

The administrative cost of conducting the medical redeterminations of the children who might be affected by the new childhood disability standards is expected to be $215 million in FY 1997 and $210 million in FY 1998.

From FYs 1999-2002, the ongoing Federal workyear savings are from fewer recipients on the rolls, i.e., from those children currently receiving benefits who will be terminated and from those children who will be denied under the stricter standards. These savings will result from fewer income and resource redeterminations, representative payee actions and maintenance of the rolls activities. The ongoing State workyear costs are for additional hearings, as well as medical reviews from additional reconsiderations, resulting from the stricter childhood disability standard.

Estimated administrative costs ($ in millions, rounded to the nearest $5 million) and workyears (rounded to the nearest 50) are:

FY1997	FY1998	FY1999	FY2000	FY2001	FY2002	Total
$215	$210	$0	$0	$0	-$5	$430

Workyears

Federal	950	950	-250	-250	-250	-250	1,000
State	1,650	1,700	300	300	300	300	4,550
Total	2,600	2,650	100	100	50	50	5,500

Note: Annual numbers may not add to total due to rounding.

Reductions in SSI Recipients (in thousands) under Alternative 1

Under this alternative, we estimate benefit eligibility for a total of 190,000 of those children receiving benefits at date of enactment would be terminated. The following figures show the estimated annual effect of the legislation on projected numbers of recipients of Federal SSI benefits.

FY1997	FY1998	FY1999	FY2000	FY2001	FY2002
-30	-170	-220	-230	-225	-225

2. Follow a Strict Interpretation of the Legislation With a Clarified Motor Domain

This alternative is based primarily on a listings-level interpretation of the intent of Congress and legislative history with an expansion of the motor domain to try to cover seriously disabled children who were not the target of the legislation. We do not recommend this option because we believe that Congress did not explicitly mandate a listings-level standard when it defined disability in terms of "marked and severe functional limitations." Also, although the expansion of the motor domain will cover some of the seriously disabled children, it is not sufficient to cover all of those who were eligible under the previous rules for SSI benefits based on disability.

We need to be clear about the listings we use in the disability evaluation process. The listings were never intended to be more than a screening device in the evaluation process to identify many disabled individuals. They were never intended to be sole criteria for determining disability, and they were never intended to cover all possible serious disabilities. Therefore, we determined that this alternative was not potentially effective nor reasonably feasible.

Program Savings under Alternative 2

It is estimated that due to the legislation there would be reduced program outlays resulting in the following savings (in millions of dollars) to the SSI program (over $4.7 billion total in a 6-year period):

FY1997	FY1998	FY1999	FY2000	FY2001	FY2002	Total
-$120	-$715	-$945	-$1,075	-$905	-$1,010	-$4,775

This is the amount we expect to spend (in millions of dollars) on SSI childhood disability benefits:

FY1997	FY1998	FY1999	FY2000	FY2001	FY2002	Total
$5,425	$5,285	$5,475	$6,300	$5,715	$6,505	$34,705

Note: Annual numbers may not add to total due to rounding.

It is also estimated that there would be reduced Medicaid program outlays (Federal share) resulting in the following savings (in millions of dollars) over a 6-year period:

FY1997	FY1998	FY1999	FY2000	FY2001	FY2002	Total
-10	-85	-110	-125	-125	-135	-590

There would also be reduced Medicaid program outlays for States.

Administrative Costs and Savings under Alternative 2

The administrative cost of conducting the medical redeterminations of the children who might be affected by the new childhood disability standards is expected to be $185 million in FY 1997 and $130 million in FY 1998. For this regulation, the administrative cost of redetermining disability in SSI childhood recipients is assumed to be the same as the cost of a full medical CDR for these individuals, including the additional appellate costs.

From FYs 1999-2002, the ongoing Federal workyear savings are from fewer recipients on the rolls, i.e., from those children currently receiving benefits who will be terminated and from those children who will be denied under the stricter standards. There will be net savings of approximately $10 million annually beginning with FY99. These savings will result from fewer income and resource redeterminations, representative payee actions, and maintenance of the rolls activities. The ongoing State workyear costs are from additional hearings, as well as medical reviews from additional reconsiderations, resulting from the stricter childhood disability standard.

Estimated administrative costs ($ in millions, rounded to the nearest $5 million) and workyears (rounded to the nearest 50) are:

FY1997	FY1998	FY1999	FY2000	FY2001	FY2002	Total
$185	$130	-$10	-$10	-$10	-$10	$265

Workyears

	FY1997	FY1998	FY1999	FY2000	FY2001	FY2002	Total
Federal	900	650	-250	-250	-250	-250	550
State	1,200	1,250	150	150	150	150	3,050
Total	2,100	1,900	-100	-100	-100	-100	3,550

Note: Annual numbers may not add to total due to rounding.

Reductions in SSI Recipients (in thousands) under Alternative 2:

We expect benefit eligibility for a total of 135,000 of those children receiving benefits at date of enactment would be terminated as a result of these changes in the law. The following figures show the estimated annual effect of the legislation on projected numbers of recipients of Federal SSI benefits:

	FY1997	FY1998	FY1999	FY2000	FY2001	FY2002
Current recipients	-10	-95	-110	-95	-80	-70
New awards	-10	-35	-50	-70	-80	-90
Total	-20	-130	-160	-165	-160	-160

With the reductions in SSI recipients shown above, we estimate the average number of disabled children (in thousands) in payment status after implementation of these interim final rules would be:

FY1997	FY1998	FY1999	FY2000	FY2001	FY2002
1,010	950	955	990	1,015	1,040

Note: Annual numbers may not add to total due to rounding.

CONCLUSION

We believe that the regulatory changes in the interim final regulations are consistent with the law and meet the intent of Congress. We carefully considered all the various policy and legal issues, and we have arrived at a childhood disability standard that is based on the level of severity represented by the Listing of Impairments. We believe that the regulatory changes meet the intent of Congress and maintain benefit eligibility for severely disabled children.

United States Senate
WASHINGTON, DC 20510

April 14, 1997

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

Dear Mr. President:

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

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

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

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

The SSA is proposing to define the phrase "marked and severe" as meaning listings levels severity or any equivalent level of severity. Congress never intended and did not require this level of severity. SSA thus ignores the law, floor debate, and the history of the program. The statutory language passed by both chambers of Congress and signed by the President is the best reflection of Congressional intent. We encourage you to instruct the SSA to reevaluate and re-target the proposed rule and establish a comprehensive functional test at a severity level that is stricter than the IFA test, but does not harm children with disabilities. In addition, we encourage you to make a commitment to undertake a complete review of the effect of these regulations on children with disabilities in consultation with experts in the field of child development

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

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

Sincerely,

Kent Conrad
Senator Kent Conrad

John Chafee
Senator John Chafee

Ted Kennedy
Senator Edward Kennedy

Tom Harkin
Senator Tom Harkin

Jay Rockefeller
Senator John D. Rockefeller IV

Jim Jeffords
Senator James Jeffords

Max Baucus
Senator Max Baucus

Patrick Leahy
Senator Patrick Leahy

Chris Dodd
Senator Christopher Dodd

Tom Daschle
Senator Tom Daschle

Social Security -
Children's Disability Standard

Diana Fortuna
06/18/97 05:17:28 PM

Record Type: Record

To: Cynthia A. Rice/OPD/EOP, Elena Kagan/OPD/EOP, Jeanne Lambrew/OPD/EOP

cc: Nicolette Highsmith/OMB/EOP, Barry White/OMB/EOP, Richard E. Green/OMB/EOP, William H. White Jr./WHO/EOP

Subject: Grandfathering Medicaid for children losing SSI

I just heard that Senate Finance didn't do the Medicaid grandfathering of kids losing SSI under the new definition -- which was part of the budget agreement. And it got struck in the House. Bad news -- disability community is very concerned. I assume our next best hope is to get Chafee and/or Conrad to do something on the floor (I don't know why they didn't in committee; they are supposedly champions of this group). In the meantime, we need to keep talking about this in our communications.

Cynthia, I think we need to talk to Chafee and Conrad about this.

Social Security -
Children's Disability
Standard

Cynthia A. Rice 06/19/97 03:12:37 PM

Record Type: Record

To: See the distribution list at the bottom of this message
cc: Bruce N. Reed/OPD/EOP, Elena Kagan/OPD/EOP
Subject: Preserving Medicaid for Kids Losing SSI

As you know, neither the House nor the Senate bills have an important provision from the Budget Agreement, which preserves Medicaid for those children losing SSI due to the new rules now being implemented. (It was in the Chafee-Rockefeller kids health substitute, which of course in the end was not adopted.)

I just spoke to Laurie Rubiner of Sen. Chafee's staff about possible next steps.

She is going to call Dennis Smith of the Finance Committee majority staff to see if it she can get it included in the kids health proposal reported out of the committee. During the walk through, Senator Chafee asked Smith why it wasn't in the Chairman's proposal, and he said it would be taken care of as part of children's health. Laurie is going to try to use this statement to get it in now.

If that doesn't work, then I think our negotiators need to push hard on the Congressional leadership to undertake remedial efforts to ensure that the reconciliation language is consistent with the agreement.

If that doesn't work, a next option could be for Chafee and others to offer an amendment on the floor to provide the coverage, using as an offset a set-aside from the kids health block grant. Let me make clear that she did not commit to this, but she raised it as an option. She also wondered if there's a non-controversial offset she could use instead of taking funds from the kids health block grant. OMB? (How much does this provision cost?)

Message Sent To:

Diana Fortuna/OPD/EOP
Christopher C. Jennings/OPD/EOP
Jeanne Lambrew/OPD/EOP
Emil E. Parker/OPD/EOP
Kenneth S. Apfel/OMB/EOP
Nancy A. Min/OMB/EOP